THE OFFICIAL
PATIENT'S SOURCEBOOK
on

LUPUS NEPHRITIS

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ICON Health Publications
ICON Group International, Inc.
4370 La Jolla Village Drive, 4th Floor
San Diego, CA 92122 USA

Printed in the United States of America.

Last digit indicates print number: 10 9 8 7 6 4 5 3 2 1

Publisher, Health Care: Tiffany LaRochelle
Editor(s): James Parker, M.D., Philip Parker, Ph.D.

Cataloging-in-Publication Data

Parker, James N., 1961-
Parker, Philip M., 1960-

The Official Patient's Sourcebook on Lupus Nephritis: A Revised and Updated Directory for the Internet Age/James N. Parker and Philip M. Parker, editors
p. cm.
Includes bibliographical references, glossary and index.
ISBN: 0-597-83224-2
1. Lupus Nephritis-Popular works. I. Title.

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Dedication

To the healthcare professionals dedicating their time and efforts to the study of lupus nephritis.

Acknowledgements

The collective knowledge generated from academic and applied research summarized in various references has been critical in the creation of this sourcebook which is best viewed as a comprehensive compilation and collection of information prepared by various official agencies which directly or indirectly are dedicated to lupus nephritis. All of the *Official Patient's Sourcebooks* draw from various agencies and institutions associated with the United States Department of Health and Human Services, and in particular, the Office of the Secretary of Health and Human Services (OS), the Administration for Children and Families (ACF), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Agency for Toxic Substances and Disease Registry (ATSDR), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Healthcare Financing Administration (HCFA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the institutions of the National Institutes of Health (NIH), the Program Support Center (PSC), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these sources, information gathered from the National Library of Medicine, the United States Patent Office, the European Union, and their related organizations has been invaluable in the creation of this sourcebook. Some of the work represented was financially supported by the Research and Development Committee at INSEAD. This support is gratefully acknowledged. Finally, special thanks are owed to Tiffany LaRochelle for her excellent editorial support.

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About ICON Health Publications

In addition to lupus nephritis, *Official Patient's Sourcebooks* are available for the following related topics:

- The Official Patient's Sourcebook on Childhood Nephrotic Syndrome
- The Official Patient's Sourcebook on Cystocele
- The Official Patient's Sourcebook on Glomerular Disease
- The Official Patient's Sourcebook on Goodpasture Syndrome
- The Official Patient's Sourcebook on Hematuria
- The Official Patient's Sourcebook on Hemochromatosis
- The Official Patient's Sourcebook on Immune Thrombocytopenic Purpura
- The Official Patient's Sourcebook on Impotence
- The Official Patient's Sourcebook on Interstitial Cystitis
- The Official Patient's Sourcebook on Kidney Failure
- The Official Patient's Sourcebook on Kidney Stones
- The Official Patient's Sourcebook on Nephrotic Syndrome
- The Official Patient's Sourcebook on Peyronie
- The Official Patient's Sourcebook on Polycystic Kidney Disease
- The Official Patient's Sourcebook on Prostate Enlargement
- The Official Patient's Sourcebook on Prostatitis
- The Official Patient's Sourcebook on Proteinuria
- The Official Patient's Sourcebook on Pyelonephritis
- The Official Patient's Sourcebook on Renal Osteodystrophy
- The Official Patient's Sourcebook on Renal Tubular Acidosis
- The Official Patient's Sourcebook on Simple Kidney Cysts
- The Official Patient's Sourcebook on Urinary Incontinence
- The Official Patient's Sourcebook on Urinary Incontinence for Women
- The Official Patient's Sourcebook on Urinary Tract Infection in Children
- The Official Patient's Sourcebook on Urinary Tract Infections in Adults
- The Official Patient's Sourcebook on Vasectomy
- The Official Patient's Sourcebook on Vesicoureteral Reflux

To discover more about ICON Health Publications, simply check with your preferred online booksellers, including Barnes & Noble.com and Amazon.com which currently carry all of our titles. Or, feel free to contact us directly for bulk purchases or institutional discounts:

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INTRODUCTION

Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, "The best prescription is knowledge."[1] The Agency for Healthcare Research and Quality (AHRQ) of the National Institutes of Health (NIH) echoes this view and recommends that every patient incorporate education into the treatment process. According to the AHRQ:

> Finding out more about your condition is a good place to start. By contacting groups that support your condition, visiting your local library, and searching on the Internet, you can find good information to help guide your treatment decisions. Some information may be hard to find—especially if you don't know where to look.[2]

As the AHRQ mentions, finding the right information is not an obvious task. Though many physicians and public officials had thought that the emergence of the Internet would do much to assist patients in obtaining reliable information, in March 2001 the National Institutes of Health issued the following warning:

> The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading.[3]

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[1] Quotation from **http://www.drkoop.com**.
[2] The Agency for Healthcare Research and Quality (AHRQ): **http://www.ahcpr.gov/consumer/diaginfo.htm**.
[3] From the NIH, National Cancer Institute (NCI): **http://cancertrials.nci.nih.gov/beyond/evaluating.html**.

Since the late 1990s, physicians have seen a general increase in patient Internet usage rates. Patients frequently enter their doctor's offices with printed Web pages of home remedies in the guise of latest medical research. This scenario is so common that doctors often spend more time dispelling misleading information than guiding patients through sound therapies. *The Official Patient's Sourcebook on Lupus Nephritis* has been created for patients who have decided to make education and research an integral part of the treatment process. The pages that follow will tell you where and how to look for information covering virtually all topics related to lupus nephritis, from the essentials to the most advanced areas of research.

The title of this book includes the word "official." This reflects the fact that the sourcebook draws from public, academic, government, and peer-reviewed research. Selected readings from various agencies are reproduced to give you some of the latest official information available to date on lupus nephritis.

Given patients' increasing sophistication in using the Internet, abundant references to reliable Internet-based resources are provided throughout this sourcebook. Where possible, guidance is provided on how to obtain free-of-charge, primary research results as well as more detailed information via the Internet. E-book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned (clicking on a hyperlink automatically opens your browser to the site indicated). Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites. Since we are working with ICON Health Publications, hard copy *Sourcebooks* are frequently updated and printed on demand to ensure that the information provided is current.

In addition to extensive references accessible via the Internet, every chapter presents a "Vocabulary Builder." Many health guides offer glossaries of technical or uncommon terms in an appendix. In editing this sourcebook, we have decided to place a smaller glossary within each chapter that covers terms used in that chapter. Given the technical nature of some chapters, you may need to revisit many sections. Building one's vocabulary of medical terms in such a gradual manner has been shown to improve the learning process.

We must emphasize that no sourcebook on lupus nephritis should affirm that a specific diagnostic procedure or treatment discussed in a research study, patent, or doctoral dissertation is "correct" or your best option. This sourcebook is no exception. Each patient is unique. Deciding on appropriate

options is always up to the patient in consultation with their physician and healthcare providers.

Organization

This sourcebook is organized into three parts. Part I explores basic techniques to researching lupus nephritis (e.g. finding guidelines on diagnosis, treatments, and prognosis), followed by a number of topics, including information on how to get in touch with organizations, associations, or other patient networks dedicated to lupus nephritis. It also gives you sources of information that can help you find a doctor in your local area specializing in treating lupus nephritis. Collectively, the material presented in Part I is a complete primer on basic research topics for patients with lupus nephritis.

Part II moves on to advanced research dedicated to lupus nephritis. Part II is intended for those willing to invest many hours of hard work and study. It is here that we direct you to the latest scientific and applied research on lupus nephritis. When possible, contact names, links via the Internet, and summaries are provided. It is in Part II where the vocabulary process becomes important as authors publishing advanced research frequently use highly specialized language. In general, every attempt is made to recommend "free-to-use" options.

Part III provides appendices of useful background reading for all patients with lupus nephritis or related disorders. The appendices are dedicated to more pragmatic issues faced by many patients with lupus nephritis. Accessing materials via medical libraries may be the only option for some readers, so a guide is provided for finding local medical libraries which are open to the public. Part III, therefore, focuses on advice that goes beyond the biological and scientific issues facing patients with lupus nephritis.

Scope

While this sourcebook covers lupus nephritis, your doctor, research publications, and specialists may refer to your condition using a variety of terms. Therefore, you should understand that lupus nephritis is often considered a synonym or a condition closely related to the following:

- Focal Glomerulonephritis
- Lupus Glomerular Disease

- Lupus Glomerulonephritis
- Nephritis - Lupus

In addition to synonyms and related conditions, physicians may refer to lupus nephritis using certain coding systems. The International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) is the most commonly used system of classification for the world's illnesses. Your physician may use this coding system as an administrative or tracking tool. The following classification is commonly used for lupus nephritis:[4]

- 710.0 lupus nephritis

For the purposes of this sourcebook, we have attempted to be as inclusive as possible, looking for official information for all of the synonyms relevant to lupus nephritis. You may find it useful to refer to synonyms when accessing databases or interacting with healthcare professionals and medical librarians.

Moving Forward

Since the 1980s, the world has seen a proliferation of healthcare guides covering most illnesses. Some are written by patients or their family members. These generally take a layperson's approach to understanding and coping with an illness or disorder. They can be uplifting, encouraging, and highly supportive. Other guides are authored by physicians or other healthcare providers who have a more clinical outlook. Each of these two styles of guide has its purpose and can be quite useful.

As editors, we have chosen a third route. We have chosen to expose you to as many sources of official and peer-reviewed information as practical, for the purpose of educating you about basic and advanced knowledge as recognized by medical science today. You can think of this sourcebook as your personal Internet age reference librarian.

Why "Internet age"? All too often, patients diagnosed with lupus nephritis will log on to the Internet, type words into a search engine, and receive several Web site listings which are mostly irrelevant or redundant. These

[4] This list is based on the official version of the World Health Organization's 9th Revision, International Classification of Diseases (ICD-9). According to the National Technical Information Service, "ICD-9CM extensions, interpretations, modifications, addenda, or errata other than those approved by the U.S. Public Health Service and the Health Care Financing Administration are not to be considered official and should not be utilized. Continuous maintenance of the ICD-9-CM is the responsibility of the federal government."

patients are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with lupus nephritis is even indexed in search engines, a non-systematic approach often leads to frustration and disappointment. With this sourcebook, we hope to direct you to the information you need that you would not likely find using popular Web directories. Beyond Web listings, in many cases we will reproduce brief summaries or abstracts of available reference materials. These abstracts often contain distilled information on topics of discussion.

Before beginning your search for information, it is important for you to realize that lupus nephritis is considered a relatively uncommon condition. Because of this, far less research is conducted on lupus nephritis compared to other health problems afflicting larger populations, like breast cancer or heart disease. Nevertheless, this sourcebook will prove useful for two reasons. First, if more information does become available on lupus nephritis, the sources given in this book will be the most likely to report or make such information available. Second, some will find it important to know about patient support, symptom management, or diagnostic procedures that may be relevant to both lupus nephritis and other conditions. By using the sources listed in the following chapters, self-directed research can be conducted on broader topics that are related to lupus nephritis but not readily uncovered using general Internet search engines (e.g. www.google.com or www.yahoo.com). In this way, we have designed this sourcebook to complement these general search engines that can provide useful information and access to online patient support groups.[5]

While we focus on the more scientific aspects of lupus nephritis, there is, of course, the emotional side to consider. Later in the sourcebook, we provide a chapter dedicated to helping you find peer groups and associations that can provide additional support beyond research produced by medical science. We hope that the choices we have made give you the most options available in moving forward. In this way, we wish you the best in your efforts to incorporate this educational approach into your treatment plan.

The Editors

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[5] For example, one can simply go to **www.google.com,** or other general search engines (e.g. **www.yahoo.com**, **www.aol.com**, **www.msn.com**) and type in "lupus nephritis support group" to find any active online support groups dedicated to lupus nephritis.

PART I: THE ESSENTIALS

ABOUT PART I

Part I has been edited to give you access to what we feel are "the essentials" on lupus nephritis. The essentials of a disease typically include the definition or description of the disease, a discussion of who it affects, the signs or symptoms associated with the disease, tests or diagnostic procedures that might be specific to the disease, and treatments for the disease. Your doctor or healthcare provider may have already explained the essentials of lupus nephritis to you or even given you a pamphlet or brochure describing lupus nephritis. Now you are searching for more in-depth information. As editors, we have decided, nevertheless, to include a discussion on where to find essential information that can complement what your doctor has already told you. In this section we recommend a process, not a particular Web site or reference book. The process ensures that, as you search the Web, you gain background information in such a way as to maximize your understanding.

CHAPTER 1. THE ESSENTIALS ON LUPUS NEPHRITIS: GUIDELINES

Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on lupus nephritis. These are typically called "Fact Sheets" or "Guidelines." They can take the form of a brochure, information kit, pamphlet, or flyer. Often they are only a few pages in length. The great advantage of guidelines over other sources is that they are often written with the patient in mind. Since new guidelines on lupus nephritis can appear at any moment and be published by a number of sources, the best approach to finding guidelines is to systematically scan the Internet-based services that post them.

The National Institutes of Health (NIH)[6]

The National Institutes of Health (NIH) is the first place to search for relatively current patient guidelines and fact sheets on lupus nephritis. Originally founded in 1887, the NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. At any given time, the NIH supports some 35,000 research grants at universities, medical schools, and other research and training institutions, both nationally and internationally. The rosters of those who have conducted research or who have received NIH support over the years include the world's most illustrious scientists and physicians. Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

[6] Adapted from the NIH: **http://www.nih.gov/about/NIHoverview.html**.

There is no guarantee that any one Institute will have a guideline on a specific disease, though the National Institutes of Health collectively publish over 600 guidelines for both common and rare diseases. The best way to access NIH guidelines is via the Internet. Although the NIH is organized into many different Institutes and Offices, the following is a list of key Web sites where you are most likely to find NIH clinical guidelines and publications dealing with lupus nephritis and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at **http://www.nih.gov/health/consumer/conkey.htm**
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines available at **http://www.nlm.nih.gov/medlineplus/healthtopics.html**
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); guidelines available at **http://www.niddk.nih.gov/health/health.htm**

Among these, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is particularly noteworthy. The NIDDK's mission is to conduct and support research on many of the most serious diseases affecting public health.[7] The Institute supports much of the clinical research on the diseases of internal medicine and related subspecialty fields as well as many basic science disciplines. The NIDDK's Division of Intramural Research encompasses the broad spectrum of metabolic diseases such as diabetes, inborn errors of metabolism, endocrine disorders, mineral metabolism, digestive diseases, nutrition, urology and renal disease, and hematology. Basic research studies include biochemistry, nutrition, pathology, histochemistry, chemistry, physical, chemical, and molecular biology, pharmacology, and toxicology. NIDDK extramural research is organized into divisions of program areas:

- Division of Diabetes, Endocrinology, and Metabolic Diseases
- Division of Digestive Diseases and Nutrition
- Division of Kidney, Urologic, and Hematologic Diseases

The Division of Extramural Activities provides administrative support and overall coordination. A fifth division, the Division of Nutrition Research Coordination, coordinates government nutrition research efforts. The Institute supports basic and clinical research through investigator-initiated

[7] This paragraph has been adapted from the NIDDK: **http://www.niddk.nih.gov/welcome/mission.htm**. "Adapted" signifies that a passage is reproduced exactly or slightly edited for this book.

grants, program project and center grants, and career development and training awards. The Institute also supports research and development projects and large-scale clinical trials through contracts. The following patient guideline was recently published by the NIDDK on lupus nephritis.

What Is Lupus Nephritis?[8]

Lupus nephritis is an inflammation of the kidney caused by systemic lupus erythematosus (SLE), a disease of the immune system. SLE causes harm to the skin, joints, kidneys, and brain.

What causes SLE is unknown. Many factors may play a role, including:

- Heredity (a gene passed down by a parent)
- Infections
- Viruses
- Air pollution

Some people with SLE may have no symptoms of kidney disease. However, lupus nephritis may cause weight gain, high blood pressure, dark urine, or swelling around the eyes, legs, ankles, or fingers.

Diagnosis may require urine and blood tests and x-rays of the kidneys. Treatment depends on the symptoms. Medicines can decrease swelling, lower blood pressure, and decrease inflammation by suppressing the immune system. The patient may need to limit protein, sodium, and potassium intake.

For More Information

More information is available from:

American Lupus Society
260 Maple Court, Suite 123
Ventura, CA 93003
(805) 339–0443
(800) 331–1802

[8] Adapted from The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK): **http://www.niddk.nih.gov/health/kidney/summary/lupuneph/lupuneph.htm**.

Lupus Foundation of America, Inc.
1300 Piccard Drive, Suite 200
Rockville, MD 20850–4303
(301) 670–9292
(800) 558–0121
E-mail: lupusInfo@aol.com
Home page: **www.lupus.org/**

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NAMSIC)
National Institutes of Health
1 AMS Circle
Bethesda, Maryland 20892–3675
NAMSIC has an online publication on Systemic Lupus Erythematosus

Additional Information on Lupus Nephritis

The National Kidney and Urologic Diseases Information Clearinghouse collects resource information on kidney and urologic diseases for the Combined Health Information Database (CHID). CHID is a database produced by health-related agencies of the Federal Government. This database provides titles, abstracts, and availability information for health information and health education resources.

To provide you with the most up-to-date resources, information specialists at the clearinghouse created an automatic search of CHID. To obtain this information you may view the results of the automatic search on Lupus Nephritis.

Or, if you wish to perform your own search of the database, you may access the CHID Online web site and search CHID yourself.

National Kidney and Urologic Diseases Information Clearinghouse
3 Information Way
Bethesda, MD 20892-3580
E-mail: National Kidney and Urologic Diseases Information Clearinghouse
The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services. Established in 1987, the clearinghouse provides information

about diseases of the kidneys and urologic system to people with kidney and urologic disorders and to their families, health care professionals, and the public. NKUDIC answers inquiries; develops, reviews, and distributes publications; and works closely with professional and patient organizations and Government agencies to coordinate resources about kidney and urologic diseases. Publications produced by the clearinghouse are carefully reviewed for scientific accuracy, content, and readability.

More Guideline Sources

The guideline above on lupus nephritis is only one example of the kind of material that you can find online and free of charge. The remainder of this chapter will direct you to other sources which either publish or can help you find additional guidelines on topics related to lupus nephritis. Many of the guidelines listed below address topics that may be of particular relevance to your specific situation or of special interest to only some patients with lupus nephritis. Due to space limitations these sources are listed in a concise manner. Do not hesitate to consult the following sources by either using the Internet hyperlink provided, or, in cases where the contact information is provided, contacting the publisher or author directly.

Topic Pages: MEDLINEplus

For patients wishing to go beyond guidelines published by specific Institutes of the NIH, the National Library of Medicine has created a vast and patient-oriented healthcare information portal called MEDLINEplus. Within this Internet-based system are "health topic pages." You can think of a health topic page as a guide to patient guides. To access this system, log on to **http://www.nlm.nih.gov/medlineplus/healthtopics.html**. From there you can either search using the alphabetical index or browse by broad topic areas.

If you do not find topics of interest when browsing health topic pages, then you can choose to use the advanced search utility of MEDLINEplus at **http://www.nlm.nih.gov/medlineplus/advancedsearch.html**. This utility is similar to the NIH Search Utility, with the exception that it only includes material linked within the MEDLINEplus system (mostly patient-oriented information). It also has the disadvantage of generating unstructured results. We recommend, therefore, that you use this method only if you have a very targeted search.

The Combined Health Information Database (CHID)

CHID Online is a reference tool that maintains a database directory of thousands of journal articles and patient education guidelines on lupus nephritis and related conditions. One of the advantages of CHID over other sources is that it offers summaries that describe the guidelines available, including contact information and pricing. CHID's general Web site is **http://chid.nih.gov/**. To search this database, go to **http://chid.nih.gov/detail/detail.html**. In particular, you can use the advanced search options to look up pamphlets, reports, brochures, and information kits. The following was recently posted in this archive:

- **Questions and Answers About Autoimmunity**

  Source: Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse. 2002. 32 p.

  Contact: Available from National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse. 1 AMS Circle, Bethesda, MD 20892-3675. (877) 226-4267 toll-free or (301) 495-4484. Fax (301) 718-6366. TTY (301) 565-2966. E-mail: NIAMSInfo@mail.nih.gov. Website: www.niams.nih.gov. Price: 1 to 25 copies free. Order Number: AR-242 QA (booklet), or AR-242L QA (large print fact sheet).

  Summary: This booklet provides people who have an autoimmune disease with information on the causes, diagnosis, and treatment of such diseases. Autoimmune diseases occur when the body attacks its own cells as invaders. Although the cause of autoimmunity is unknown, most scientists believe that genetic and environmental factors are involved. Autoimmunity can affect almost any part of the body, and the problems caused by autoimmunity depend on the tissues targeted. Diagnosis is based on the medical history, a physical examination, and medical tests. Treatment depends on the type of disease and its symptoms and severity. The goals of treatment are to relieve symptoms, preserve organ function, and target disease mechanisms. The types of doctors who provide treatment for autoimmune diseases vary, and they include rheumatologists, endocrinologists, neurologists, hematologists, gastroenterologists, dermatologists, and nephrologists. Problems that people experience with an autoimmune disease also vary and may be related to self esteem, self care, family relationships, sexual relations, and pregnancy. Research is being conducted to help people with autoimmune diseases such as rheumatoid arthritis, systemic lupus erythematosus, lupus nephritis, vitiligo, type 1 diabetes, multiple sclerosis, and multiple autoimmune diseases. The booklet includes a list of government and

other organizations that can provide information about autoimmunity. Appendices provide glossaries of terms and diseases.

- **Kidney Disease and Lupus**

  Source: Rockville, MD: Lupus Foundation of America. 1999. 6 p.

  Contact: Available from Lupus Foundation of America. 1300 Piccard Drive, Suite 200, Rockville, MD 20850-4303. (800) 558-0121 or (301) 670-9292. Fax (301) 670-9486. Website: www.lupus.org/lupus. Price: Available as part of a package of 21 different lupus related brochures for $3.95 plus shipping and handling.

  Summary: This pamphlet provides people who have systemic lupus erythematosus (SLE) with information on the kidney disease that accompanies it. This type of kidney disease, which is known as lupus nephritis or lupus glomerulonephritis, may affect about one third of those who have SLE. Symptoms that indicate the possibility of lupus nephritis include foamy, frothy urine; nocturnal urination; and fluid retention with weight gain and swelling. The clinical path of lupus nephritis is highly variable, with some people experiencing mild abnormalities and others experiencing more persistent, severe ones. Studies that can be performed to test for lupus nephritis are urinalysis, blood studies, 24 hour urine collection, imaging, and kidney biopsy. Corticosteroids and cytotoxic or immunosuppressive drugs are the major forms of drug therapy used to treat lupus nephritis. Despite treatment, some people may experience progressive loss of kidney function. These people will need hemodialysis or peritoneal dialysis and eventually kidney transplantation. The pamphlet also provides information on the Lupus Foundation of America. 1 table.

The National Guideline Clearinghouse™

The National Guideline Clearinghouse™ offers hundreds of evidence-based clinical practice guidelines published in the United States and other countries. You can search their site located at **http://www.guideline.gov** by using the keyword "lupus nephritis" or synonyms. The following was recently posted:

- **Intravenous immunoglobulin preparations.**

  Source: University HealthSystem Consortium.; 1999 March; 216 pages

  http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=001202&sSearch_string=lupus+nephritis

Healthfinder™

Healthfinder™ is an additional source sponsored by the U.S. Department of Health and Human Services which offers links to hundreds of other sites that contain healthcare information. This Web site is located at **http://www.healthfinder.gov**. Again, keyword searches can be used to find guidelines. The following was recently found in this database:

- **Lupus Nephritis**

  Summary: Brief overview of the symptoms, diagnosis, and treatment of lupus nephritis.

  Source: National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=6519

The NIH Search Utility

After browsing the references listed at the beginning of this chapter, you may want to explore the NIH Search Utility. This allows you to search for documents on over 100 selected Web sites that comprise the NIH-WEB-SPACE. Each of these servers is "crawled" and indexed on an ongoing basis. Your search will produce a list of various documents, all of which will relate in some way to lupus nephritis. The drawbacks of this approach are that the information is not organized by theme and that the references are often a mix of information for professionals and patients. Nevertheless, a large number of the listed Web sites provide useful background information. We can only recommend this route, therefore, for relatively rare or specific disorders, or when using highly targeted searches. To use the NIH search utility, visit the following Web page: **http://search.nih.gov/index.html**.

Additional Web Sources

A number of Web sites that often link to government sites are available to the public. These can also point you in the direction of essential information. The following is a representative sample:

- AOL: **http://search.aol.com/cat.adp?id=168&layer=&from=subcats**
- drkoop.com®: **http://www.drkoop.com/conditions/ency/index.html**
- Family Village: **http://www.familyvillage.wisc.edu/specific.htm**
- Google: **http://directory.google.com/Top/Health/Conditions_and_Diseases/**
- Med Help International: **http://www.medhelp.org/HealthTopics/A.html**
- Open Directory Project: **http://dmoz.org/Health/Conditions_and_Diseases/**
- Yahoo.com: **http://dir.yahoo.com/Health/Diseases_and_Conditions/**
- WebMD®Health: **http://my.webmd.com/health_topics**

Vocabulary Builder

The material in this chapter may have contained a number of unfamiliar words. The following Vocabulary Builder introduces you to terms used in this chapter that have not been covered in the previous chapter:

Ankle: That part of the lower limb directly above the foot. [NIH]

Autoimmunity: Process whereby the immune system reacts against the body's own tissues. Autoimmunity may produce or be caused by autoimmune diseases. [NIH]

Biopsy: The removal and examination, usually microscopic, of tissue from the living body, performed to establish precise diagnosis. [EU]

Cytotoxic: Pertaining to or exhibiting cytotoxicity. [EU]

Endocrinology: A subspecialty of internal medicine concerned with the metabolism, physiology, and disorders of the endocrine system. [NIH]

Glomerulonephritis: A variety of nephritis characterized by inflammation of the capillary loops in the glomeruli of the kidney. It occurs in acute, subacute, and chronic forms and may be secondary to haemolytic streptococcal infection. Evidence also supports possible immune or autoimmune mechanisms. [EU]

Hematology: A subspecialty of internal medicine concerned with

morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Heredity: 1. the genetic transmission of a particular quality or trait from parent to offspring. 2. the genetic constitution of an individual. [EU]

Inflammation: A pathological process characterized by injury or destruction of tissues caused by a variety of cytologic and chemical reactions. It is usually manifested by typical signs of pain, heat, redness, swelling, and loss of function. [NIH]

Lupus: A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

Molecular: Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

Nephritis: Inflammation of the kidney; a focal or diffuse proliferative or destructive process which may involve the glomerulus, tubule, or interstitial renal tissue. [EU]

Potassium: An element that is in the alkali group of metals. It has an atomic symbol K, atomic number 19, and atomic weight 39.10. It is the chief cation in the intracellular fluid of muscle and other cells. Potassium ion is a strong electrolyte and it plays a significant role in the regulation of fluid volume and maintenance of the water-electrolyte balance. [NIH]

Progressive: Advancing; going forward; going from bad to worse; increasing in scope or severity. [EU]

Rheumatoid: Resembling rheumatism. [EU]

Sclerosis: A induration, or hardening; especially hardening of a part from inflammation and in diseases of the interstitial substance. The term is used chiefly for such a hardening of the nervous system due to hyperplasia of the connective tissue or to designate hardening of the blood vessels. [EU]

Spectrum: A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

Systemic: Pertaining to or affecting the body as a whole. [EU]

Toxicology: The science concerned with the detection, chemical composition, and pharmacologic action of toxic substances or poisons and the treatment and prevention of toxic manifestations. [NIH]

Transplantation: The grafting of tissues taken from the patient's own body or from another. [EU]

Urinalysis: Examination of urine by chemical, physical, or microscopic means. Routine urinalysis usually includes performing chemical screening

tests, determining specific gravity, observing any unusual color or odor, screening for bacteriuria, and examining the sediment microscopically. [NIH]

Urology: A surgical specialty concerned with the study, diagnosis, and treatment of diseases of the urinary tract in both sexes and the genital tract in the male. It includes the specialty of andrology which addresses both male genital diseases and male infertility. [NIH]

Viruses: Minute infectious agents whose genomes are composed of DNA or RNA, but not both. They are characterized by a lack of independent metabolism and the inability to replicate outside living host cells. [NIH]

Vitiligo: A disorder consisting of areas of macular depigmentation, commonly on extensor aspects of extremities, on the face or neck, and in skin folds. Age of onset is often in young adulthood and the condition tends to progress gradually with lesions enlarging and extending until a quiescent state is reached. [NIH]

CHAPTER 2. SEEKING GUIDANCE

Overview

Some patients are comforted by the knowledge that a number of organizations dedicate their resources to helping people with lupus nephritis. These associations can become invaluable sources of information and advice. Many associations offer aftercare support, financial assistance, and other important services. Furthermore, healthcare research has shown that support groups often help people to better cope with their conditions.[9] In addition to support groups, your physician can be a valuable source of guidance and support. Therefore, finding a physician that can work with your unique situation is a very important aspect of your care.

In this chapter, we direct you to resources that can help you find patient organizations and medical specialists. We begin by describing how to find associations and peer groups that can help you better understand and cope with lupus nephritis. The chapter ends with a discussion on how to find a doctor that is right for you.

Associations and Lupus Nephritis

As mentioned by the Agency for Healthcare Research and Quality, sometimes the emotional side of an illness can be as taxing as the physical side.[10] You may have fears or feel overwhelmed by your situation. Everyone has different ways of dealing with disease or physical injury. Your attitude, your expectations, and how well you cope with your condition can all

[9] Churches, synagogues, and other houses of worship might also have groups that can offer you the social support you need.
[10] This section has been adapted from **http://www.ahcpr.gov/consumer/diaginf5.htm**.

influence your well-being. This is true for both minor conditions and serious illnesses. For example, a study on female breast cancer survivors revealed that women who participated in support groups lived longer and experienced better quality of life when compared with women who did not participate. In the support group, women learned coping skills and had the opportunity to share their feelings with other women in the same situation.

In addition to associations or groups that your doctor might recommend, we suggest that you consider the following list (if there is a fee for an association, you may want to check with your insurance provider to find out if the cost will be covered):

- **American Autoimmune Related Diseases Association, Inc**

  Address: American Autoimmune Related Diseases Association, Inc. Michigan National Bank Building, 15475 Gratiot Avenue, Detroit, MI 48205

  Telephone: (313) 371-8600 Toll-free: (800) 598- 4668

  Fax: (313) 371-6002

  Email: aarda@aol.com

  Web Site: http://www.aarda.org

  Background: The American Autoimmune Related Diseases Association, Inc. (AARDA) is a national not-for-profit voluntary health agency dedicated to bringing a national focus to autoimmunity, a major cause of serious chronic diseases. The Association was founded for the purposes of supporting research to find a cure for autoimmune diseases and providing services to affected individuals. In addition, the Association's goals include increasing the public's awareness that autoimmunity is the cause of more than 80 serious chronic diseases; bringing national focus and collaborative effort among state and national voluntary health groups that represent autoimmune diseases; and serving as a national advocate for individuals and families affected by the physical, emotional, and financial effects of autoimmune disease. The American Autoimmune Related Diseases Association produces educational and support materials including fact sheets, brochures, pamphlets, and a newsletter entitled 'In Focus.'.

  Relevant area(s) of interest: Interstitial Cystitis

Finding More Associations

There are a number of directories that list additional medical associations that you may find useful. While not all of these directories will provide

different information than what is listed above, by consulting all of them, you will have nearly exhausted all sources for patient associations.

The National Health Information Center (NHIC)

The National Health Information Center (NHIC) offers a free referral service to help people find organizations that provide information about lupus nephritis. For more information, see the NHIC's Web site at **http://www.health.gov/NHIC/** or contact an information specialist by calling 1-800-336-4797.

DIRLINE

A comprehensive source of information on associations is the DIRLINE database maintained by the National Library of Medicine. The database comprises some 10,000 records of organizations, research centers, and government institutes and associations which primarily focus on health and biomedicine. DIRLINE is available via the Internet at the following Web site: **http://dirline.nlm.nih.gov/**. Simply type in "lupus nephritis" (or a synonym) or the name of a topic, and the site will list information contained in the database on all relevant organizations.

The Combined Health Information Database

Another comprehensive source of information on healthcare associations is the Combined Health Information Database. Using the "Detailed Search" option, you will need to limit your search to "Organizations" and "lupus nephritis". Type the following hyperlink into your Web browser: **http://chid.nih.gov/detail/detail.html**. To find associations, use the drop boxes at the bottom of the search page where "You may refine your search by." For publication date, select "All Years." Then, select your preferred language and the format option "Organization Resource Sheet." By making these selections and typing in "lupus nephritis" (or synonyms) into the "For these words:" box, you will only receive results on organizations dealing with lupus nephritis. You should check back periodically with this database since it is updated every 3 months.

The National Organization for Rare Disorders, Inc.

The National Organization for Rare Disorders, Inc. has prepared a Web site that provides, at no charge, lists of associations organized by specific diseases. You can access this database at the following Web site: **http://www.rarediseases.org/cgi-bin/nord/searchpage**. Select the option called "Organizational Database (ODB)" and type "lupus nephritis" (or a synonym) in the search box.

Online Support Groups

In addition to support groups, commercial Internet service providers offer forums and chat rooms for people with different illnesses and conditions. WebMD®, for example, offers such a service at their Web site: **http://boards.webmd.com/roundtable**. These online self-help communities can help you connect with a network of people whose concerns are similar to yours. Online support groups are places where people can talk informally. If you read about a novel approach, consult with your doctor or other healthcare providers, as the treatments or discoveries you hear about may not be scientifically proven to be safe and effective. The following Internet sites may be of particular interest:

- **Missouri Arthritis Rehabilitation Research and Training Center**
  http://www.muhealth.org/~arthritis/lupus/links.html

- **National Kidney Foundation of Southern California**
  http://www.kidneysocal.org/calendar_supportgroups.html

- **Lupus Foundation of America, Georgia Chapter**
  http://www.lfaga.org/serv02.htm

Finding Doctors

One of the most important aspects of your treatment will be the relationship between you and your doctor or specialist. All patients with lupus nephritis must go through the process of selecting a physician. While this process will vary from person to person, the Agency for Healthcare Research and Quality makes a number of suggestions, including the following:[11]

- If you are in a managed care plan, check the plan's list of doctors first.

[11] This section is adapted from the AHRQ: **www.ahrq.gov/consumer/qntascii/qntdr.htm**.

- Ask doctors or other health professionals who work with doctors, such as hospital nurses, for referrals.
- Call a hospital's doctor referral service, but keep in mind that these services usually refer you to doctors on staff at that particular hospital. The services do not have information on the quality of care that these doctors provide.
- Some local medical societies offer lists of member doctors. Again, these lists do not have information on the quality of care that these doctors provide.

Additional steps you can take to locate doctors include the following:

- Check with the associations listed earlier in this chapter.
- Information on doctors in some states is available on the Internet at **http://www.docboard.org**. This Web site is run by "Administrators in Medicine," a group of state medical board directors.
- The American Board of Medical Specialties can tell you if your doctor is board certified. "Certified" means that the doctor has completed a training program in a specialty and has passed an exam, or "board," to assess his or her knowledge, skills, and experience to provide quality patient care in that specialty. Primary care doctors may also be certified as specialists. The AMBS Web site is located at **http://www.abms.org/newsearch.asp**.[12] You can also contact the ABMS by phone at 1-866-ASK-ABMS.
- You can call the American Medical Association (AMA) at 800-665-2882 for information on training, specialties, and board certification for many licensed doctors in the United States. This information also can be found in "Physician Select" at the AMA's Web site: **http://www.ama-assn.org/aps/amahg.htm**.

Finding a Urologist

The American Urological Association (AUA) provides the public with a free-to-use "Find A Urologist" service to help patients find member urologists in their area. The database can be searched by physician name, city, U.S. State, or country and is available via the AUA's Web site located at **http://www.auanet.org/patient_info/find_urologist/index.cfm**. According to the AUA: "The American Urological Association is the professional

[12] While board certification is a good measure of a doctor's knowledge, it is possible to receive quality care from doctors who are not board certified.

association for urologists. As the premier professional association for the advancement of urologic patient care, the AUA is pleased to provide Find A Urologist, an on-line referral service for patients to use when looking for a urologist. All of our active members are certified by the American Board of Urology, which is an important distinction of the urologist's commitment to continuing education and superior patient care."[13]

If the previous sources did not meet your needs, you may want to log on to the Web site of the National Organization for Rare Disorders (NORD) at **http://www.rarediseases.org/**. NORD maintains a database of doctors with expertise in various rare diseases. The Metabolic Information Network (MIN), 800-945-2188, also maintains a database of physicians with expertise in various metabolic diseases.

Selecting Your Doctor[14]

When you have compiled a list of prospective doctors, call each of their offices. First, ask if the doctor accepts your health insurance plan and if he or she is taking new patients. If the doctor is not covered by your plan, ask yourself if you are prepared to pay the extra costs. The next step is to schedule a visit with your chosen physician. During the first visit you will have the opportunity to evaluate your doctor and to find out if you feel comfortable with him or her. Ask yourself, did the doctor:

- Give me a chance to ask questions about lupus nephritis?
- Really listen to my questions?
- Answer in terms I understood?
- Show respect for me?
- Ask me questions?
- Make me feel comfortable?
- Address the health problem(s) I came with?
- Ask me my preferences about different kinds of treatments for lupus nephritis?
- Spend enough time with me?

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[13] Quotation taken from the AACE's Web site: **http://www.aace.com/memsearch.php**.
[14] This section has been adapted from the AHRQ:
www.ahrq.gov/consumer/qntascii/qntdr.htm.

Trust your instincts when deciding if the doctor is right for you. But remember, it might take time for the relationship to develop. It takes more than one visit for you and your doctor to get to know each other.

Working with Your Doctor[15]

Research has shown that patients who have good relationships with their doctors tend to be more satisfied with their care and have better results. Here are some tips to help you and your doctor become partners:

- You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.
- It is important to tell your doctor personal information, even if it makes you feel embarrassed or uncomfortable.
- Bring a "health history" list with you (and keep it up to date).
- Always bring any medications you are currently taking with you to the appointment, or you can bring a list of your medications including dosage and frequency information. Talk about any allergies or reactions you have had to your medications.
- Tell your doctor about any natural or alternative medicines you are taking.
- Bring other medical information, such as x-ray films, test results, and medical records.
- Ask questions. If you don't, your doctor will assume that you understood everything that was said.
- Write down your questions before your visit. List the most important ones first to make sure that they are addressed.
- Consider bringing a friend with you to the appointment to help you ask questions. This person can also help you understand and/or remember the answers.
- Ask your doctor to draw pictures if you think that this would help you understand.
- Take notes. Some doctors do not mind if you bring a tape recorder to help you remember things, but always ask first.

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[15] This section has been adapted from the AHRQ: **www.ahrq.gov/consumer/qntascii/qntdr.htm**.

- Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff or schedule a telephone appointment.
- Take information home. Ask for written instructions. Your doctor may also have brochures and audio and videotapes that can help you.
- After leaving the doctor's office, take responsibility for your care. If you have questions, call. If your symptoms get worse or if you have problems with your medication, call. If you had tests and do not hear from your doctor, call for your test results. If your doctor recommended that you have certain tests, schedule an appointment to get them done. If your doctor said you should see an additional specialist, make an appointment.

By following these steps, you will enhance the relationship you will have with your physician.

Broader Health-Related Resources

In addition to the references above, the NIH has set up guidance Web sites that can help patients find healthcare professionals. These include:[16]

- Caregivers:
  http://www.nlm.nih.gov/medlineplus/caregivers.html
- Choosing a Doctor or Healthcare Service:
  http://www.nlm.nih.gov/medlineplus/choosingadoctororhealthcareservice.html
- Hospitals and Health Facilities:
  http://www.nlm.nih.gov/medlineplus/healthfacilities.html

[16] You can access this information at:
http://www.nlm.nih.gov/medlineplus/healthsystem.html.

CHAPTER 3. CLINICAL TRIALS AND LUPUS NEPHRITIS

Overview

Very few medical conditions have a single treatment. The basic treatment guidelines that your physician has discussed with you, or those that you have found using the techniques discussed in Chapter 1, may provide you with all that you will require. For some patients, current treatments can be enhanced with new or innovative techniques currently under investigation. In this chapter, we will describe how clinical trials work and show you how to keep informed of trials concerning lupus nephritis.

What Is a Clinical Trial?[17]

Clinical trials involve the participation of people in medical research. Most medical research begins with studies in test tubes and on animals. Treatments that show promise in these early studies may then be tried with people. The only sure way to find out whether a new treatment is safe, effective, and better than other treatments for lupus nephritis is to try it on patients in a clinical trial.

[17] The discussion in this chapter has been adapted from the NIH and the NEI: **www.nei.nih.gov/netrials/ctivr.htm**.

What Kinds of Clinical Trials Are There?

Clinical trials are carried out in three phases:

- **Phase I.** Researchers first conduct Phase I trials with small numbers of patients and healthy volunteers. If the new treatment is a medication, researchers also try to determine how much of it can be given safely.
- **Phase II.** Researchers conduct Phase II trials in small numbers of patients to find out the effect of a new treatment on lupus nephritis.
- **Phase III.** Finally, researchers conduct Phase III trials to find out how new treatments for lupus nephritis compare with standard treatments already being used. Phase III trials also help to determine if new treatments have any side effects. These trials--which may involve hundreds, perhaps thousands, of people--can also compare new treatments with no treatment.

How Is a Clinical Trial Conducted?

Various organizations support clinical trials at medical centers, hospitals, universities, and doctors' offices across the United States. The "principal investigator" is the researcher in charge of the study at each facility participating in the clinical trial. Most clinical trial researchers are medical doctors, academic researchers, and specialists. The "clinic coordinator" knows all about how the study works and makes all the arrangements for your visits.

All doctors and researchers who take part in the study on lupus nephritis carefully follow a detailed treatment plan called a protocol. This plan fully explains how the doctors will treat you in the study. The "protocol" ensures that all patients are treated in the same way, no matter where they receive care.

Clinical trials are controlled. This means that researchers compare the effects of the new treatment with those of the standard treatment. In some cases, when no standard treatment exists, the new treatment is compared with no treatment. Patients who receive the new treatment are in the treatment group. Patients who receive a standard treatment or no treatment are in the "control" group. In some clinical trials, patients in the treatment group get a new medication while those in the control group get a placebo. A placebo is a harmless substance, a "dummy" pill, that has no effect on lupus nephritis. In other clinical trials, where a new surgery or device (not a medicine) is being tested, patients in the control group may receive a "sham treatment."

This treatment, like a placebo, has no effect on lupus nephritis and does not harm patients.

Researchers assign patients "randomly" to the treatment or control group. This is like flipping a coin to decide which patients are in each group. If you choose to participate in a clinical trial, you will not know which group you will be appointed to. The chance of any patient getting the new treatment is about 50 percent. You cannot request to receive the new treatment instead of the placebo or sham treatment. Often, you will not know until the study is over whether you have been in the treatment group or the control group. This is called a "masked" study. In some trials, neither doctors nor patients know who is getting which treatment. This is called a "double masked" study. These types of trials help to ensure that the perceptions of the patients or doctors will not affect the study results.

Natural History Studies

Unlike clinical trials in which patient volunteers may receive new treatments, natural history studies provide important information to researchers on how lupus nephritis develops over time. A natural history study follows patient volunteers to see how factors such as age, sex, race, or family history might make some people more or less at risk for lupus nephritis. A natural history study may also tell researchers if diet, lifestyle, or occupation affects how a disease or disorder develops and progresses. Results from these studies provide information that helps answer questions such as: How fast will a disease or disorder usually progress? How bad will the condition become? Will treatment be needed?

What Is Expected of Patients in a Clinical Trial?

Not everyone can take part in a clinical trial for a specific disease or disorder. Each study enrolls patients with certain features or eligibility criteria. These criteria may include the type and stage of disease or disorder, as well as, the age and previous treatment history of the patient. You or your doctor can contact the sponsoring organization to find out more about specific clinical trials and their eligibility criteria. If you are interested in joining a clinical trial, your doctor must contact one of the trial's investigators and provide details about your diagnosis and medical history.

If you participate in a clinical trial, you may be required to have a number of medical tests. You may also need to take medications and/or undergo

surgery. Depending upon the treatment and the examination procedure, you may be required to receive inpatient hospital care. Or, you may have to return to the medical facility for follow-up examinations. These exams help find out how well the treatment is working. Follow-up studies can take months or years. However, the success of the clinical trial often depends on learning what happens to patients over a long period of time. Only patients who continue to return for follow-up examinations can provide this important long-term information.

Recent Trials on Lupus Nephritis

The National Institutes of Health and other organizations sponsor trials on various diseases and disorders. Because funding for research goes to the medical areas that show promising research opportunities, it is not possible for the NIH or others to sponsor clinical trials for every disease and disorder at all times. The following lists recent trials dedicated to lupus nephritis.[18] If the trial listed by the NIH is still recruiting, you may be eligible. If it is no longer recruiting or has been completed, then you can contact the sponsors to learn more about the study and, if published, the results. Further information on the trial is available at the Web site indicated. Please note that some trials may no longer be recruiting patients or are otherwise closed. Before contacting sponsors of a clinical trial, consult with your physician who can help you determine if you might benefit from participation.

- **Immune System Related Kidney Disease**

  Condition(s): Glomerulonephritis; Lupus Nephritis; Membranous Glomerulonephritis; Nephritis; Nephrotic Syndrome

  Study Status: This study is currently recruiting patients.

  Sponsor(s): National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

  Purpose - Excerpt: Kidney diseases related to the immune system include, nephrotic syndrome, glomerulonephritis, membranous nephropathy, lupus nephritis, and nephritis associated with connective tissue disorders. This study will allow researchers to admit and follow patients suffering from autoimmune diseases of the kidney. It will attempt to provide information about the causes and specific abnormalities associated with autoimmune kidney disease. Patients with kidney disease as a result of their immune system, and patients with diseases of the immune system who may later develop kidney disease, will be potential subjects for this study. Patients will undergo a history

[18] These are listed at **www.ClinicalTrials.gov**.

and physical examination, and standard laboratory test to more closely understand the causes, signs, symptoms, and responses to medication of these diseases. Based on these evaluations the patients may qualify as candidates for other experimental studies. At any time these patients may be asked to submit blood or urine samples for further research.

Study Type: Observational

Contact(s): Maryland; National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), 9000 Rockville Pike Bethesda, Maryland, 20892, United States; Recruiting; Patient Recruitment and Public Liaison Office 1-800-411-1222 prpl@mail.cc.nih.gov; TTY 1-866-411-1010

Web Site: http://clinicaltrials.gov/ct/gui/show/NCT00001979

- **Safety and Efficacy Study of LJP 394 (abetimus sodium) to treat lupus kidney disease**

  Condition(s): Immunologic Diseases; Autoimmune Diseases; Systemic Lupus Erythematosus; Lupus Nephritis; Lupus Glomerulonephritis

  Study Status: This study is currently recruiting patients.

  Sponsor(s): La Jolla Pharmaceutical Company

  Purpose - Excerpt: The purpose of this study is to determine whether LJP 394 (abetimus sodium) is safe and effective in delaying and reducing renal flares in patients with lupus nephritis.

  Phase(s): Phase III

  Study Type: Interventional

  Contact(s): see Web site below

  Web Site: http://clinicaltrials.gov/ct/gui/show/NCT00035308

- **Study of Systemic Lupus Erythematosus**

  Condition(s): Lupus Nephritis; Systemic Lupus Erythematosus

  Study Status: This study is currently recruiting patients.

  Sponsor(s): National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

  Purpose - Excerpt: This protocol will evaluate patients with systemic lupus erythematosus (SLE) and their relatives to learn more about how the disease develops and changes over time. It will also study genetic factors that make a person susceptible to SLE. Patients 10 years of age and older with known or suspected SLE and their relatives may be eligible for this study. Patients will be evaluated with a medical history and physical examination, blood and urine tests. Other procedures may

include: 1. Electrocardiogram 2. 24-hour urine collection 3. Imaging studies, such as chest and joint X-rays, magnetic resonance imaging (MRI) scans, bone scans, and bone densitometry. 4. Questionnaire about the degree of disease activity, and survey of risk factors for disease complications. 5. Apheresis-Collection of plasma (fluid portion of blood) or blood cells for analysis. Whole blood is collected through a needle in an arm vein. The blood circulates through a machine that separates it into its components. The required component (plasma or cells) is removed and the rest of the blood is returned to the body through the same needle or through a second needle in the other arm. 6. Skin biopsy-Removal of a small skin sample for microscopic analysis. An area of skin is numbed with an anesthetic and a small circular portion (about 1/4 inch in diameter) is removed, using a sharp cookie cutter-type instrument. 7. Kidney, bone marrow or other organ biopsy-Removal of a small sample of organ tissue. These biopsies are done only if they can provide information useful in better understanding the disease or making treatment decisions. 8. Genetic studies-Collection of a blood sample for gene testing. Patients will be followed at least once a year with a brief history and physical examination and routine blood and urine tests. Some patients may be seen more often. Treatment recommendations will be offered to patients' physicians, and patients who are eligible for other research treatment studies will be invited to enroll. Participating relatives of patients will fill out a brief medical history questionnaire and provide a DNA sample (either a blood sample or tissue swab from the inside of the cheek) for genetic testing.

Study Type: Observational

Contact(s): Maryland; National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), 9000 Rockville Pike Bethesda, Maryland, 20892, United States; Recruiting; Patient Recruitment and Public Liaison Office 1-800-411-1222 prpl@mail.cc.nih.gov; TTY 1-866-411-1010

Web Site: http://clinicaltrials.gov/ct/gui/show/NCT00001372

- **Cyclophosphamide and Fludarabine to Treat Lupus Nephritis**

  Condition(s): Glomerulonephritis; Lupus Nephritis; Systemic Lupus Erythematosus

  Study Status: This study is no longer recruiting patients.

  Sponsor(s): National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

  Purpose - Excerpt: This study will test the safety and effectiveness of combination therapy with cyclophosphamide (Cytoxan) and fludarabine in treating lupus nephritis (kidney inflammation). This condition,

common in patients with systemic lupus erythematosus, is caused by abnormal action of immune cells called lymphocytes against the kidneys. Left untreated, severe cases can result in loss of kidney function. The current treatment of choice-intermittent high doses (pulses) of cyclophosphamide-does not work in all patients and causes infertility in many women. The rate of infertility in men is not known. This study will examine whether fludarabine can safely be given with significantly lower doses of cyclophosphamide, and if this combination controls kidney inflammation. Patients 18 years of age and older with severe lupus nephritis (called proliferative lupus nephritis) may be eligible for this study. Candidates will have a history and physical examination; blood and urine tests; chest X-ray; electrocardiogram; cancer screening that may include a Pap smear, mammogram, rectal examination, PSA testing, and sigmoidoscopy. Participants will be divided into one of the following treatment groups: Group 1-Patients undergo three treatment cycles of cyclophosphamide, taken by mouth, and fludarabine, injected subcutaneously (under the skin). Patients receive both drugs on day 1 of the cycle, and fludarabine alone on days 2 and 3. This regimen is repeated once every 5 weeks for three cycles. Group 2-Same as for Group 1, except fludarabine injections are given intravenously (through a vein) for the second treatment cycle. Patients in this group have frequent blood sampling during the first and second treatment cycles to monitor blood levels of the drug. Samples are collected before the first injection is given and at 0.5, 1, 1.5, 2, 4, 8, 24 and 48 hours after the third injection. A total 12 tablespoons of blood is drawn over a 2-month period. All patients will have blood drawn once or twice a week during the first two cycles and then less frequently to monitor blood counts. Some patients will have the following additional procedures to test the effects of treatment on lymphocytes: 1. Blood sample collection 2. Bone marrow aspiration-The skin over the hip bone is cleaned and a local anesthetic is injected into the outer covering of the bone. Bone marrow is suctioned through the needle into an attached syringe. The procedure is done before treatment begins, at the end of treatment, and 6 months after treatment. 3. Tonsillar biopsy-The tonsils are numbed with a local anesthetic and 1 to 4 pieces of tissue are removed using special forceps. The procedure is done before treatment begins, at the end of treatment, and 6 months after treatment. 4. Magnetic resonance imaging (MRI) of the abdomen-The patients lies on a table in a narrow cylinder (the MRI scanner) containing a strong magnetic field, which is used to create images of parts of the body in small section views. Patients will be followed for at least 24 months to monitor late side effects and the response to treatment.

Phase(s): Phase I

Study Type: Interventional

Contact(s): Maryland; National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), 9000 Rockville Pike Bethesda, Maryland, 20892, United States; Patient Recruitment and Public Liaison Office 1-800-411-1222 prpl@mail.cc.nih.gov; TTY 1-866-411-1010

Web Site: http://clinicaltrials.gov/ct/gui/show/NCT00001676

Benefits and Risks[19]

What Are the Benefits of Participating in a Clinical Trial?

If you are interested in a clinical trial, it is important to realize that your participation can bring many benefits to you and society at large:

- A new treatment could be more effective than the current treatment for lupus nephritis. Although only half of the participants in a clinical trial receive the experimental treatment, if the new treatment is proved to be more effective and safer than the current treatment, then those patients who did not receive the new treatment during the clinical trial may be among the first to benefit from it when the study is over.
- If the treatment is effective, then it may improve health or prevent diseases or disorders.
- Clinical trial patients receive the highest quality of medical care. Experts watch them closely during the study and may continue to follow them after the study is over.
- People who take part in trials contribute to scientific discoveries that may help other people with lupus nephritis. In cases where certain diseases or disorders run in families, your participation may lead to better care or prevention for your family members.

The Informed Consent

Once you agree to take part in a clinical trial, you will be asked to sign an "informed consent." This document explains a clinical trial's risks and benefits, the researcher's expectations of you, and your rights as a patient.

[19] This section has been adapted from ClinicalTrials.gov, a service of the National Institutes of Health: **http://www.clinicaltrials.gov/ct/gui/c/a1r/info/whatis?JServSessionIdzone_ct=9jmun6f291**.

What Are the Risks?

Clinical trials may involve risks as well as benefits. Whether or not a new treatment will work cannot be known ahead of time. There is always a chance that a new treatment may not work better than a standard treatment. There is also the possibility that it may be harmful. The treatment you receive may cause side effects that are serious enough to require medical attention.

How Is Patient Safety Protected?

Clinical trials can raise fears of the unknown. Understanding the safeguards that protect patients can ease some of these fears. Before a clinical trial begins, researchers must get approval from their hospital's Institutional Review Board (IRB), an advisory group that makes sure a clinical trial is designed to protect patient safety. During a clinical trial, doctors will closely watch you to see if the treatment is working and if you are experiencing any side effects. All the results are carefully recorded and reviewed. In many cases, experts from the Data and Safety Monitoring Committee carefully monitor each clinical trial and can recommend that a study be stopped at any time. You will only be asked to take part in a clinical trial as a volunteer giving informed consent.

What Are a Patient's Rights in a Clinical Trial?

If you are eligible for a clinical trial, you will be given information to help you decide whether or not you want to participate. As a patient, you have the right to:

- Information on all known risks and benefits of the treatments in the study.
- Know how the researchers plan to carry out the study, for how long, and where.
- Know what is expected of you.
- Know any costs involved for you or your insurance provider.
- Know before any of your medical or personal information is shared with other researchers involved in the clinical trial.
- Talk openly with doctors and ask any questions.

After you join a clinical trial, you have the right to:

- Leave the study at any time. Participation is strictly voluntary. However, you should not enroll if you do not plan to complete the study.
- Receive any new information about the new treatment.
- Continue to ask questions and get answers.
- Maintain your privacy. Your name will not appear in any reports based on the study.
- Know whether you participated in the treatment group or the control group (once the study has been completed).

What about Costs?

In some clinical trials, the research facility pays for treatment costs and other associated expenses. You or your insurance provider may have to pay for costs that are considered standard care. These things may include inpatient hospital care, laboratory and other tests, and medical procedures. You also may need to pay for travel between your home and the clinic. You should find out about costs before committing to participation in the trial. If you have health insurance, find out exactly what it will cover. If you don't have health insurance, or if your insurance company will not cover your costs, talk to the clinic staff about other options for covering the cost of your care.

What Should You Ask before Deciding to Join a Clinical Trial?

Questions you should ask when thinking about joining a clinical trial include the following:

- What is the purpose of the clinical trial?
- What are the standard treatments for lupus nephritis? Why do researchers think the new treatment may be better? What is likely to happen to me with or without the new treatment?
- What tests and treatments will I need? Will I need surgery? Medication? Hospitalization?
- How long will the treatment last? How often will I have to come back for follow-up exams?
- What are the treatment's possible benefits to my condition? What are the short- and long-term risks? What are the possible side effects?

- Will the treatment be uncomfortable? Will it make me feel sick? If so, for how long?
- How will my health be monitored?
- Where will I need to go for the clinical trial? How will I get there?
- How much will it cost to be in the study? What costs are covered by the study? How much will my health insurance cover?
- Will I be able to see my own doctor? Who will be in charge of my care?
- Will taking part in the study affect my daily life? Do I have time to participate?
- How do I feel about taking part in a clinical trial? Are there family members or friends who may benefit from my contributions to new medical knowledge?

Keeping Current on Clinical Trials

Various government agencies maintain databases on trials. The U.S. National Institutes of Health, through the National Library of Medicine, has developed ClinicalTrials.gov to provide patients, family members, and physicians with current information about clinical research across the broadest number of diseases and conditions.

The site was launched in February 2000 and currently contains approximately 5,700 clinical studies in over 59,000 locations worldwide, with most studies being conducted in the United States. ClinicalTrials.gov receives about 2 million hits per month and hosts approximately 5,400 visitors daily. To access this database, simply go to their Web site (**www.clinicaltrials.gov**) and search by "lupus nephritis" (or synonyms).

While ClinicalTrials.gov is the most comprehensive listing of NIH-supported clinical trials available, not all trials are in the database. The database is updated regularly, so clinical trials are continually being added. The following is a list of specialty databases affiliated with the National Institutes of Health that offer additional information on trials:

- For clinical studies at the Warren Grant Magnuson Clinical Center located in Bethesda, Maryland, visit their Web site:
  http://clinicalstudies.info.nih.gov/

- For clinical studies conducted at the Bayview Campus in Baltimore, Maryland, visit their Web site: **http://www.jhbmc.jhu.edu/studies/index.html**
- For trials on diseases of the digestive system and kidneys, and diabetes, visit the National Institute of Diabetes and Digestive and Kidney Diseases: **http://www.niddk.nih.gov/patient/patient.htm**

General References

The following references describe clinical trials and experimental medical research. They have been selected to ensure that they are likely to be available from your local or online bookseller or university medical library. These references are usually written for healthcare professionals, so you may consider consulting with a librarian or bookseller who might recommend a particular reference. The following includes some of the most readily available references (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **A Guide to Patient Recruitment : Today's Best Practices & Proven Strategies** by Diana L. Anderson; Paperback - 350 pages (2001), CenterWatch, Inc.; ISBN: 1930624115; **http://www.amazon.com/exec/obidos/ASIN/1930624115/icongroupinterna**
- **A Step-By-Step Guide to Clinical Trials** by Marilyn Mulay, R.N., M.S., OCN; Spiral-bound - 143 pages Spiral edition (2001), Jones & Bartlett Pub; ISBN: 0763715697; **http://www.amazon.com/exec/obidos/ASIN/0763715697/icongroupinterna**
- **The CenterWatch Directory of Drugs in Clinical Trials** by CenterWatch; Paperback - 656 pages (2000), CenterWatch, Inc.; ISBN: 0967302935; **http://www.amazon.com/exec/obidos/ASIN/0967302935/icongroupinterna**
- **The Complete Guide to Informed Consent in Clinical Trials** by Terry Hartnett (Editor); Paperback - 164 pages (2000), PharmSource Information Services, Inc.; ISBN: 0970153309; **http://www.amazon.com/exec/obidos/ASIN/0970153309/icongroupinterna**
- **Dictionary for Clinical Trials** by Simon Day; Paperback - 228 pages (1999), John Wiley & Sons; ISBN: 0471985961; **http://www.amazon.com/exec/obidos/ASIN/0471985961/icongroupinterna**
- **Extending Medicare Reimbursement in Clinical Trials** by Institute of Medicine Staff (Editor), et al; Paperback 1st edition (2000), National Academy Press; ISBN: 0309068886; **http://www.amazon.com/exec/obidos/ASIN/0309068886/icongroupinterna**

- **Handbook of Clinical Trials** by Marcus Flather (Editor); Paperback (2001), Remedica Pub Ltd; ISBN: 1901346293; **http://www.amazon.com/exec/obidos/ASIN/1901346293/icongroupinterna**

Vocabulary Builder

The following vocabulary builder gives definitions of words used in this chapter that have not been defined in previous chapters:

Abdomen: That portion of the body that lies between the thorax and the pelvis. [NIH]

Antibody: An immunoglobulin molecule that has a specific amino acid sequence by virtue of which it interacts only with the antigen that induced its synthesis in cells of the lymphoid series (especially plasma cells), or with antigen closely related to it. Antibodies are classified according to their ode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

Aspiration: The act of inhaling. [EU]

Biopsy: The removal and examination, usually microscopic, of tissue from the living body, performed to establish precise diagnosis. [EU]

Catheter: A tubular, flexible, surgical instrument for withdrawing fluids from (or introducing fluids into) a cavity of the body, especially one for introduction into the bladder through the urethra for the withdraw of urine. [EU]

Cyclophosphamide: Precursor of an alkylating nitrogen mustard antineoplastic and immunosuppressive agent that must be activated in the liver to form the active aldophosphamide. It is used in the treatment of lymphomas, leukemias, etc. Its side effect, alopecia, has been made use of in defleecing sheep. Cyclophosphamide may also cause sterility, birth defects, mutations, and cancer. [NIH]

Glomerulonephritis: A variety of nephritis characterized by inflammation of the capillary loops in the glomeruli of the kidney. It occurs in acute, subacute, and chronic forms and may be secondary to haemolytic streptococcal infection. Evidence also supports possible immune or autoimmune mechanisms. [EU]

Infertility: The diminished or absent ability to conceive or produce an offspring while sterility is the complete inability to conceive or produce an offspring. [NIH]

Inflammation: A pathological process characterized by injury or destruction of tissues caused by a variety of cytologic and chemical reactions. It is

usually manifested by typical signs of pain, heat, redness, swelling, and loss of function. [NIH]

Infusion: The therapeutic introduction of a fluid other than blood, as saline solution, solution, into a vein. [EU]

Intermittent: Occurring at separated intervals; having periods of cessation of activity. [EU]

Lupus: A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

Nephritis: Inflammation of the kidney; a focal or diffuse proliferative or destructive process which may involve the glomerulus, tubule, or interstitial renal tissue. [EU]

Nephropathy: Disease of the kidneys. [EU]

Nephrotic: Pertaining to, resembling, or caused by nephrosis. [EU]

Prednisone: A synthetic anti-inflammatory glucocorticoid derived from cortisone. It is biologically inert and converted to prednisolone in the liver. [NIH]

Pulse: The rhythmical expansion and contraction of an artery produced by waves of pressure caused by the ejection of blood from the left ventricle of the heart as it contracts. [NIH]

Rectal: Pertaining to the rectum (= distal portion of the large intestine). [EU]

Sigmoidoscopy: Endoscopic examination, therapy or surgery of the sigmoid flexure. [NIH]

Systemic: Pertaining to or affecting the body as a whole. [EU]

PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL

ABOUT PART II

In Part II, we introduce you to additional resources and advanced research on lupus nephritis. All too often, patients who conduct their own research are overwhelmed by the difficulty in finding and organizing information. The purpose of the following chapters is to provide you an organized and structured format to help you find additional information resources on lupus nephritis. In Part II, as in Part I, our objective is not to interpret the latest advances on lupus nephritis or render an opinion. Rather, our goal is to give you access to original research and to increase your awareness of sources you may not have already considered. In this way, you will come across the advanced materials often referred to in pamphlets, books, or other general works. Once again, some of this material is technical in nature, so consultation with a professional familiar with lupus nephritis is suggested.

CHAPTER 4. STUDIES ON LUPUS NEPHRITIS

Overview

Every year, academic studies are published on lupus nephritis or related conditions. Broadly speaking, there are two types of studies. The first are peer reviewed. Generally, the content of these studies has been reviewed by scientists or physicians. Peer-reviewed studies are typically published in scientific journals and are usually available at medical libraries. The second type of studies is non-peer reviewed. These works include summary articles that do not use or report scientific results. These often appear in the popular press, newsletters, or similar periodicals.

In this chapter, we will show you how to locate peer-reviewed references and studies on lupus nephritis. We will begin by discussing research that has been summarized and is free to view by the public via the Internet. We then show you how to generate a bibliography on lupus nephritis and teach you how to keep current on new studies as they are published or undertaken by the scientific community.

The Combined Health Information Database

The Combined Health Information Database summarizes studies across numerous federal agencies. To limit your investigation to research studies and lupus nephritis, you will need to use the advanced search options. First, go to **http://chid.nih.gov/index.html**. From there, select the "Detailed Search" option (or go directly to that page with the following hyperlink: **http://chid.nih.gov/detail/detail.html**). The trick in extracting studies is found in the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the

format option "Journal Article." At the top of the search form, select the number of records you would like to see (we recommend 100) and check the box to display "whole records." We recommend that you type in "lupus nephritis" (or synonyms) into the "For these words:" box. Consider using the option "anywhere in record" to make your search as broad as possible. If you want to limit the search to only a particular field, such as the title of the journal, then select this option in the "Search in these fields" drop box. The following is a sample of what you can expect from this type of search:

- **Advances in the Treatment of Lupus Nephritis**

  Source: in Coggins, C.H.; Hancock, E.W., Eds. Annual Review of Medicine: Selected Topics in the Clinical Sciences, Volume 45. Palo Alto, CA: Annual Reviews Inc. 2001. p. 63-78.

  Contact: Available from Annual Reviews Inc. 4139 El Camino Way, P.O. Box 10139, Palo Alto, CA 94303-0139. (800) 523-8635. Fax: (415) 855-9815. Price: $47. ISBN: 0824305450.

  Summary: Systemic lupus erythematosus (SLE) is an autoimmune disease that leads to the formation and deposition of immune complexes throughout the body, which are pathogenic (causing disease) for SLE. Different forms of glomerulonephritis (inflammation of the filtering units of the kidney) can occur in patients with SLE and can contribute significantly to the associated morbidity (illness and complications) and, ultimately, mortality (death) from the disease. Over the past two decades, there have been significant strides in the understanding of the disease and in treatments that attempt to control the formation and deposition of anti-DNA auto-antibodies and immune complexes, as well as the subsequent inflammatory cascade mediated through various cellular and humoral pathways leading to progressive renal (kidney) damage and end stage renal disease (ESRD). This article reviews the current understanding of the pathogenesis and treatment of lupus nephritis in its various stages and discusses the experimental and human data regarding some of the potential newer forms of therapy. The authors discuss data regarding the use of steroids, azathioprine, cyclophosphamide, cyclosporine A, mycophenolate mofetil, gammaglobulin, plasmapheresis, LJP 394, flaxseed oil, bindarit, anti-CD-40 ligand, and CRLA41g. The authors conclude that the long term morbidity and mortality for patients with lupus nephritis (LN) has improved markedly over the past two decades. This is due in part to the addition of newer adjunctive therapies to control blood pressure and intraglomerular pressure, reduce proteinuria (protein in the urine), and manage hyperlipidemia (high levels of fats in the blood). 89 references.

- **Treatment of Lupus Nephritis**

  Source: Seminars in Nephrology. 20(3): 265-276. May 2000.

  Contact: Available from W.B. Saunders Company. Periodicals Department. 6277 Sea Harbor Drive, Orlando, FL 32887-4800. (800) 654-2452.

  Summary: Patients with lupus nephritis pose a therapeutic challenge and stimulate investigation of innovative treatment strategies. This article reviews those current and potential strategies that may optimize management of lupus nephritis. The clinical presentations of lupus nephritis can vary from asymptomatic hematuria (blood in the urine) or proteinuria (protein in the urine) to acute nephritic or nephrotic syndromes and from rapidly progressive glomerulonephritis to insidious chronic renal insufficiency. Although patient survival and renal function outcomes have improved over the last 4 decades, contemporary immunosuppressive regimens are not consistently effective and often require extended courses (resulting in negative drug effects and toxicity). Several strategies are under investigation to induce remissions more rapidly and to reduce the risk of long courses of cytotoxic drug therapy. The combination of pulse methylprednisolone and pulse cyclophosphamide may be more effective than pulse cyclophosphamide alone for patients with relatively severe proliferative lupus nephritis. A particularly vigorous strategy employs immunoablative cyclophosphamide, with or without stem cell rescue. Several studies of sequential immunosuppressive therapy are in progress. It is anticipated that long term toxicities can be lessened by substituting various maintenance agents (e.g., azathioprine or mycophenolate mofetil) after initial cyclophosphamide therapy has induced a renal responses. Innovative approaches (e.g., costimulatory blockade) offer the hope of more effective treatments without the risks of contemporary regimens. 2 figures. 2 tables. 88 references.

- **Progress in the Treatment of Proliferative Lupus Nephritis**

  Source: Current Opinion in Nephrology and Hypertension. 9(2): 107-115. 2000.

  Contact: Available from Lippincott Williams and Wilkins. P.O. Box 1600, Hagerstown, MD 21741. (800) 638-3030 or (301) 223-2300. Fax (301) 223-2400. Website: www.currentopinion.com.

  Summary: Lupus nephritis (kidney inflammation associated with systemic lupus erythematosus, or SLE) is often well developed at the time of diagnosis. This article reviews progress in the treatment of proliferative lupus nephritis. High dose corticosteroids are universally

accepted as the initial approach to the control of severe inflammation in the kidney. Long term disease control and the minimization of iatrogenic (physician caused) risk usually require adjunctive therapies that target the more fundamental immunoregulatory disturbances of lymphoid cells. Of the available cytotoxic drugs, cyclophosphamide is currently among the most effective, although it cannot be considered ideal in terms of efficacy or toxicity. New prospects for the treatment of proliferative lupus nephritis include novel immunosuppressive agents (e.g., mycophenolate, cyclosporine, fludarabine), combination chemotherapy (e.g., cyclophosphamide plus fludarabine), and sequential chemotherapy (e.g., cyclophosphamide followed by azathioprine), immunological reconstitution using intensive cytoreductive chemotherapy (with or without stem cell rescue), and co stimulatory molecule inhibition. Gene therapy remains an attractive prospect, but its feasibility clearly depends on the further definition of lupus promoting genes and the availability of methods to establish stable expression of disease corrective genes in the appropriate lymphoid cells. 3 figures. 83 references.

- **Efficacy of Mycophenolate Mofetil in Patients with Diffuse Proliferative Lupus Nephritis**

  Source: New England Journal of Medicine. 343(16): 1156-1162. October 19, 2000.

  Summary: The combination of cyclophosphamide and prednisolone is effective for the treatment of severe lupus nephritis (kidney inflammation associated with systemic lupus erythematosus or SLE) but has serious adverse effects. This article reports on a study that investigated the efficacy of mycophenolate mofetil in patients (n = 42) with proliferative lupus nephritis. The authors compared the efficacy and side effects of a regimen of prednisolone and mycophenolate mofetil given for 12 months (group 1) with those of a regimen of prednisolone and cyclophosphamide given for 6 months, followed by prednisolone and azathioprine for 6 months (group 2). Of the patients in Group 1 (n = 21), 81 percent had a complete remission, and 14 percent had a partial remission, as compared with 76 percent and 14 percent, respectively, of the 21 patients in Group 2. The improvements in the degree of proteinuria (protein in the urine) and the serum albumin (protein levels in the blood) and creatinine concentrations were similar in the two groups. One patient in each group discontinued treatment because of side effects. Infections were noted in 19 percent of the patients in Group 1 and in 33 percent of those in Group 2. Other adverse effects occurred only in group 2; they included amenorrhea (23 percent), hair loss (19 percent), leukopenia (10 percent), and death (10 percent). The rates of relapse were 15 percent in Group 1,

and 11 percent in Group 2. The authors conclude that for the treatment of diffuse proliferative lupus nephritis, the combination of mycophenolate mofetil and prednisolone is as effective as a regimen of cyclophosphamide and prednisolone followed by azathioprine and prednisolone, with similar levels of toxicity. 2 figures. 4 tables. 15 references.

- **Natural History and Treatment of Lupus Nephritis**

  Source: Seminars in Nephrology. 19(1): 2-11. January 1999.

  Contact: Available from W.B. Saunders Company. Periodicals Department. 6277 Sea Harbor Drive, Orlando, FL 32887-4800. (800) 654-2452.

  Summary: Renal involvement occurs in most patients with systemic lupus erythematosus (SLE). This article discusses the natural history and treatment of lupus nephritis. Contemporary therapeutic regimens for immunosuppression and for the treatment of hypertension, hyperlipidemia, infections, and seizures have likely contributed to improvements in the prognosis of these patients over the past four decades. Corticosteroids usually ameliorate the manifestations of lupus nephritis but achieve less complete and sustained remissions than cytotoxic drugs. Among the cytotoxic drugs, pulse cyclophosphamide has one of the best profiles of efficacy and toxicity. Because each episode of lupus nephritis exacerbation results in cumulative scarring, atrophy, and fibrosis, the authors recommend continued maintenance treatment for 1 year beyond the point of complete remission of proliferative lupus nephritis. Studies are in progress to determine whether innovative treatment strategies will enhance efficacy and minimize toxicity associated with cytotoxic drug therapies. Lupus membranous nephropathy poses a lower risk of renal failure, but persistent nephrotic syndrome confers risks of cardiovascular events; this form of lupus nephritis is usually treated with less intensive regimens of corticosteroids, cytotoxic drugs, or cyclosporine. The prognosis and overall success of treatment for lupus nephritis seem to vary widely among geographically and racially diverse populations. The causes for the apparently worse prognosis and poorer responses to treatment of lupus nephritis in African American patients are currently unexplained and require further study. Until such data are available, caution is clearly warranted in extrapolating evidence, particularly about the prognosis and effects of treatment among different populations of patients with lupus nephritis. 4 figures. 2 tables. 85 references. (AA).

- **Renal Vascular Lesions in Lupus Nephritis**

  Source: Medicine. 76(5): 355-368. September 1997.

  Contact: Available from Lippincott Williams and Wilkins. 227 East Washington Square, Philadelphia, PA 19106. (800) 638-6423.

  Summary: This article reports on a study of a series of 169 kidney biopsies performed between 1980 and 1994 in 132 patients with lupus nephritis (LN). The biopsies were performed to obtain a comprehensive clinical and histologic description of the intrarenal vascular lesions in LN and, more specifically, to clarify two incompletely resolved issues: first, to outline the clinical manifestations associated with the different types of renal vascular lesions and the prognostic significance of each; second, to better understand the so-called lupus vasculopathy (also called noninflammatory renal microangiopathy, renal angiitis, and other names). The terms used suggest that blood clotting and endothelial lesions are involved; however, the research reported in this article does not support these mechanisms. The authors favor the hypothesis that lupus vasculopathy could in fact be due to formation of immunoglobulin microvascular casts. The authors call for a better description of the clinical significance of these renal vascular lesions in LN, with particular attention to lupus vasculopathy. The most common vascular lesions were nonspecific sclerotic changes, found in 37 percent of the biopsies; the other common vascular lesions were immunoglobulin microvascular casts (24 percent of biopsies). Vasculitis and thrombotic microangiopathy were rare lesions (2.4 percent and 0.6 percent of cases, respectively). The authors conclude that, taken as a whole, their data confirm that the presence of active and severe forms of diffuse proliferative LN (WHO class IV) carries a worse prognosis compared with the other forms of LN. The long term renal survival of patients with class IV LN was significantly worse than that of patients with other forms of LN, with a 10 year renal survival of 70 percent compared with 85 percent, respectively. However, the data do not support the conclusions of some previous studies that the presence of intrarenal vascular lesions is a marker of poor renal prognosis in LN. 4 figures. 8 tables. 43 references. (AA-M).

- **Reliability of Histologic Scoring for Lupus Nephritis: A Community-Based Evaluation**

  Source: Annals of Internal Medicine. 119(8): 805-811. 1993.

  Summary: This article reports on a research study undertaken to determine the reliability of the National Institutes of Health (NIH)-modified semiquantitative histologic scoring system for lupus nephritis. Five pathologists, all experienced in reading renal biopsy specimens,

assessed 25 specimens that had been obtained from patients with a clinical diagnosis of systemic lupus erythematosus and showed diffuse proliferative glomerulonephritis. Biopsy specimens were scored independently and blindly by pathologists for components of nephritis chronicity and activity. Reliability was measured by percentage agreement, intraclass correlation coefficient or kappa statistic, and individual reader effect on the group arithmetic mean. The results show that, in a nonreferral setting, the NIH-modified scoring system for lupus nephritis is only moderately reproducible. The authors stress that, if this system is used to predict renal outcome, it may result in erroneous predictions of risk for renal failure and response to therapy. 2 figures. 5 tables. 39 references. (AA-M).

- **Treatment of Lupus Nephritis: A Work in Progress (editorial)**

  Source: New England Journal of Medicine. 343(16): 1182-1183. October 19, 2000.

  Summary: Until the pathogenesis (development of disease state) of nephritis (kidney infection) due to systemic lupus erythematosus (SLE) is unraveled, optimal treatment for patients with this disease remains an elusive goal. This article outlines one option for treatment of lupus nephritis, serving as an introduction to a separate article in this issue of the Journal. The author first reviews the differing presentations of SLE, noting that in some patients the kidneys are not involved but in others, there is rapidly progressive destructive kidney disease. This difference may be due in part to genetic risk factors, to environmental factors (such as exposure to ultraviolet light, infectious pathogens, and silica dust), race, or socioeconomic factors. In general, the treatment of lupus glomerulonephritis depends on the severity of the disease. Intravenous cyclophosphamide is given, in addition to oral glucocorticoids, for the aggressive forms of the disorder. However, the adverse effects of these therapies have prompted the search for alternative treatments. The author then comments on the accompanying article which presents the results of a study in which patients with diffuse proliferative lupus nephritis were successfully treated with prednisolone and mycophenolate mofetil. The editorial author notes that there are several reasons for caution before generalizing these findings to other patients with proliferative lupus glomerulonephritis, notably underrepresentation of patients with poor prognosis and certain demographic characteristics. 10 references.

Federally-Funded Research on Lupus Nephritis

The U.S. Government supports a variety of research studies relating to lupus nephritis and associated conditions. These studies are tracked by the Office of Extramural Research at the National Institutes of Health.[20] CRISP (Computerized Retrieval of Information on Scientific Projects) is a searchable database of federally-funded biomedical research projects conducted at universities, hospitals, and other institutions. Visit the CRISP Web site at **http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket**. You can perform targeted searches by various criteria including geography, date, as well as topics related to lupus nephritis and related conditions.

For most of the studies, the agencies reporting into CRISP provide summaries or abstracts. As opposed to clinical trial research using patients, many federally-funded studies use animals or simulated models to explore lupus nephritis and related conditions. In some cases, therefore, it may be difficult to understand how some basic or fundamental research could eventually translate into medical practice. The following sample is typical of the type of information found when searching the CRISP database for lupus nephritis:

- **Project Title: ACE Inhibitors In Lupus Nephritis--TGFB and Autoantibody Production**

  Principal Investigator & Institution: Singh, Ram R.; Associate Professor; Children's Hospital Med Ctr (Cincinnati) 3333 Burnet Ave Cincinnati, Oh 45229

  Timing: Fiscal Year 2001; Project Start 5-MAR-2001; Project End 8-FEB-2006

  Summary: Angiotensin-converting enzyme inhibitors (ACEIs), such as captopril, are widely used to control hypertension in patients who have chronic renal disease. ACEIs improve renal function in patients with chronic renal disease, however, than would be expected from their suppression of hypertension. ACEI-induced improvement in renal function is associated with decreased renal TGF-beta expression and matrix deposition. We anticipate that ACEIs may have a similar effect on TGF-beta production, renal fibrosis and end stage renal disease in patients with lupus. However, because TGF-beta can inhibit T and B cell

[20] Healthcare projects are funded by the National Institutes of Health (NIH), Substance Abuse and Mental Health Services (SAMHSA), Health Resources and Services Administration (HRSA), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDCP), Agency for Healthcare Research and Quality (AHRQ), and Office of Assistant Secretary of Health (OASH).

activation and auto-antibody productions, an ACEI-induced decrease in TGF-beta may exacerbate auto-antibody-mediated disease in lupus by enhancing auto-antibody production. Consequently, this proposal will explore potential therapeutic and damaging effects of ACEIs in SLE, inflammatory component of lupus nephritis, its continued presence enhances renal matrix deposition and fibrosis. To test this hypothesis we will: 1) evaluate autoantibody responses and renal disease in lupus-prone mice treated with ACEIs; and 2) generate and characterize mice that have kidney-specific deletion of the Tgfb1 gene. These mice will be used in future to determine the effect of TGF-beta deletion on lupus nephritis. Lupus-prone and control mice will be treated with captopril or a control anti-hypertensive agent; the effect on blood pressure, renal functions, renal histology, renal immune and collagen deposition will be determined. These changes will be correlated with TGF-beta expression in kidneys and spleens, and serum auto-antibodies. We will then generate mice that have renal-specific Tgfb1 gene deletion, and characterize their phenotype, specifically for any inflammatory changes in kidneys and other organs. The broad objectives of this proposal are to understand the role of TGF- beta in the pathogenesis of lupus nephritis, to explore how manipulation of in vivo TGF-beta can influence lupus, and to elucidate the mechanism and clinical utility of ACEIs in lupus. Delineation of pathways that cause matrix deposition in kidneys, but do not affect T and B cell activation, may lead to treatment strategies that improve end stage renal disease in SLE.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Antic5 Therapy of Lupus Nephritis**

  Principal Investigator & Institution: Holers, Michael; University of Colorado Hlth Sciences Ctr 4200 E 9Th Ave Denver, Co 80262

  Timing: Fiscal Year 2000

  Summary: This is an investigator-initiated collaborative Phase II treatment study in which we will examine the hypothesis that treatment of patients with systemic lupus erythematosus (SLE) and active lupus nephritis with a blocking anti-human complement C5 monoclonal antibody will lead to objective improvement in renal disease parameters. The anti-C5 monoclonal antibody will lead to objective improvement in renal disease parameters. The anti-G5 monoclonal antibody will be provided by Alexion Pharmaceuticals. Several lines of investigation have supported the concept that C5 plays a central role in renal injury in antibody- mediated diseases such as SLE. While short term studies using a similar inhibitor have shown efficacy in patients with inflammatory complications of coronary artery bypass surgery, the proposed study

represents the first application of this therapeutic strategy, chronic inhibition of complement C5 activation, to patients with autoimmune diseases. Patients enrolled in this double blinded, placebo controlled Phase II study will be those who have active but clinically stable nephritis and, thus, do not require immediate introduction of high dose cyclophosphamide or other cytotoxic drug therapy. Two patient groups, treated and untreated (vehicle control only as a placebo), will be studied. The primary outcome variable will be proteinuria. Secondary outcomes will include other measures of renal disease activity, other measures of lupus activity and measure of complement activation. Three Specific Aims will be pursued. Specific Aim #1. Determine the changes in renal disease activity that accompany short term treatment with an anti-C5 monoclonal antibody in patients with active lupus nephritis. Specific Aim #2. Identify changes in levels of complement activation fragments that accompany treatment with anti-c5 monoclonal antibody in patients with active lupus nephritis. Specific Aim #3. Assess these patients treated with an inhibitory anti-C5 monoclonal antibody for evidence of toxicity. This study is integrated into other components and goals of the Denver Autoimmunity Center itself in several ways. First, it utilizes a population of patients drawn from several sources in the Denver Autoimmunity Center. Second, it meets the goal of extending the use of complement inhibitors from animal models, which are being extensively studied here in the laboratory of the P.I. and others, into clinical trials in patients. Third, the analysis of the role of complement inhibitors as compared to cytokine inhibitors is a major component of the Basic Science Project #2 headed by Dr. William P. Arend.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Immune Mechanisms in Pristane Induced Lupus Nephritis**

  Principal Investigator & Institution: Reeves, Westley H.; Professor; Medicine; University of Florida Gainesville, Fl 32611

  Timing: Fiscal Year 2000; Project Start 1-JAN-1999; Project End 1-DEC-2003

  Summary: Intraperitoneal injection of pristane (2,6, 10, 14-tetramethylpentadecane) induces a lupus-like syndrome in nearly all "normal" strains of inbred mice. This syndrome is characterized by disease-specific autoantibody production (anti-Sm, RNP, Su, ribosomal P, double stranded DNA), hypergammaglobulinemia, and severe immune complex-mediated glomerulonephritis closely resembling lupus nephritis. In preliminary studies, it was shown that the disease develops in two phases, each with characteristic types of autoantibodies. cytokines,

and renal involvement. Microbial stimulation was found to be an important co-factor in progression to the second. more severe, phase. This project will examine the hypothesis that immune complex deposition is necessary, but not sufficient, for the development of nephritis in pristane-induced lupus. Further, it is hypothesized that a systemic abnormality in macrophage or monocyte phenotype resulting from pristane and/or microbial stimulation leads to the production of proinflammatory cytokines and disease progression. The goal of this project is to define pathways leading to glomerulonephritis in pristane-treated mice and ultimately to relate them to human lupus nephritis. Three specific aims are proposed. The pathology of the renal lesions will be defined in Aim 1. Mesangial and mesangiocapillary lesions will be studied by immunohistochemical techniques to determine whether hypercellularity reflects proliferation of endogenous (mesangial or endothelial) cells vs. influx of exogenous macrophages, lymphocytes or neutrophils. In addition, mesangial matrix deposition will be evaluated, and the time course of the renal changes will be studied. The roles of pro- vs. anti- inflammatory cytokines will be evaluated in Aim 2. Cytokine production in the glomerulus will be compared with that by phagocytes in the peritoneal exudate, spleen and liver to see if systemic abnormalities are present. Expression of cytokine-inducible markers will be studied as a means to evaluate whether the effects of pro-or anti-inflammatory cytokines predominate. The contribution of microbial stimulation to the development of nephritis in pristane-induced lupus will be examined in Aim 3. It is hypothesized that enhanced intestinal permeability resulting from pristane injection increases the translocation of microbial products, such as lipopolysaccharide, into the bloodstream. This may cause systemic activation of monocytes and macrophages, which then are recruited to the glomerulus in response to immune complex deposition, causing progression instead of resolution of the renal lesion. In view of the widespread susceptibility among "normal" mice to pristane-induced lupus, it seems likely that pristane causes lupus- like disease by its effects on a common, distal, part of a lupus pathway, largely bypassing the genetic abnormalities that predispose to spontaneous forms of the disease. The mechanisms involved in this new inducible model of SLE may, therefore, be common to other forms of lupus, including human SLE. Future studies will address the question of whether renal abnormalities similar to those induced by pristane are involved in the pathogenesis of human lupus nephritis.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Immunologic Mechanism in Lupus Nephritis**

  Principal Investigator & Institution: Madaio, Michael P.; Associate Professor; Medicine; University of Pennsylvania 1 College Hall Philadelphia, Pa 19104

  Timing: Fiscal Year 2000; Project Start 1-JAN-1985; Project End 0-JUN-2002

  Summary: (Adapted from Investigator's Abstract): The overall aim of this project is to develop a better understanding of the immunologic events leading to glomerular immune deposit formation in individuals with Systemic Lupus Erythematosus. In previous studies, murine and human monoclonal anti-DNA antibodies (Ab) were identified that produced glomerulonephritis following transfer to normal mice. Of particular relevance, the location of immune deposit formation and disease phenotype varied with the mAb. Furthermore, these individual pathogenic Ab bound directly to glomerular cell surface antigens, however each monoclonal anti-DNA Ab recognized a different cell surface proteins. Based on these observations, it was postulated that different autoantibody-glomerular antigen interactions, in vivo, contributes to the phenotypic diversity observed both among the monoclonal Ab and among individuals with lupus. A primary goal of this project is to fully identify the glomerular cell surface antigens for three nephritogenic lupus autoantibodies: anti-DNA MES and anti-DNA SE, derived from MRL-lpr/lpr mice; and RH-14, a human anti-DNA Ab. Anti-DNA MES produces mesangial deposits and binds to mesangial cells, whereas anti-DNA SE produces subendothelial deposits and binds to glomerular endothelial cells. RH14 produces massive subendothelial deposits on transfer to SCID mice, and it binds to glomerular endothelial cells. Candidate cell surface protein antigens were isolated for the autoantibodies. Peptides derived from the isolated proteins will be sequenced and then used to generate both degenerate oligonucleotides and anti-peptide antibodies to screen cDNA libraries, in order to define the full sequence and identity of the immunoreactive proteins. Another primary goal of the project is to further determine the pathogenic relevance of these autoantibody-glomerular cell interactions by examining: i) the immune response to the purified cell surface proteins, ii) other spontaneously produced autoantibodies with anti-cell surface protein activity; and iii) the cellular and functional consequences of Ab ligation of the cell surface proteins. Studies will be performed to begin to determine the overall relevance of direct binding of human lupus autoantibodies to glomerular antigens, in general, using: human lupus sera from the Lupus Collaborative Study and controls, the purified cell surface antigens, and individual glomerular cells. Collectively, the results

should identify disease-relevant glomerular antigens for pathogenic lupus autoantibodies and provide insights into the overall pathogenic relevance of autoantibody-glomerular cell surface antigen interactions in lupus nephritis.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Cell Mediated Renal Injury in Lupus**

  Principal Investigator & Institution: Kelley, Vicki R.; Associate Professor; Brigham and Women's Hospital 75 Francis St Boston, Ma 02115

  Timing: Fiscal Year 2000; Project Start 1-FEB-1985; Project End 0-NOV-2002

  Summary: The broad objective of this proposal is to test the hypothesis that increased intrarenal macrophage colony stimulating factor (CSF-1) expression is central to the pathogenesis of autoimmune renal disease in MRL-lpr/lpr mice. Using the MRL-lpr/lpr mouse with rapid, uniform, severe and predictable renal disease regulated by the lpr gene we will investigate the importance of CSF-1 in the pathogenesis of lupus nephritis. We propose to test whether the increase in circulating CSF-1 detected in neonatal MRL-lpr/lpr mice is contributed by the kidney alone or if other tissues are responsible for elevating serum levels. We will establish whether a molecule(s) in the circulation of MRL-lpr/lpr mice induces intrarenal CSF-1. We will determine whether increased renal expression of CSF-1 recruits macrophages. We will then investigate whether an increased expression of CSF-1 can induce renal disease in mice with normal kidneys including another strain with the lpr gene (C3H- lpr/lpr) and C3H-++ mice or accelerate an indolent, mild nephritis in congenic MRL-++, lacking the lpr gene. We will eliminate CSF-1 by creating a cytokine deficient MRL-lpr/lpr mouse and evaluate the impact on the development of lupus nephritis. In the event that the CSF-1 deficient MRL-lpr/lpr strain does not develop lupus nephritis we will determine if the inability of renal cells to express CSF-1 is responsible for preventing kidney disease. Through the advent of cellular and molecular techniques we now have the capacity to transfer a cytokine gene using a retroviral vector and establish tubular epithelial (TEC) and mesangial cell lines which can constitutively secrete high levels of a stable cytokine. By implanting these cells under the renal capsule we have created a system to introduce the continuing presence of CSF-1 (or other cytokines) into the kidney. We can then establish if CSF-1 recruits macrophages and determine whether CSF-1 will induce or accelerate renal injury in the MRL-++, C3H-lpr/lpr strains. To definitely establish whether CSF-1 or other cytokines have an enhanced glomerular expression prior to the influx of macrophages, we will isolate and pool individual glomeruli

(glom) from MRL-lpr/lpr, congenic, and normal mice at varying ages and quantitate the level of cytokine and macrophages specific marker mRNA using the competitive template polymerase chain reaction. Finally, we will cross the MRL-++ or the C3H- lpr/lpr mice with CSF-1 transgenic mice and select for hybrids with these backgrounds overexpressing macrophage growth factors. In addition, we will eliminate CSF-1 from MRL-lpr/lpr mice by crossing them with the op/+ strain and select for a strain with op/op (producing a non-functional CSF-1) and lpr genes. By increasing or eliminating CSF-1, we will test the impact of this cytokine in promoting renal disease. In addition, we will use the approach of transplanting a kidney into a bilaterally nephrectomized recipient to determine when the MRL-lpr/lpr kidney is responsible for increasing serum CSF-1 and establish if this production is constitutive or is dependent on a stimulus. In addition, we will determine whether a circulating stimulant in the serum of MRL-lpr/lpr mice induces intrarenal CSF-1 and at what age this begins. Finally, we will test whether a kidney unable to express CSF-1 transplanted in the MRL-lpr/lpr mice develops renal injury. Taken together, using several novel approaches we will be able to clarify the importance of CSF-1 in the pathogenesis of lupus nephritis.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Cellular and Genetic Basis of Systemic Lupus**

  Principal Investigator & Institution: Fu, Shu Man M.; Professor; Internal Medicine; University of Virginia Charlottesville Box 400195 Charlottesville, Va 22904

  Timing: Fiscal Year 2001; Project Start 8-SEP-2001; Project End 1-JUL-2005

  Summary: (provided by applicant): Systemic lupus erythematosus (SLE) is an autoimmune disorder affecting multiple organs with considerable morbidity and mortality. The disorder is characterized by multiple autoantibody production including antinuclear antibodies (ANA and anti-dsDNA antibodies with immune complex formation leading to intense inflammation and end organ damage. Immune complex-mediated glomerulonephritis (GN) is a major manifestation of this disorder. Both genetic and environmental factors play important roles in its pathogenesis. Our laboratory has focused on the origin(s) of the autoantibodies detected in SLE and the genetic factors important in the generation of ANA and anti-dsDNA antibodies and lupus nephritis. Recently, a new model of SLE NZM2328 has been characterized. In this strain, there is female bias for ANA and chronic GN. In a backcross (NZM2328 X C57L/J F1) X NZM2328 analysis, a genetic interval has been identified on chromosome 1 in NZM2328 to control the development of

chronic GN. An interval on chromosome 4 was shown to be linked to the production of ANA and anti-dsDNA antibodies. By a marker assisted method, two congenics NZM2328.C57Lc1 and NZM2328.C57L.c4 were generated by moving the genetic segments of interest from chromosomes 1 and 4 respectively from C57L/J to NZM2328. In NZM2328.C57Lc1 little ANA, anti-dsDNA or chronic GN were seen. In contrast in NZM2328.C57Lc4, chronic GN was detected despite marked reductions in ANA and anti dsDNA, dissociating ANA and anti-dsDNA production from lupus nephritis. It appeared that the genetic segment on chromosome 1 controls lupus nephritis and regulates ANA and anti-dsDNA production. These genetic loci have been named Lnc 1, the lupus nephritis controlling gene 1 and Adn1, the anti-dsDNA and ANA production gene 1. For this proposal, Lnc 1 is assumed to be different from Adn1. This application is focused on the elucidation of the cellular and immunochemical basis for autoantibody production and the generation of GN and to identify the genes, Lnc 1 and Adn1. Four specific aims proposed are (1) to characterize further NZM2328 and its two congenic lines NZM2328.C57Lc1 an NZM2328.C57Lc4; (2) to determine the specificities of immunoglobulins eluted from diseased kidneys from NZM2328.Lc4, clarifying the basis for the dissociation of anti-dsDNA antibody and ANA production from sever proteinuria and chronic GN; (3) to determine the cellular basis of severe proteinuria, chronic GN, and autoantibody production by adoptive cell transfer analysis; and (4) to generate intra c1 congenic recombinant strains from the parental strain NZM2328.C57Lc1, which contain smaller genetic intervals of chromosome 1 derived from C57LIJ to determine the minimal C57L/J genetic segment(s) to suppress anti-dsDNA antibody and ANA production, and/or severe proteinuria an chronic GN. Thus, we will refine the genetics for this interval so that we may identify the genes, Lnc 1 and Adn1, relevant to the phenotypic expression by positional cloning. The results from these experiments will provide us further understanding of the pathogenesis of SLE. This information should lead to orthologous gene(s) identification in the SLE patients and provide us potential targets for more specific and novel therapeutic interventions.

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- **Project Title: Characterization of SLE Susceptibility Loci on Mouse Chromosome 4**

  Principal Investigator & Institution: Morel, Laurence; University of Texas Sw Med Ctr/Dallas Southwestern Medical Ctr/Dallas Dallas, Tx 75390

  Timing: Fiscal Year 2000; Project Start 1-JUN-1996; Project End 1-AUG-2005

Summary: Sle2 on mouse chromosome 4 is a strong recessive locus associated with lupus nephritis in the NZM2410 model. Other groups have identify other SLE-associated loci in the centromeric half of this chromosome. Congenic analysis has showed that Sle2 is associated with B cell hyperactivity resulting in producing of polyclonal IgM antibodies, in vivo and in vitro hyper-responsiveness, increased B7.2 expression, and enlargement of the Bl1 population. Characterization of polycongenic strains combining Sle1, -2. and -3 has shown that Sle2 is necessary for full disease expression, and that, in combination of Sle3, Sle2 results in highly penetrant non-pathogenic hyaline and mesangial renal lesions that might constitute an accelerating factor for lupus nephritis. Using the congenic dissection approach, and following the steps that we are following in the functional and genetic dissection of the role of telomeric chromosome 4 in SLE pathogenesis. To achieve this goal, we have produced a series of 10 sub-congenic strains covering the area. We will use these strains in two specific aims: 1) We will assess whether the various phenotypes associated with Sle2 result from a single or several loci and generate a high resolution genetic map of these loci. The immunological defects and gene expression profile associated with each of these loci will be established. 2) We will determine the contribution of these loci to SLE pathogenesis by combining the corresponding sub-intervals to either Sle3 or the Sle1/Sle3 combination to reconstitute the Sle2/Sle3 or Sle1/Sle2/Sle3 immunopathology, respectively. Preliminary results indicate that the elevated B7.2 expression, but not increased Bl1 compartment, is associated with increased pathogenicity. These experiments are a necessary step towards the identification of the SLE-susceptibility genes on mouse chromosome 4. A high resolution genetic map that leads to the physical map and ultimate cloning of the gene cannot be constructed without a solid evaluation of the number of loci and their associated defects. Finally, the understanding of their relative contribution to the disease process will establish priorities for gene identification.

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- **Project Title: FC Receptor Function in Normals and SLE**

  Principal Investigator & Institution: Salmon, Jane E.; Professor; Hospital for Special Surgery 535 E 70Th St New York, Ny 10021

  Timing: Fiscal Year 2000; Project Start 1-DEC-1992; Project End 1-AUG-2002

  Summary: (Adapted from Investigator's abstract): Human Fc receptors (FcgR) consist of three families with extensive diversity of structure and function. Recent advances bring into focus four observations pertinent to

SLE: 1) FcgRIIa is a crucial receptor mediating phagocytic function; 2) FcgRIIa is unique among FcgR in that it is targeted for oxidant and protease-induced amplification of effector function as well as avidity modulation, independent of receptor number; 3) the H131 allele of FcgRIIa is the only human FcgR which recognizes IgG2 efficiently; 4) the distribution of FcgRIIa alleles is skewed in SLE patients compared to normals, with a highly significant decrease in FcgRIIa-H131 in lupus nephritis. In SLE, FcgR-specific immune complex removal by the mononuclear phagocytes system is impaired. This defect is related to renal disease, emphasizing the possible role of FcgR dysfunction in immune complex deposition and the pathogenesis of SLE. Despite the decrease in FcgR function in vivo , there is a paradoxical increase in FcgR binding in vitro. Preliminary data indicate that FcgRIIa is a compelling candidate for the FcgR dysfunction in SLE. Monocytes in SLE patients have increased FcgRIIa-mediated binding, but markedly decreased FcgRIIa phagocytosis, indicating dissociation of receptor-effector coupling. Disease-induced dysfunction superimposed upon inherited polymorphisms of FcgRIIa with decreased functional capacity may provide the milieu for the development of immune complex deposition and nephritis. Recent evidence for a role of IgG2 autoantibodies in nephritis underscores the importance of FcgRIIa in disease phenotype. Based on these observations, the investigators hypothesize that 1) abnormal FcgRIIa function provides a basis for disease-related defects in SLE, and 2) that alleles of FcgRIIa which affect ligand binding are important heritable disease susceptibility factors. Therefore, the specific aims of this application: 1. to define the mechanism of activation of FcgRIIa; 2. to define the basis for the defect in phagocytosis by FcgRIIa in SLE; 3. to define the role of FcgRIIa alleles as risk factors for lupus nephritis: (a) to establish genetic linkage of lupus and nephritis to FcgRIIa and (b) to define the relative importance of FcgRIIa alleles among different ethnic groups; and 4. to define subclasses of IgG deposited within glomeruli in lupus nephritis and their relationships to FcgRIIa alleles, autoantibodies, and induction of glomerular injury.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Immunological Mechanisms of Nephritis in Childhood SLE**

  Principal Investigator & Institution: Reichlin, Morris; Professor and Scientific Director; Oklahoma Medical Research Foundation 825 Ne 13Th St, Ms 31 Oklahoma City, Ok 73104

  Timing: Fiscal Year 2000; Project Start 0-SEP-1995; Project End 1-MAR-2005

Summary: (Adapted from the Investigator's abstract): Childhood systemic lupus erythematosus (SLE) differs from the disease in adults by a higher prevalence of nephritis. The investigators hypothesize that this higher prevalence of nephritis is due to several types of nephritogenic autoantibodies that occur concurrently in the childhood form of SLE. Two major candidates for these autoantibodies are those directed against dsDNA which have long been recognized to play a role in adult lupus nephritis and autoantibodies to ribosomal "P" protein which have not been reported previously to be associated with either adult or pediatric lupus nephritis. Aside from recent preliminary clinical and animal data that support a role for anti-P in lupus nephritis, both anti-dsDNA and anti-ribosomal "P" antibodies have been found to contain subsets that directly bind and injure cells in culture. According to the investigators, this antibody-mediated, in vitro cell injury phenomenon could be a surrogate for their immunopathogenic potential in vivo. The investigators propose to define the pathogenic potential of the autoantibodies in individual patients by affinity purifying their autoantibodies and by studying their interaction with various cell types in culture and the effects on cell function and viability. In preliminary studies, they have reproduced previous work by showing that some human anti-dsDNA antibodies injure cells by a complement dependent mechanism at the cell surface, and others penetrate the cell, localize in either the nucleus or the cytoplasm, and like anti-P, inhibit protein synthesis. The investigators will correlate these immunopathogenetic properties in vitro with the patients' clinical status. They propose to expand their studies of the idiotypic regulation of these antibodies in patients with anti-P antibodies. Parallel studies in adults suggest that, like children, the presence of both anti-dsDNA and anti-P antibodies greatly increase the risk of active nephritis. The investigators also have preliminary data that anti-P may be enriched in human glomerular eluates and propose to expand these studies. Lastly, they propose to develop an animal model to assess the nephritogenic potential of induced anti-P antibodies. They hope that these studies would expand perspectives on the immunopathogenesis of nephritis in both children and adults with SLE.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Regulation of TNF-Alpha Production in SLE**

  Principal Investigator & Institution: Liu, Yi; Medicine; University of Southern California University Park Los Angeles, Ca 90007

  Timing: Fiscal Year 2000; Project Start 1-JUN-2000; Project End 1-JUL-2000

Summary: It is estimated that 1.4 to 2 million people in the USA suffer from Systemic lupus erythematosis (SLE). At present, there is no cure for SLE. The pathogenesis of SLE is still unknown. Studies have suggested that cytokines may play an important role in its pathogenesis. Tumor necrosis factor alpha (TNFalpha) is a cytokine with very diverse physiological and pathological activities. Several lines of evidence have suggested that TNFalpha play an essential role in the development and progression of SLE. First, it has been reported that TNFalpha production in activated monocytes from SLE patients is significantly decreased. Second, it has also been shown that lupus patients with low TNFalpha production have an increased incidence of lupus nephritis. Lastly, in a SLE murine model, the levels of TNFalpha production by activated macrophages are significantly lower in NZW lupus prone mice. Treatment with recombinant TNFalpha significantly reduces the incidence of lupus nephritis in these mice. Recent studies have demonstrated that reduced production of TNFalpha in NZW lupus-prone mice is mainly regulated at the translational level, mediated by the 3' untranslated region (3'UTR) of the TNFalpha gene. In this project, I will dissect the 3'UTR of the TNFalpha gene and characterize its role in the regulation of TNFalpha production. My specific aims are: 1. To delineate the translational regulatory cis-acting elements in the TNFalpha 3'UTR of NZW lupus-prone mice through deletion and site- directed mutagenesis using transient transfection assays with the luciferase reporter system. 2. To test whether the RNA-protein binding profile is different between the mutated 3'UTR of the lupus-prone NZW mouse and the non-mutated 3'UTR of the non-lupus-prone mouse and to further characterize the trans- acting factors involved in regulating the T'NFalpha gene. The elucidation of the mechanism of regulation of TNFalpha production is fundamental in understanding the pathogenesis of SLE, with possible implications in SLE treatment through manipulation of TNFalpha production. Accomplishment of the proposed project also has the potential to enhance our understanding of post-transcriptional gene regulation in general.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Role of Complement Factor B in the Pathogenesis of SLE**

  Principal Investigator & Institution: Gilkeson, Gary S.; Professor; Medicine; Medical University of South Carolina 171 Ashley Ave Charleston, Sc 29403

  Timing: Fiscal Year 2000; Project Start 1-APR-2000; Project End 1-MAR-2005

Summary: (Adapted from the Investigator's abstract): The complement cascade plays an important role in the pathogenesis of immune complex mediated diseases, including lupus nephritis. The alternative complement pathway is activated in lupus nephritis, though its role in the pathogenesis of disease is unclear. To provide insight into the role of the alternative pathway, and specifically the role of Factor B (Bf), in disease, mice deficient in Bf were derived. Bf deficient mice were found to have normal immune function despite being unable to activate the alternative pathway. To determine what role Bf and the alternative pathway play in autoimmune disease, we bred the Bf knockout genotype to the lupus prone MRL/lpr background. Compared to Bf expressing litter mates, the Bf deficient MRL/lpr mice developed significantly less proteinuria, pathologic renal disease, glomerular IgG immune deposits and vasculitis. Surprisingly, C3 levels were normal in the MRL/lpr Bf deficient mice in contrast to significantly, depressed levels in the Bf producing litter mates, typical of disease in MRL/lpr mice. These findings suggest Bf has a key pathogenic role in lupus nephritis in MRL/lpr mice and that the alternative pathway is an important mechanism for C3 activation and consumption in MRL/lpr disease. Our central hypothesis is that Factor B and the alternative pathway are pro-inflammatory in lupus and that blocking Factor B activity provides a novel approach to treating this disease. To further define the role of Factor B in immune complex mediated diseases and activation of C3, the following specific aims are proposed: Aim 1- Determine the mechanisms by which renal damage is diminished in Bf deficient MRL/lpr mice. Aim 2 - Determine the mechanism for the maintenance of normal serum C3 levels in MRL/lpr Bf-/- mice . Aim 3 - Identify the effects of Bf deficiency on autoimmune B cell function including isotype switching and tolerance as well as macrophage/mesangial cell function. Aim 4 - Determine the potential for disease modification by inhibition of Bf activation using additional therapeutic strategies and models of glomerular injury. These studies will provide new insight into the role of the alternative pathway in disease and potentially provide a new therapeutic target (Factor B) in immune complex mediated diseases.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: SLE Triggered Disease Pathways**

  Principal Investigator & Institution: Mohan, Chandra; University of Texas Sw Med Ctr/Dallas Southwestern Medical Ctr/Dallas Dallas, Tx 75390

  Timing: Fiscal Year 2000; Project Start 1-JUN-1996; Project End 1-AUG-2005

Summary: Functional dissection of lupus pathogenesis using B6 congenic strains, bearing NZM2410-derived lupus susceptibility intervals (Sle1, Sle2 and Sle3) have collectively added fresh insights to our understanding of this disease, In effect these efforts have collapsed the problem of understanding a polygenic (and hence, multi-factorial) disease into a series of monogenic (and hopefully, unifactorial models) These studies allude to the existence of 3 distinct genetically-programmed pathogenic steps: Initial breach in tolerance to chromatin, "pathogenic maturation" of the initial response., and finally, end-organ damage. Sle1 appears to trigger the first process, since it apparently leads to anti-chromatin autoimmunity, in a surprisingly, antigen-specific manner. In contrast, Sl32 and Sl32 appear to impact the immune system in a generalized fashion (leading to B-cell hyperactivity, and -cell aberrations, respectively), in effect, promoting the "pathogenic maturation" of anti- nuclear autoantibodies. Finally, how the Sle loci might facilitate end- organ damage remains unknown. In addition, what role(s) T-cells play in these 3 events is also not clear. This proposal aims to address these knowledge gaps, with the following specific aims. (1) To determine the role of T-cells in mediating the genetically dictated pathogenic processes leading to lupus nephritis. We will test this hypothesis by breeding the TCR -/- mutation onto selected B6.SLE congenics. (2) To gauge the complexity versus clonality of the T-cell repertoire mediating the genetically dictated pathogenic processes leading to lupus nephritis. This will be tested by analyzing the TCR repertoire by FACS analysis and TCR V CDR3 spectratyping in lymphoid and intrarenal T- cells isolated from selected B6. Sle congenics. (3) To define the role of B-cells and autoantibodies in mediating renal pathology in the B6.Sle polycongenic model. This will be verified by breeding either the Igh-/- (lacking B-cells and Ig), or the slgM-/- (lacking Ig but not B-cells) onto selected B6.Sle congenics. (4) To determine if the Sle loci confer intrinsic renal susceptibility to nephrophilic autoantibody-mediated damage. This will be tested by exposing and studying kidneys bearing different genotypes to potentially pathogenic autoantibodies.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

E-Journals: PubMed Central[21]

PubMed Central (PMC) is a digital archive of life sciences journal literature developed and managed by the National Center for Biotechnology

[21] Adapted from the National Library of Medicine:
http://www.pubmedcentral.nih.gov/about/intro.html.

Information (NCBI) at the U.S. National Library of Medicine (NLM).[22] Access to this growing archive of e-journals is free and unrestricted.[23] To search, go to **http://www.pubmedcentral.nih.gov/index.html#search**, and type "lupus nephritis" (or synonyms) into the search box. This search gives you access to full-text articles. The following is a sample of items found for lupus nephritis in the PubMed Central database:

- **Effect of genetic background on the contribution of New Zealand Black loci to autoimmune lupus nephritis** by Stephen J. Rozzo, Timothy J. Vyse, Charles G. Drake, and Brian L. Kotzin; 1996 December 24 http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=26374
- **Immunophilins, Refsum disease, and lupus nephritis: The peroxisomal enzyme phytanoyl-COA [alpha]-hydroxylase is a new FKBP-associated protein** by Beatrice Chambraud, Christine Radanyi, Jacques H. Camonis, Krzysztof Rajkowski, Michael Schumacher, and Etienne-Emile Baulieu; 1999 March 2 http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=26744
- **Pathogenic Anti-DNA Autoantibody-Inducing T Helper Cell Lines from Patients with Active Lupus Nephritis: Isolation of CD4-8- T Helper Cell Lines That Express the [gamma][delta] T-Cell Antigen Receptor** by S Rajagopalan, T Zordan, GC Tsokos, and SK Datta; 1990 September 15 http://www.pubmedcentral.nih.gov/articlerender.fcgi?rendertype=abstract&artid=54674

The National Library of Medicine: PubMed

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[22] With PubMed Central, NCBI is taking the lead in preservation and maintenance of open access to electronic literature, just as NLM has done for decades with printed biomedical literature. PubMed Central aims to become a world-class library of the digital age.

[23] The value of PubMed Central, in addition to its role as an archive, lies the availability of data from diverse sources stored in a common format in a single repository. Many journals already have online publishing operations, and there is a growing tendency to publish material online only, to the exclusion of print.

[24] PubMed was developed by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine (NLM) at the National Institutes of Health (NIH). The PubMed database was developed in conjunction with publishers of biomedical literature as a search tool for accessing literature citations and linking to full-text journal articles at Web

offers full text of its journals, PubMed will provide links to that site, as well as to sites offering other related data. User registration, a subscription fee, or some other type of fee may be required to access the full text of articles in some journals.

To generate your own bibliography of studies dealing with lupus nephritis, simply go to the PubMed Web site at **www.ncbi.nlm.nih.gov/pubmed**. Type "lupus nephritis" (or synonyms) into the search box, and click "Go." The following is the type of output you can expect from PubMed for "lupus nephritis" (hyperlinks lead to article summaries):

- **Clinical trials in lupus nephritis.**
  Author(s): Ginzler EM.
  Source: Curr Rheumatol Rep. 2001 June; 3(3): 199-204. Review.
  http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11352788&dopt=Abstract

- **Improvement in lupus nephritis following treatment with a Chinese herbal preparation.**
  Author(s): Yap HK, Ang SG, Lai YH, Ramgolam V, Jordan SC.
  Source: Archives of Pediatrics & Adolescent Medicine. 1999 August; 153(8): 850-2.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10437759&dopt=Abstract

Vocabulary Builder

Alkalosis: A pathologic condition resulting from accumulation of base, or from loss of acid without comparable loss of base in the body fluids, and characterized by decrease in hydrogen ion concentration (increase in pH). [EU]

Alleles: Mutually exclusive forms of the same gene, occupying the same locus on homologous chromosomes, and governing the same biochemical and developmental process. [NIH]

Amenorrhea: Absence or abnormal stoppage of the menses; called also amenia. [EU]

Angiitis: Inflammation of a vessel, chiefly of a blood or a lymph vessel; called also vasculitis. [EU]

Antibody: An immunoglobulin molecule that has a specific amino acid

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sequence by virtue of which it interacts only with the antigen that induced its synthesis in cells of the lymphoid series (especially plasma cells), or with antigen closely related to it. Antibodies are classified according to their ode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

Antigen: Any substance which is capable, under appropriate conditions, of inducing a specific immune response and of reacting with the products of that response, that is, with specific antibody or specifically sensitized T-lymphocytes, or both. Antigens may be soluble substances, such as toxins and foreign proteins, or particulate, such as bacteria and tissue cells; however, only the portion of the protein or polysaccharide molecule known as the antigenic determinant (q.v.) combines with antibody or a specific receptor on a lymphocyte. Abbreviated Ag. [EU]

Antioxidant: One of many widely used synthetic or natural substances added to a product to prevent or delay its deterioration by action of oxygen in the air. Rubber, paints, vegetable oils, and prepared foods commonly contain antioxidants. [EU]

Arthralgia: Pain in a joint. [EU]

Assay: Determination of the amount of a particular constituent of a mixture, or of the biological or pharmacological potency of a drug. [EU]

Asymptomatic: Showing or causing no symptoms. [EU]

Atrophy: A wasting away; a diminution in the size of a cell, tissue, organ, or part. [EU]

Biochemical: Relating to biochemistry; characterized by, produced by, or involving chemical reactions in living organisms. [EU]

Capillary: Any one of the minute vessels that connect the arterioles and venules, forming a network in nearly all parts of the body. Their walls act as semipermeable membranes for the interchange of various substances, including fluids, between the blood and tissue fluid; called also vas capillare. [EU]

Captopril: A potent and specific inhibitor of peptidyl-dipeptidase A. It blocks the conversion of angiotensin I to angiotensin II, a vasoconstrictor and important regulator of arterial blood pressure. Captopril acts to suppress the renin-angiotensin system and inhibits pressure responses to exogenous angiotensin. [NIH]

Chemotherapy: The treatment of disease by means of chemicals that have a specific toxic effect upon the disease - producing microorganisms or that selectively destroy cancerous tissue. [EU]

Collagen: The protein substance of the white fibres (collagenous fibres) of skin, tendon, bone, cartilage, and all other connective tissue; composed of

molecules of tropocollagen (q.v.), it is converted into gelatin by boiling. collagenous pertaining to collagen; forming or producing collagen. [EU]

Coronary: Encircling in the manner of a crown; a term applied to vessels; nerves, ligaments, etc. The term usually denotes the arteries that supply the heart muscle and, by extension, a pathologic involvement of them. [EU]

Cyclophosphamide: Precursor of an alkylating nitrogen mustard antineoplastic and immunosuppressive agent that must be activated in the liver to form the active aldophosphamide. It is used in the treatment of lymphomas, leukemias, etc. Its side effect, alopecia, has been made use of in defleecing sheep. Cyclophosphamide may also cause sterility, birth defects, mutations, and cancer. [NIH]

Cytokines: Non-antibody proteins secreted by inflammatory leukocytes and some non-leukocytic cells, that act as intercellular mediators. They differ from classical hormones in that they are produced by a number of tissue or cell types rather than by specialized glands. They generally act locally in a paracrine or autocrine rather than endocrine manner. [NIH]

Cytoplasm: The protoplasm of a cell exclusive of that of the nucleus; it consists of a continuous aqueous solution (cytosol) and the organelles and inclusions suspended in it (phaneroplasm), and is the site of most of the chemical activities of the cell. [EU]

Distal: Remote; farther from any point of reference; opposed to proximal. In dentistry, used to designate a position on the dental arch farther from the median line of the jaw. [EU]

Endogenous: Developing or originating within the organisms or arising from causes within the organism. [EU]

Enzyme: A protein molecule that catalyses chemical reactions of other substances without itself being destroyed or altered upon completion of the reactions. Enzymes are classified according to the recommendations of the Nomenclature Committee of the International Union of Biochemistry. Each enzyme is assigned a recommended name and an Enzyme Commission (EC) number. They are divided into six main groups; oxidoreductases, transferases, hydrolases, lyases, isomerases, and ligases. [EU]

Exogenous: Developed or originating outside the organism, as exogenous disease. [EU]

Extracorporeal: Situated or occurring outside the body. [EU]

Exudate: Material, such as fluid, cells, or cellular debris, which has escaped from blood vessels and has been deposited in tissues or on tissue surfaces, usually as a result of inflammation. An exudate, in contrast to a transudate, is characterized by a high content of protein, cells, or solid materials derived from cells. [EU]

Genotype: The genetic constitution of the individual; the characterization of the genes. [NIH]

Humoral: Of, relating to, proceeding from, or involving a bodily humour - now often used of endocrine factors as opposed to neural or somatic. [EU]

Hypertension: Persistently high arterial blood pressure. Various criteria for its threshold have been suggested, ranging from 140 mm. Hg systolic and 90 mm. Hg diastolic to as high as 200 mm. Hg systolic and 110 mm. Hg diastolic. Hypertension may have no known cause (essential or idiopathic h.) or be associated with other primary diseases (secondary h.). [EU]

Hypotension: Abnormally low blood pressure; seen in shock but not necessarily indicative of it. [EU]

Iatrogenic: Resulting from the activity of physicians. Originally applied to disorders induced in the patient by autosuggestion based on the physician's examination, manner, or discussion, the term is now applied to any adverse condition in a patient occurring as the result of treatment by a physician or surgeon, especially to infections acquired by the patient during the course of treatment. [EU]

Induction: The act or process of inducing or causing to occur, especially the production of a specific morphogenetic effect in the developing embryo through the influence of evocators or organizers, or the production of anaesthesia or unconsciousness by use of appropriate agents. [EU]

Infusion: The therapeutic introduction of a fluid other than blood, as saline solution, solution, into a vein. [EU]

Ingestion: The act of taking food, medicines, etc., into the body, by mouth. [EU]

Intrinsic: Situated entirely within or pertaining exclusively to a part. [EU]

Lesion: Any pathological or traumatic discontinuity of tissue or loss of function of a part. [EU]

Ligation: Application of a ligature to tie a vessel or strangulate a part. [NIH]

Membrane: A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ. [EU]

Monocytes: Large, phagocytic mononuclear leukocytes produced in the vertebrate bone marrow and released into the blood; contain a large, oval or somewhat indented nucleus surrounded by voluminous cytoplasm and numerous organelles. [NIH]

Mutagenesis: Process of generating genetic mutations. It may occur spontaneously or be induced by mutagens. [NIH]

Myalgia: Pain in a muscle or muscles. [EU]

Necrosis: The sum of the morphological changes indicative of cell death and

caused by the progressive degradative action of enzymes; it may affect groups of cells or part of a structure or an organ. [EU]

Nephrology: A subspecialty of internal medicine concerned with the anatomy, physiology, and pathology of the kidney. [NIH]

Nephropathy: Disease of the kidneys. [EU]

Neutrophil: Having an affinity for neutral dyes. [EU]

Pediatrics: A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

Phagocytosis: Endocytosis of particulate material, such as microorganisms or cell fragments. The material is taken into the cell in membrane-bound vesicles (phagosomes) that originate as pinched off invaginations of the plasma membrane. Phagosomes fuse with lysosomes, forming phagolysosomes in which the engulfed material is killed and digested. [EU]

Phenotype: The outward appearance of the individual. It is the product of interactions between genes and between the genotype and the environment. This includes the killer phenotype, characteristic of yeasts. [NIH]

Plasmapheresis: Procedure whereby plasma is separated and extracted from anticoagulated whole blood and the red cells retransfused to the donor. Plasmapheresis is also employed for therapeutic use. [NIH]

Precursor: Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

Prevalence: The total number of cases of a given disease in a specified population at a designated time. It is differentiated from incidence, which refers to the number of new cases in the population at a given time. [NIH]

Protease: Proteinase (= any enzyme that catalyses the splitting of interior peptide bonds in a protein). [EU]

Proteins: Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

Pulse: The rhythmical expansion and contraction of an artery produced by waves of pressure caused by the ejection of blood from the left ventricle of the heart as it contracts. [NIH]

Purpura: Purplish or brownish red discoloration, easily visible through the epidermis, caused by hemorrhage into the tissues. [NIH]

Receptor: 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid

hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

Recombinant: 1. a cell or an individual with a new combination of genes not found together in either parent; usually applied to linked genes. [EU]

Reconstitution: 1. a type of regeneration in which a new organ forms by the rearrangement of tissues rather than from new formation at an injured surface. 2. the restoration to original form of a substance previously altered for preservation and storage, as the restoration to a liquid state of blood serum or plasma that has been dried and stored. [EU]

Remission: A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

Seizures: Clinical or subclinical disturbances of cortical function due to a sudden, abnormal, excessive, and disorganized discharge of brain cells. Clinical manifestations include abnormal motor, sensory and psychic phenomena. Recurrent seizures are usually referred to as EPILEPSY or "seizure disorder." [NIH]

Serum: The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

Stimulant: 1. producing stimulation; especially producing stimulation by causing tension on muscle fibre through the nervous tissue. 2. an agent or remedy that produces stimulation. [EU]

Tolerance: 1. the ability to endure unusually large doses of a drug or toxin. 2. acquired drug tolerance; a decreasing response to repeated constant doses of a drug or the need for increasing doses to maintain a constant response. [EU]

Toxicity: The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

CHAPTER 5. PATENTS ON LUPUS NEPHRITIS

Overview

You can learn about innovations relating to lupus nephritis by reading recent patents and patent applications. Patents can be physical innovations (e.g. chemicals, pharmaceuticals, medical equipment) or processes (e.g. treatments or diagnostic procedures). The United States Patent and Trademark Office defines a patent as a grant of a property right to the inventor, issued by the Patent and Trademark Office.[25] Patents, therefore, are intellectual property. For the United States, the term of a new patent is 20 years from the date when the patent application was filed. If the inventor wishes to receive economic benefits, it is likely that the invention will become commercially available to patients with lupus nephritis within 20 years of the initial filing. It is important to understand, therefore, that an inventor's patent does not indicate that a product or service is or will be commercially available to patients with lupus nephritis. The patent implies only that the inventor has "the right to exclude others from making, using, offering for sale, or selling" the invention in the United States. While this relates to U.S. patents, similar rules govern foreign patents.

In this chapter, we show you how to locate information on patents and their inventors. If you find a patent that is particularly interesting to you, contact the inventor or the assignee for further information.

[25]Adapted from The U. S. Patent and Trademark Office:
http://www.uspto.gov/web/offices/pac/doc/general/whatis.htm.

Patents on Lupus Nephritis

By performing a patent search focusing on lupus nephritis, you can obtain information such as the title of the invention, the names of the inventor(s), the assignee(s) or the company that owns or controls the patent, a short abstract that summarizes the patent, and a few excerpts from the description of the patent. The abstract of a patent tends to be more technical in nature, while the description is often written for the public. Full patent descriptions contain much more information than is presented here (e.g. claims, references, figures, diagrams, etc.). We will tell you how to obtain this information later in the chapter. The following is an example of the type of information that you can expect to obtain from a patent search on lupus nephritis:

- **Method for Treatment of Lupus Nephritis**

  Inventor(s): Clark; William F. (1132 Richmond Street, London, Ontario, CA), Parbtani; Anwar (418 Rippleton Rd., London, Ontario, CA)

  Assignee(s): none reported

  Patent Number: 5,837,256

  Date filed: December 19, 1996

  Abstract: It has been found that by administering secoisolariciresinol ›2,3-bis(3-methyl-4-hydroxybenzyl)butane-1,4-diol! from flaxseed in substantially pure form to a human or non-human animal, lupus nephritis can be controlled. The secoisolariciresinol (Seco) may be used per se or in the form of secoisolariciresinol diglucoside (SDG). Both compounds may be extracted from flaxseed and the SDG converts to Seco in the gut of a human or animal.

  Excerpt(s): This invention relates to a method for the treatment of lupus nephritis. ... Lupus nephritis is considered in medical circles to be the "classical" auto-immune disease in which the patient's immune system attacks his/her own organs. It has been estimated that 45-75% of lupus patient's eventually suffer from some form or other of kidney damage. Lupus varies greatly in severity from mild cases requiring minimal intervention to those in which significant damage occurs to vital organs such as lungs, kidneys, heart and brain, and which ultimately can be fatal. Lupus is predominantly a female disease, an approximate female to male ratio being 9:1. In North America, it is estimated to affect 1 in 500 female mainly between the age of 20 to 40 years. Treatment is directed at controlling the symptoms with the hope of putting the disease into remission. There are several chemotherapeutic agents in commercial use and available for remedial purposes. Most of these agents are not without

side effects, some of which are severe and debilitating to the patient. Some non-steroidal anti-inflammatory agents may cause stomach upsets and changes in kidney function which can mimic some lupus symptoms themselves. Some anti-malarial drugs, when required at high dosage levels over prolonged time frame, may accumulate in the retina and cause loss of vision. Certain steroidal preparations are used for their anti-inflammatory activity. These can exhibit side effects such as pronounced swelling of the face and abdomen, weight gain, excessive growth of body hair, cataracts, osteoporosis and heart attacks. Use of immunosuppressants can have serious side effects such as changes in bone marrow, increased risk of infection to which the body normally shows resistance and a slight increase in the risk of developing certain types of cancer. There is no known cure for lupus. ... Several reports have appeared in the scientific and medical literature concerning the ability of ground flaxseed to act as a mediator in the partial control of Lupus nephritis. At a level of intake of up to 30 grams per day, ground flaxseed has been shown to reduce the total cholesterol and LDL cholesterol levels by 12% and improve renal function in patients with lupus nephritis ›(Clark, Parbtani et al., (1995) Flaxseed: A potential treatment for lupus nephritis, Kidney International 48: 475-480!. Beyond this intake level, side effects are evident such as Taxation probably due to increased fibre/mucilage intake.

Web site: http://www.delphion.com/details?pn=US05837256__

Patent Applications on Lupus Nephritis

As of December 2000, U.S. patent applications are open to public viewing.[26] Applications are patent requests which have yet to be granted (the process to achieve a patent can take several years).

Keeping Current

In order to stay informed about patents and patent applications dealing with lupus nephritis, you can access the U.S. Patent Office archive via the Internet at no cost to you. This archive is available at the following Web address: **http://www.uspto.gov/main/patents.htm**. Under "Services," click on "Search Patents." You will see two broad options: (1) Patent Grants, and (2) Patent Applications. To see a list of granted patents, perform the following steps: Under "Patent Grants," click "Quick Search." Then, type "lupus nephritis"

[26] This has been a common practice outside the United States prior to December 2000.

(or synonyms) into the "Term 1" box. After clicking on the search button, scroll down to see the various patents which have been granted to date on lupus nephritis. You can also use this procedure to view pending patent applications concerning lupus nephritis. Simply go back to the following Web address: **http://www.uspto.gov/main/patents.htm**. Under "Services," click on "Search Patents." Select "Quick Search" under "Patent Applications." Then proceed with the steps listed above.

Vocabulary Builder

Abdomen: That portion of the body that lies between the thorax and the pelvis. [NIH]

Cataract: An opacity, partial or complete, of one or both eyes, on or in the lens or capsule, especially an opacity impairing vision or causing blindness. The many kinds of cataract are classified by their morphology (size, shape, location) or etiology (cause and time of occurrence). [EU]

Cholesterol: The principal sterol of all higher animals, distributed in body tissues, especially the brain and spinal cord, and in animal fats and oils. [NIH]

Immunosuppressant: An agent capable of suppressing immune responses. [EU]

Mediator: An object or substance by which something is mediated, such as (1) a structure of the nervous system that transmits impulses eliciting a specific response; (2) a chemical substance (transmitter substance) that induces activity in an excitable tissue, such as nerve or muscle; or (3) a substance released from cells as the result of the interaction of antigen with antibody or by the action of antigen with a sensitized lymphocyte. [EU]

Osteoporosis: Reduction in the amount of bone mass, leading to fractures after minimal trauma. [EU]

Retina: The ten-layered nervous tissue membrane of the eye. It is continuous with the optic nerve and receives images of external objects and transmits visual impulses to the brain. Its outer surface is in contact with the choroid and the inner surface with the vitreous body. The outer-most layer is pigmented, whereas the inner nine layers are transparent. [NIH]

Stomach: An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

CHAPTER 6. BOOKS ON LUPUS NEPHRITIS

Overview

This chapter provides bibliographic book references relating to lupus nephritis. You have many options to locate books on lupus nephritis. The simplest method is to go to your local bookseller and inquire about titles that they have in stock or can special order for you. Some patients, however, feel uncomfortable approaching their local booksellers and prefer online sources (e.g. **www.amazon.com** and **www.bn.com**). In addition to online booksellers, excellent sources for book titles on lupus nephritis include the Combined Health Information Database and the National Library of Medicine. Once you have found a title that interests you, visit your local public or medical library to see if it is available for loan.

Book Summaries: Federal Agencies

The Combined Health Information Database collects various book abstracts from a variety of healthcare institutions and federal agencies. To access these summaries, go to **http://chid.nih.gov/detail/detail.html**. You will need to use the "Detailed Search" option. To find book summaries, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer. For the format option, select "Monograph/Book." Now type "lupus nephritis" (or synonyms) into the "For these words:" box. You will only receive results on books. You should check back periodically with this database which is updated every 3 months. The following is a typical result when searching for books on lupus nephritis:

- **Clinical Nephrology**

  Source: River Edge, NJ: World Scientific Publishing Co., Inc. 1998. 340 p.

  Contact: Available from World Scientific Publishing Co., Inc. 1060 Main Street, River Edge, NJ 07661. (800) 227-7562 or (201) 487-9655. Fax (888) 977-2665 or (201) 487-9656. E-mail: wspc@wspc.com. Website: www.wspc.com. Price: $15.00 plus shipping and handling. ISBN: 9810234848.

  Summary: This book provides a broad review of kidney diseases, with regard to symptoms, diagnosis, and treatment; the book is designed to help medical students prepare for their examinations and also to be useful to practicing physicians who need an overview of kidney disease. Twenty-seven chapters are included: the structure and function of the kidneys; symptoms and signs in renal (kidney) medicine; renal investigations (diagnostic tests); glomerulonephritis (inflammation of the kidney glomeruli, bundles of filtering units called nephrons); the nephrotic syndrome (a condition with symptoms of fluid accumulation, protein in the urine, and susceptibility to infections); the pathogenesis (development) and treatment of IgA nephritis (kidney inflammation due to a specific immune system disorder); lupus nephritis (kidney inflammation due to lupus erythematosus, a systemic inflammatory disorder); urinary tract infection; sex and the kidney; hypertension (high blood pressure) and the kidney; diuretics (drugs used to promote the formation of urine); kidney stones (calculi, nephrolithiasis); diabetes mellitus and the kidney; fluid and electrolytes; acid base balance; clinical problems in fluids, electrolytes, and acid base balance; renal tubular acidosis; renal tubular disorders; systemic disease and the kidney; pregnancy and the kidney; cancer and the kidney; inherited kidney diseases; drugs and the kidney; acute renal failure (ARF); chronic renal failure (CRF); dialysis; and renal transplantation. Each chapter includes illustrations, tables, answers to common questions, and a list of references for additional study; a subject index concludes the book.

- **Renal Disease: Classification and Atlas of Glomerular Diseases. 2nd ed**

  Source: New York, NY: Igaku-Shoin Medical Publishers, Inc. 1995. 541 p.

  Contact: Available from Igaku-Shoin. One Madison Avenue, New York, NY 10010. (800) 765-0800 or (212) 779-0123. Fax (212) 779-0322. Price: $159.95 (as of 1996). ISBN: 0896402576.

  Summary: This atlas of renal diseases has two sections. The first provides a listing of glomerular lesions and gives their definitions. It also presents the main clinical and morphological features of glomerular processes in a tabular format. The second section describes and illustrates the various

glomerular processes. Topics include: primary glomerular disease, including glomerulonephritis; lupus nephritis; IgA nephropathy; glomerular lesions in systemic bacterial infections; parasitic glomerulopathies; systemic vasculitis; thrombotic microangiopathy, including the hemolytic-uremic syndrome and thrombotic thrombocytopenic purpura; benign nephrosclerosis; diabetic glomerulopathy; dense deposit disease; the nephropathy of liver disease; Alport syndrome; Fabry disease; nephropathy of toxemia of pregnancy; and end-stage kidney glomerular lesions following transplantation. The appendix contains information about some of the more useful histologic techniques and about examination of renal specimens. The atlas presents numerous microscopy reproductions, in both black and white and color. A subject index concludes the volume. 306 references.

Book Summaries: Online Booksellers

Commercial Internet-based booksellers, such as Amazon.com and Barnes & Noble.com, offer summaries which have been supplied by each title's publisher. Some summaries also include customer reviews. Your local bookseller may have access to in-house and commercial databases that index all published books (e.g. Books in Print®). The following have been recently listed with online booksellers as relating to lupus nephritis (sorted alphabetically by title; follow the hyperlink to view more details at Amazon.com):

- **Lupus Nephritis (Oxford Clinical Nephrology Series)** by Edmund J. Lewis (Editor), Melvin M. Schwartz (Editor), Stephen Korbet (Editor); http://www.amazon.com/exec/obidos/ASIN/b>Publishe/icongroupinterna

The National Library of Medicine Book Index

The National Library of Medicine at the National Institutes of Health has a massive database of books published on healthcare and biomedicine. Go to the following Internet site, **http://locatorplus.gov/**, and then select "Search LOCATORplus." Once you are in the search area, simply type "lupus nephritis" (or synonyms) into the search box, and select "books only." From there, results can be sorted by publication date, author, or relevance. The following was recently catalogued by the National Library of Medicine:[27]

[27] In addition to LOCATORPlus, in collaboration with authors and publishers, the National Center for Biotechnology Information (NCBI) is adapting biomedical books for the Web. The

- **Autoimmunity in nephritis.** Author: edited by Francis W. Ballardie; Year: 1992; Chur; Philadelphia: Harwood Academic Publishers, c1992; ISBN: 3718651955
  http://www.amazon.com/exec/obidos/ASIN/3718651955/icongroupinterna
- **Hereditary nephritis.** Author: International Meeting on Recent Advances in Hereditary Nephritis, Vimercate, July 1, 1989; volume editors, Adalberto Sessa, Mietta Meroni, Graziana Battini; Year: 1990; Basel; New York: Karger, 1990; ISBN: 380555172X
  http://www.amazon.com/exec/obidos/ASIN/380555172X/icongroupinterna
- **Kidney in systemic lupus erythematosus.** Author: Rothfield, Naomi F., 1929-; Year: 1972; Denver, National Kidney Foundation, 1972
- **Lectures on nephritis and hypertension: New York University, College of Medicine.** Author: William Goldring; Year: 1938; Ann Arbor, Mich.: Edwards, 1938
- **Lupus nephritis, by Robert C. Muehrcke [and others].** Author: Muehrcke, Robert Carl, 1921-; Year: 1957; Baltimore, Williams & Wilkins, 1957
- **Lupus nephritis.** Author: edited by Edmund J. Lewis, Melvin M. Schwartz, and Stephen M. Korbet; Year: 1999; Oxford; New York: Oxford University Press, c1999; ISBN: 0192627554
  http://www.amazon.com/exec/obidos/ASIN/0192627554/icongroupinterna
- **Multisystem diseases.** Author: editor, G.R.D. Catto; Year: 1989; Dordrecht; Boston: Kluwer Academic Publishers, c1989; ISBN: 0746200609 (U.S.)
  http://www.amazon.com/exec/obidos/ASIN/0746200609/icongroupinterna
- **Renal Disease: classification and atlas of tubulo-interstitial and vascular diseases\ Surya Venkata Seshan ... [et al.].** Author: Christophers, Allen J., 1915-; Year: 1998; Baltimore: Williams & Wilkins, c1999; ISBN: 0683306774

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books may be accessed in two ways: (1) by searching directly using any search term or phrase (in the same way as the bibliographic database PubMed), or (2) by following the links to PubMed abstracts. Each PubMed abstract has a "Books" button that displays a facsimile of the abstract in which some phrases are hypertext links. These phrases are also found in the books available at NCBI. Click on hyperlinked results in the list of books in which the phrase is found. Currently, the majority of the links are between the books and PubMed. In the future, more links will be created between the books and other types of information, such as gene and protein sequences and macromolecular structures. See **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Books.**

http://www.amazon.com/exec/obidos/ASIN/0683306774/icongroupinterna

- **Renal disease: classification and atlas of tubulo-interstitial diseases.** Author: prepared by the World Health Organization Collaborating Centre for the Histological Classification of Renal Diseases; Jacob Churg ... [et al.]; Year: 1985; Tokyo; New York: Igaku-Shoin, c1985; ISBN: 0896401049 (U.S.)
  http://www.amazon.com/exec/obidos/ASIN/0896401049/icongroupinterna
- **Rheumatology and the kidney.** Author: edited by Dwomoa Adu, Paul Emery and Michael P. Madaio; Year: 2001; Oxford; New York: Oxford University Press, c2001; ISBN: 0192631780 (Hbk: alk. paper)
  http://www.amazon.com/exec/obidos/ASIN/0192631780/icongroupinterna

Chapters on Lupus Nephritis

Frequently, lupus nephritis will be discussed within a book, perhaps within a specific chapter. In order to find chapters that are specifically dealing with lupus nephritis, an excellent source of abstracts is the Combined Health Information Database. You will need to limit your search to book chapters and lupus nephritis using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find book chapters, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the format option "Book Chapter." By making these selections and typing in "lupus nephritis" (or synonyms) into the "For these words:" box, you will only receive results on chapters in books. The following is a typical result when searching for book chapters on lupus nephritis:

- **Course and Treatment of Lupus Nephritis**

  Source: in Coggins, C.H.; Hancock, E.W., Eds. Annual Review of Medicine: Selected Topics in the Clinical Sciences, Volume 45. Palo Alto, CA: Annual Reviews Inc. 1994. p. 525-537.

  Contact: Available from Annual Reviews Inc. 4139 El Camino Way, P.O. Box 10139, Palo Alto, CA 94303-0139. (800) 523-8635. Fax: (415) 855-9815. Price: $47. ISBN: 0824305450.

  Summary: This chapter, from an 'Annual Review of Medicine,' discusses the course and treatment of lupus nephritis. The authors note that renal involvement by systemic lupus is variable; some patients have minimal

clinical and histologic involvement, whereas others have fulminant renal failure and severe proliferative renal lesions. The chapter focuses on the World Health Organization (WHO) classification system which defines six major patterns of renal involvement, each with characteristic clinical correlates and a typical course and prognosis. The WHO classification is advantageous because it uses light microscopy, immunofluorescence, and electron microscopy to classify glomerular involvement in systemic lupus erythematosus. The chapter discusses each of the six levels of the classification system and includes reproductions of light microscopy photographs for five of the six levels. 5 figures. 38 references. (AA-M).

General Home References

In addition to references for lupus nephritis, you may want a general home medical guide that spans all aspects of home healthcare. The following list is a recent sample of such guides (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Urodynamics Made Easy** by Christopher R. Chapple, Scott A. MacDiarmid; Paperback -- 2nd edition (April 15, 2000), Churchill Livingstone; ISBN: 0443054630; **http://www.amazon.com/exec/obidos/ASIN/0443054630/icongroupinterna**

Vocabulary Builder

Acidosis: A pathologic condition resulting from accumulation of acid or depletion of the alkaline reserve (bicarbonate content) in the blood and body tissues, and characterized by an increase in hydrogen ion concentration. [EU]

Arterial: Pertaining to an artery or to the arteries. [EU]

Benign: Not malignant; not recurrent; favourable for recovery. [EU]

Calculi: An abnormal concretion occurring mostly in the urinary and biliary tracts, usually composed of mineral salts. Also called stones. [NIH]

Electrolyte: A substance that dissociates into ions when fused or in solution, and thus becomes capable of conducting electricity; an ionic solute. [EU]

Idiopathic: Of the nature of an idiopathy; self-originated; of unknown causation. [EU]

Microscopy: The application of microscope magnification to the study of materials that cannot be properly seen by the unaided eye. [NIH]

Nephrons: The functional units of the kidney, consisting of the glomerulus

and the attached tubule. [NIH]

Poisoning: A condition or physical state produced by the ingestion, injection or inhalation of, or exposure to a deleterious agent. [NIH]

Puromycin: An antibiotic from Streptomyces alboniger that inhibits protein synthesis by binding to RNA. It is a antineoplastic and antitrypanosomal agent and is used in research as an inhibitor of protein synthesis. [NIH]

Toxemia: A generalized intoxication produced by toxins and other substances elaborated by an infectious agent. [NIH]

Urinary: Pertaining to the urine; containing or secreting urine. [EU]

CHAPTER 7. MULTIMEDIA ON LUPUS NEPHRITIS

Overview

Information on lupus nephritis can come in a variety of formats. Among multimedia sources, video productions, slides, audiotapes, and computer databases are often available. In this chapter, we show you how to keep current on multimedia sources of information on lupus nephritis. We start with sources that have been summarized by federal agencies, and then show you how to find bibliographic information catalogued by the National Library of Medicine. If you see an interesting item, visit your local medical library to check on the availability of the title.

Bibliography: Multimedia on Lupus Nephritis

The National Library of Medicine is a rich source of information on healthcare-related multimedia productions including slides, computer software, and databases. To access the multimedia database, go to the following Web site: **http://locatorplus.gov/**. Select "Search LOCATORplus." Once in the search area, simply type in lupus nephritis (or synonyms). Then, in the option box provided below the search box, select "Audiovisuals and Computer Files." From there, you can choose to sort results by publication date, author, or relevance. The following multimedia has been indexed on lupus nephritis. For more information, follow the hyperlink indicated:

- **[motion picture].** Source: a Telsho production; Year: 1939; Format: Edema--cardiac and renal; United States: Telsho, [1939]
- **Autoimmune diseases.** Source: [presented by] Journal of women's health; Year: 1993; Format: Videorecording; Bethesda, MD: BioConferences International, c1993

- **Chronic empyema with bronchial fistula and complicated by nephritis.** Source: [production company unknown]; S.W. Harrington; Year: 1935; Format: Motion picture; [S.l.: s.n., 1935]
- **Current concepts in collagen vascular diseases.** Source: presented by the Department of Pediatrics, Emory University, School of Medicine; Year: 1983; Format: Videorecording; Atlanta, Ga.: Emory Medical Television Network, 1983
- **Drug-induced systemic lupus erythematosus.** Source: Dept. of Medicine, Emory University, School of Medicine; Year: 1978; Format: Videorecording; Atlanta: Georgia Regional Medical Television Network: [for loan and sale by A. W. Calhoun Medical Library], 1978
- **Immunofluorescence in the study of renal diseases.** Source: Giuseppe A. Andres, Paul D. Leber, Robert T. McCluskey; Year: 1973; Format: Slide; New York: Medcom, c1973
- **Interstitial nephritis : an overview.** Source: Academy of Health Sciences, Health Sciences Media Division; produced through the mobile facilities of the Health Sciences Media Division TV Branch; Year: 1977; Format: Videorecording; Ft. Sam Houston, Tex.: The Academy, [1977]
- **Lupas subsets as manifested in dermatologic disease [videorecording].** Source: [presented by] the Marshfield Regional Video Network, in cooperation with Marshfield Clinic & St. Joseph's Hospital; Year: 1981; Format: I.e. lupus; Marshfield, WI: The Network, 1981
- **Lupus: wolf in disguise.** Source: Los Angeles County Medical Association; produced by Dave Bell Associates; Year: 1974; Format: Videorecording; Garden Grove, Ca.: Trainex, 1974
- **Lupus erythematosus, collagen-vascular diseases, and eczema.** Source: Dept. of Medicine, Emory University, School of Medicine; Year: 1979; Format: Videorecording; Atlanta: Emory Medical Television Network: [for loan and sale by A. W. Calhoun Medical Library, 1979]
- **Lupus-- insights, emotions, encouragements.** Source: written and produced by William & Estelle Gill, in cooperation with the Lupus Foundation of America, Inc., Marcy Zitron Chapter, Columbus, Ohio; Year: 1993; Format: Videorecording; Columbus, Ohio: Production House; Media, PA: Media Inc., c1993
- **Nephrology.** Source: American Medical Association; Year: 1997; Format: Electronic resource; Newton, MA: SilverPlatter Education, 1997
- **Nephrotic syndrome in chronic nephritis.** Source: Department of Medicine, Emory University, School of Medicine; Year: 1980; Format: Videorecording; Atlanta: Emory Medical Television Network: [for loan or sale by A. W. Calhoun Medical Library], 1980

- **Nephrotic syndrome.** Source: E. Lovell Becker, Jacob Churg; Year: 1972; Format: Slide; New York: Medcom, c1972
- **Renal biopsy.** Source: Richard R. Lindquist; Year: 1970; Format: Slide; [New York]: Medcom, c1970
- **Steroids and immunosuppressive drugs in renal disease.** Source: Video Digest, inc; Year: 1972; Format: Motion picture; Cincinnati, Ohio: Video Digest, c1972
- **Systemic lupus erythematosis.** Source: presented by the Department of Pediatrics, Emory University, School of Medicine; Year: 1984; Format: Videorecording; Atlanta, Ga.: Emory Medical Television Network, 1984
- **Systemic lupus erythematosus (SLE) : it means some changes.** Source: Biomedical Media Production Unit, the University of Michigan Medical Center, Office of Educational Resources & Research; Year: 1981; Format: Videorecording; Ann Arbor, Mich.: University of Michigan, c1981
- **Systemic lupus erythematosus.** Source: Ellen M. Ginzler; Year: 1979; Format: Slide; [New York]: Medcom, c1979
- **Systemic lupus.** Source: produced by Audio Master; Year: 1988; Format: Sound recording; [Atlanta, Ga.]: American Rheumatism Association, [1988]
- **Treatment of lupus.** Source: presented by the Department of Medicine, Emory University, School of Medicine; Year: 1985; Format: Videorecording; Atlanta, Ga.: Emory Medical Television Network, 1985
- **Tubulo-interstitial disease.** Source: Harry G. Preuss, George E. Schreiner; Year: 9999; Format: Slide; [New York]: Medcom, c1980-
- **Voices of lupus.** Source: [presented by] Films for the Humanities & Sciences, the Wolf Pack and the Hospital for Special Surgery; a Harriet Fier & Stephen Mantell Production; Year: 1992; Format: Videorecording; Princeton, N.J.: Films for the Humanities & Sciences, c1992

Vocabulary Builder

Dermatology: A medical specialty concerned with the skin, its structure, functions, diseases, and treatment. [NIH]

Eczema: A pruritic papulovesicular dermatitis occurring as a reaction to many endogenous and exogenous agents, characterized in the acute stage by erythema, edema associated with a serous exudate between the cells of the epidermis (spongiosis) and an inflammatory infiltrate in the dermis, oozing and vesiculation, and crusting and scaling; and in the more chronic stages by lichenification or thickening or both, signs of excoriations, and

hyperpigmentation or hypopigmentation or both. Atopic dermatitis is the most common type of dermatitis. Called also eczematous dermatitis. [EU]

Edema: Excessive amount of watery fluid accumulated in the intercellular spaces, most commonly present in subcutaneous tissue. [NIH]

Empyema: Accumulation of pus in a cavity of the body; when used without a descriptive qualifier, it refers to thoracic empyema (q.v.). [EU]

Fistula: An abnormal passage or communication, usually between two internal organs, or leading from an internal organ to the surface of the body; frequently designated according to the organs or parts with which it communicates, as anovaginal, brochocutaneous, hepatopleural, pulmonoperitoneal, rectovaginal, urethrovaginal, and the like. Such passages are frequently created experimentally for the purpose of obtaining body secretions for physiologic study. [EU]

CHAPTER 8. PERIODICALS AND NEWS ON LUPUS NEPHRITIS

Overview

Keeping up on the news relating to lupus nephritis can be challenging. Subscribing to targeted periodicals can be an effective way to stay abreast of recent developments on lupus nephritis. Periodicals include newsletters, magazines, and academic journals.

In this chapter, we suggest a number of news sources and present various periodicals that cover lupus nephritis beyond and including those which are published by patient associations mentioned earlier. We will first focus on news services, and then on periodicals. News services, press releases, and newsletters generally use more accessible language, so if you do chose to subscribe to one of the more technical periodicals, make sure that it uses language you can easily follow.

News Services & Press Releases

Well before articles show up in newsletters or the popular press, they may appear in the form of a press release or a public relations announcement. One of the simplest ways of tracking press releases on lupus nephritis is to search the news wires. News wires are used by professional journalists, and have existed since the invention of the telegraph. Today, there are several major "wires" that are used by companies, universities, and other organizations to announce new medical breakthroughs. In the following sample of sources, we will briefly describe how to access each service. These services only post recent news intended for public viewing.

PR Newswire

Perhaps the broadest of the wires is PR Newswire Association, Inc. To access this archive, simply go to **http://www.prnewswire.com**. Below the search box, select the option "The last 30 days." In the search box, type "lupus nephritis" or synonyms. The search results are shown by order of relevance. When reading these press releases, do not forget that the sponsor of the release may be a company or organization that is trying to sell a particular product or therapy. Their views, therefore, may be biased.

- **Lupus, Psoriasis and Arthritis Foundation Leaders and Biotechnology Industry Discuss Ways to Increase Clinical Trial Enrollment at BIO 2002**

  Summary: San Diego, June 11 /PRNewswire-FirstCall/ -- La Jolla Pharmaceutical Company (Nasdaq: LJPC) today announced that industry and leaders of the national lupus, arthritis and psoriasis patient advocacy organizations will discuss clinical trial enrollment at the Biotechnology Industry Organization (BIO) 2002 International Conference and Exhibition in Toronto, Canada this morning at 8:30 a.m.

  "The good news is that the biotechnology industry is developing an unprecedented wave of drug candidates, offering hope of potential new therapies. Unfortunately, a lack of patients to participate in this growing number of clinical trials will pose a significant bottleneck to the availability of these promising drugs," said Steven B. Engle, La Jolla Pharmaceutical Company's Chairman and CEO. "By working together, patient advocacy groups, biotechnology companies and others can educate the public on the critical importance of clinical trial participation."

  "Voluntary health associations bring together patients and companies seeking to develop new therapies for a range of diseases," said Gail M.

  Zimmerman, President and CEO of the National Psoriasis Foundation. "Through awareness, education and ensuring access to clinical trials, we can help in the race to provide new treatments to patients who may otherwise be faced with limited options for care."

  The panel will include Ms. Zimmerman; Sandra Claire Raymond, President and CEO of the Lupus Foundation of America; and Tino J. Mantella, President and CEO of the Arthritis Foundation. Mr. Engle will chair the panel. The panel discussion is entitled "Changing the Future of Clinical Trial Recruitment by Building Ties with Patient Advocates."

La Jolla Pharmaceutical Company is a biotechnology company leading the development of therapeutics for antibody-mediated autoimmune diseases afflicting several million people in the United States and Europe. The Company is conducting a Phase III trial of LJP 394 in patients with lupus kidney disease, a leading cause of sickness and death in these patients. The Company is also conducting a Phase I/II trial of LJP 1082 for the treatment of antibody-mediated thrombosis, a condition in which patients suffer from recurrent stroke, deep-vein thrombosis and other thrombotic events. The Company's common stock is traded on The Nasdaq Stock Market under the symbol LJPC. For more information about the Company, visit our Web site: http://www.ljpc.com . Patients interested in the Phase III lupus trial may call 1-800-30-LUPUS for information.

Reuters

The Reuters' Medical News database can be very useful in exploring news archives relating to lupus nephritis. While some of the listed articles are free to view, others can be purchased for a nominal fee. To access this archive, go to **http://www.reutershealth.com/frame2/arch.html** and search by "lupus nephritis" (or synonyms). The following was recently listed in this archive for lupus nephritis:

- **Oral cyclophosphamide may have advantages in severe lupus nephritis**
  Source: Reuters Industry Breifing
  Date: August 20, 2001
  http://www.reuters.gov/archive/2001/08/20/business/links/20010820clin017.html
- **Lupus nephritis may be mediated by molecular mimicry**
  Source: Reuters Medical News
  Date: May 16, 2001
  http://www.reuters.gov/archive/2001/05/16/professional/links/20010516scie001.html
- **Anti-C1q antibodies are associated with lupus nephritis activity**
  Source: Reuters Medical News
  Date: March 30, 2001
  http://www.reuters.gov/archive/2001/03/30/professional/links/20010330clin003.html

- **Increased risk of lupus nephritis linked to genetic factor in Caucasians**
  Source: Reuters Medical News
  Date: March 13, 2001
  http://www.reuters.gov/archive/2001/03/13/professional/links/20010313clin007.html
- **Experimental agent may prevent flares of lupus nephritis**
  Source: Reuters Industry Breifing
  Date: March 07, 2001
  http://www.reuters.gov/archive/2001/03/07/business/links/20010307drgd002.html
- **Mycophenolate mofetil plus prednisolone effective for lupus nephritis**
  Source: Reuters Medical News
  Date: October 19, 2000
  http://www.reuters.gov/archive/2000/10/19/professional/links/20001019clin014.html
- **Chinese herbal preparation helps woman with lupus nephritis**
  Source: Reuters Medical News
  Date: August 16, 1999
  http://www.reuters.gov/archive/1999/08/16/professional/links/19990816clin007.html
- **Tolerization with autoepitopes slows lupus nephritis in mice**
  Source: Reuters Medical News
  Date: May 18, 1999
  http://www.reuters.gov/archive/1999/05/18/professional/links/19990518scie001.html
- **Compounds That Block DNA Antibodies May Prevent Lupus Nephritis**
  Source: Reuters Medical News
  Date: November 11, 1996
  http://www.reuters.gov/archive/1996/11/11/professional/links/19961111scie003.html
- **Genetic Risk Factor For Lupus Nephritis Identified**
  Source: Reuters Medical News
  Date: March 06, 1996
  http://www.reuters.gov/archive/1996/03/06/professional/links/19960306clin002.html

The NIH

Within MEDLINEplus, the NIH has made an agreement with the New York Times Syndicate, the AP News Service, and Reuters to deliver news that can be browsed by the public. Search news releases at **http://www.nlm.nih.gov/medlineplus/alphanews_a.html.** MEDLINEplus allows you to browse across an alphabetical index. Or you can search by date at **http://www.nlm.nih.gov/medlineplus/newsbydate.html**. Often, news items are indexed by MEDLINEplus within their search engine.

Business Wire

Business Wire is similar to PR Newswire. To access this archive, simply go to **http://www.businesswire.com**. You can scan the news by industry category or company name.

Internet Wire

Internet Wire is more focused on technology than the other wires. To access this site, go to **http://www.internetwire.com** and use the "Search Archive" option. Type in "lupus nephritis" (or synonyms). As this service is oriented to technology, you may wish to search for press releases covering diagnostic procedures or tests that you may have read about.

Search Engines

Free-to-view news can also be found in the news section of your favorite search engines (see the health news page at Yahoo: **http://dir.yahoo.com/Health/News_and_Media/,** or use this Web site's general news search page **http://news.yahoo.com/.** Type in "lupus nephritis" (or synonyms). If you know the name of a company that is relevant to lupus nephritis, you can go to any stock trading Web site (such as **www.etrade.com**) and search for the company name there. News items across various news sources are reported on indicated hyperlinks.

BBC

Covering news from a more European perspective, the British Broadcasting Corporation (BBC) allows the public free access to their news archive located at **http://www.bbc.co.uk/**. Search by "lupus nephritis" (or synonyms).

Newsletter Articles

If you choose not to subscribe to a newsletter, you can nevertheless find references to newsletter articles. We recommend that you use the Combined Health Information Database, while limiting your search criteria to "newsletter articles." Again, you will need to use the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. Go to the bottom of the search page where "You may refine your search by." Select the dates and language that you prefer. For the format option, select "Newsletter Article."

By making these selections, and typing in "lupus nephritis" (or synonyms) into the "For these words:" box, you will only receive results on newsletter articles. You should check back periodically with this database as it is updated every 3 months. The following is a typical result when searching for newsletter articles on lupus nephritis:

- **Lupus and Pregnancy: Can They Go Together?**

  Source: Lupus News. 20(5): 8-11. Winter 2000.

  Contact: Available from Lupus Foundation of America. 1300 Piccard Drive, Suite 200, Rockville, MD 20850-4303. (800) 558-0121 or (301) 670-9292. Fax (301) 670-9486. Website: www.lupus.org/lupus.

  Summary: This newsletter article uses a question and answer format to provide women who have lupus with information on managing a pregnancy. Lupus is more common among women than men, and it is often diagnosed during the childbearing years. Therefore, women with lupus are faced with the difficult decision of whether or not to become pregnant. Most women who have lupus can have successful pregnancies. One of the most common questions women who have lupus ask is how pregnancy will affect their lupus. Although recent studies show that lupus flares are common in pregnancy, most are mild or moderate and are manageable. Women who have lupus nephritis appear to be at more risk during pregnancy than women without kidney disease, and recent studies support this observation. However, most women with lupus nephritis, particularly women with well controlled lupus nephritis, have a satisfactory pregnancy outcome. Another issue of concern to women with lupus is how it will affect them and their baby during pregnancy. Pregnancy loss is one complication. Women who have antiphospholipid syndrome are at particular risk for pregnancy loss. Preeclampsia is a common complication in all pregnancies, but some patients with lupus are at greater risk for this complication than others, including women using steroids, women with kidney damage, and women with lupus

nephritis. Other complications that women or their baby may experience include preterm birth, fetal growth impairment, and neonatal lupus erythematosus. Women with lupus may also be concerned about the effect of the drugs used to treat lupus on their pregnancy. Drugs that may safely be used to treat lupus during pregnancy are glucocorticoids. A final issue of concern to women with lupus is prenatal care. The article offers guidelines for prepregnancy, prenatal, and postnatal care and care during labor and delivery.

- **Lupus Nephritis: A Practical Guide for the Patient**

  Source: Lupus News. 19(1): 1,3-5. Winter 1998-1999.

  Contact: Available from Lupus Foundation of America. 1300 Piccard Drive, Suite 200, Rockville, MD 20850-4303. (800) 558-0121 or (301) 670-9292. Fax (301) 670-9486. Website: www.lupus.org/lupus.

  Summary: This newsletter article provides people who have systemic lupus erythematous (SLE) with information on lupus kidney disease, also known as lupus nephritis. Estimates indicate that more than half of the patients who have lupus will develop lupus nephritis. Early diagnosis and treatment of lupus nephritis and good followup care are important to ensuring a normal lifespan for patients with SLE. The article explains the normal physiology of the kidney and identifies the mechanisms responsible for lupus nephritis. Lupus kidney disease occurs when immune complexes build up in the kidneys and activate other proteins in the blood called complement. Activation of complement releases chemicals that cause inflammation and result in possible damage to kidney tissue. Symptoms of lupus nephritis include edema and foamy, frothy urine. The diagnosis of is generally made by established criteria. Urine tests that are helpful in diagnosing lupus nephritis are analyzing an early morning specimen and a 24 hour collection. Blood studies that assess blood urea nitrogen and serum creatinine and monitor the levels of anti-DNA antibodies and serum complement are helpful in monitoring lupus nephritis. A kidney biopsy may be needed to determine whether kidney tissue is inflamed or scarred and the severity of the inflammation and scarring. The biopsy will confirm the diagnosis of lupus nephritis, determine the extent of the disease, and classify the type of lupus that is present. Treatment options include using prednisone or immunosuppressive agents such as azathioprine or cyclophosphamide in conjunction with prednisone. In addition to drug therapy, patients who have lupus nephritis should quit smoking, control high cholesterol with diet and exercise, and maintain normal weight. Patients who actively participate in their treatment plan will increase the likelihood of a positive outcome. 3 figures and 3 tables.

- **Facing Lupus Nephritis**

  Source: Lupus Horizons. 21(2):8-10; Fall 1997.

  Contact: Greater Atlanta Chapter of the Lupus Foundation of America, 150 Interstate North Parkway, NW, Suite 285, Atlanta, GA 30339-2201. (800) 800-4FLA. (770) 952-3891.

  Summary: This newsletter article for health professionals and individuals with lupus focuses on lupus nephritis. Reasons why individuals with lupus may fear kidney disease are presented. The types of tests that are useful in the evaluation of patients with suspected nephritis are described, including urinalysis, immunologic tests, and kidney biopsy. In addition, drug therapies that are effective for the treatment of lupus are highlighted, including corticosteroids, chemotherapy, diuretics, and antihypertensives. Dialysis or kidney transplantation may be required if kidney failure develops.

- **Kidney Transplantation**

  Source: SLE Newsletter. 19(2):3,13; Summer 1996.

  Contact: Bay Area Lupus Foundation, Inc., 2635 North First Street, Suite 206, San Jose, CA 95134. (408) 954-8600.

  Summary: This newsletter article for health professionals addresses the issue of kidney transplantation for patients with lupus nephritis. Kidney involvement with lupus nephritis occurs in approximately 10 percent of patients with systemic lupus erythematosus. Although advances have been made in the treatment of lupus nephritis during the past decade, some patients still lose kidney function completely and develop end stage renal disease (ESRD). Once ESRD develops, patients must undergo dialysis or kidney transplantation. Issues that physicians should consider prior to kidney transplantation are examined, including how soon after the onset of kidney failure, when kidney transplantation should occur, whether the risk of developing SLE is too great in a relative to allow kidney donation, whether a patient's tissue type will affect the outcome of kidney transplantation, and whether a woman with a history of SLE should become pregnant after kidney transplantation.

Academic Periodicals covering Lupus Nephritis

Academic periodicals can be a highly technical yet valuable source of information on lupus nephritis. We have compiled the following list of periodicals known to publish articles relating to lupus nephritis and which are currently indexed within the National Library of Medicine's PubMed

database (follow hyperlinks to view more information, summaries, etc., for each). In addition to these sources, to keep current on articles written on lupus nephritis published by any of the periodicals listed below, you can simply follow the hyperlink indicated or go to the following Web site: **www.ncbi.nlm.nih.gov/pubmed**. Type the periodical's name into the search box to find the latest studies published.

If you want complete details about the historical contents of a periodical, you can also visit **http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi**. Here, type in the name of the journal or its abbreviation, and you will receive an index of published articles. At **http://locatorplus.gov/** you can retrieve more indexing information on medical periodicals (e.g. the name of the publisher). Select the button "Search LOCATORplus." Then type in the name of the journal and select the advanced search option "Journal Title Search." The following is a sample of periodicals which publish articles on lupus nephritis:

- **American Journal of Kidney Diseases : the Official Journal of the National Kidney Foundation. (Am J Kidney Dis)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=American+Journal+of+Kidney+Diseases+:+the+Official+Journal+of+the+National+Kidney+Foundation&dispmax=20&dispstart=0

- **Archives of Pediatrics & Adolescent Medicine. (Arch Pediatr Adolesc Med)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Archives+of+Pediatrics+&+Adolescent+Medicine&dispmax=20&dispstart=0

- **Arthritis and Rheumatism. (Arthritis Rheum)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Arthritis+and+Rheumatism&dispmax=20&dispstart=0

- **Biochemical and Biophysical Research Communications. (Biochem Biophys Res Commun)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Biochemical+and+Biophysical+Research+Communications&dispmax=20&dispstart=0

- **Nephrology, Dialysis, Transplantation : Official Publication of the European Dialysis and Transplant Association - European Renal Association. (Nephrol Dial Transplant)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Nephrology,+Dialysis,+Transplantation+:+Official+Publication+of+the+European+Dialysis+and+Transplant+Association+-+European+Renal+Association&dispmax=20&dispstart=0

Vocabulary Builder

Antihypertensive: An agent that reduces high blood pressure. [EU]

Nitrogen: An element with the atomic symbol N, atomic number 7, and atomic weight 14. Nitrogen exists as a diatomic gas and makes up about 78% of the earth's atmosphere by volume. It is a constituent of proteins and nucleic acids and found in all living cells. [NIH]

Prednisone: A synthetic anti-inflammatory glucocorticoid derived from cortisone. It is biologically inert and converted to prednisolone in the liver. [NIH]

Preeclampsia: A toxaemia of late pregnancy characterized by hypertension, edema, and proteinuria, when convulsions and coma are associated, it is called eclampsia. [EU]

Prenatal: Existing or occurring before birth, with reference to the fetus. [EU]

CHAPTER 9. PHYSICIAN GUIDELINES AND DATABASES

Overview

Doctors and medical researchers rely on a number of information sources to help patients with their conditions. Many will subscribe to journals or newsletters published by their professional associations or refer to specialized textbooks or clinical guides published for the medical profession. In this chapter, we focus on databases and Internet-based guidelines created or written for this professional audience.

NIH Guidelines

For the more common diseases, The National Institutes of Health publish guidelines that are frequently consulted by physicians. Publications are typically written by one or more of the various NIH Institutes. For physician guidelines, commonly referred to as "clinical" or "professional" guidelines, you can visit the following Institutes:

- Office of the Director (OD); guidelines consolidated across agencies available at **http://www.nih.gov/health/consumer/conkey.htm**
- National Institute of General Medical Sciences (NIGMS); fact sheets available at **http://www.nigms.nih.gov/news/facts/**
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines: **http://www.nlm.nih.gov/medlineplus/healthtopics.html**
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); guidelines available at **http://www.niddk.nih.gov/health/health.htm**

NIH Databases

In addition to the various Institutes of Health that publish professional guidelines, the NIH has designed a number of databases for professionals.[28] Physician-oriented resources provide a wide variety of information related to the biomedical and health sciences, both past and present. The format of these resources varies. Searchable databases, bibliographic citations, full text articles (when available), archival collections, and images are all available. The following are referenced by the National Library of Medicine:[29]

- **Bioethics:** Access to published literature on the ethical, legal and public policy issues surrounding healthcare and biomedical research. This information is provided in conjunction with the Kennedy Institute of Ethics located at Georgetown University, Washington, D.C.: **http://www.nlm.nih.gov/databases/databases_bioethics.html**
- **HIV/AIDS Resources:** Describes various links and databases dedicated to HIV/AIDS research: **http://www.nlm.nih.gov/pubs/factsheets/aidsinfs.html**
- **NLM Online Exhibitions:** Describes "Exhibitions in the History of Medicine": **http://www.nlm.nih.gov/exhibition/exhibition.html**. Additional resources for historical scholarship in medicine: **http://www.nlm.nih.gov/hmd/hmd.html**
- **Biotechnology Information:** Access to public databases. The National Center for Biotechnology Information conducts research in computational biology, develops software tools for analyzing genome data, and disseminates biomedical information for the better understanding of molecular processes affecting human health and disease: **http://www.ncbi.nlm.nih.gov/**
- **Population Information:** The National Library of Medicine provides access to worldwide coverage of population, family planning, and related health issues, including family planning technology and programs, fertility, and population law and policy: **http://www.nlm.nih.gov/databases/databases_population.html**
- **Cancer Information:** Access to caner-oriented databases: **http://www.nlm.nih.gov/databases/databases_cancer.html**

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[28] Remember, for the general public, the National Library of Medicine recommends the databases referenced in MEDLINE*plus* (**http://medlineplus.gov/** or **http://www.nlm.nih.gov/medlineplus/databases.html**).

[29] See **http://www.nlm.nih.gov/databases/databases.html**.

- **Profiles in Science:** Offering the archival collections of prominent twentieth-century biomedical scientists to the public through modern digital technology: **http://www.profiles.nlm.nih.gov/**
- **Chemical Information:** Provides links to various chemical databases and references: **http://sis.nlm.nih.gov/Chem/ChemMain.html**
- **Clinical Alerts:** Reports the release of findings from the NIH-funded clinical trials where such release could significantly affect morbidity and mortality: **http://www.nlm.nih.gov/databases/alerts/clinical_alerts.html**
- **Space Life Sciences:** Provides links and information to space-based research (including NASA): **http://www.nlm.nih.gov/databases/databases_space.html**
- **MEDLINE:** Bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the healthcare system, and the pre-clinical sciences: **http://www.nlm.nih.gov/databases/databases_medline.html**
- **Toxicology and Environmental Health Information (TOXNET):** Databases covering toxicology and environmental health: **http://sis.nlm.nih.gov/Tox/ToxMain.html**
- **Visible Human Interface:** Anatomically detailed, three-dimensional representations of normal male and female human bodies: **http://www.nlm.nih.gov/research/visible/visible_human.html**

While all of the above references may be of interest to physicians who study and treat lupus nephritis, the following are particularly noteworthy.

The Combined Health Information Database

A comprehensive source of information on clinical guidelines written for professionals is the Combined Health Information Database. You will need to limit your search to "Brochure/Pamphlet," "Fact Sheet," or "Information Package" and lupus nephritis using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find associations, use the drop boxes at the bottom of the search page where "You may refine your search by." For the publication date, select "All Years," select your preferred language, and the format option "Fact Sheet." By making these selections and typing "lupus nephritis" (or synonyms) into the "For these words:" box above, you will only receive results on fact sheets dealing with lupus nephritis. The following is a sample result:

The NLM Gateway[30]

The NLM (National Library of Medicine) Gateway is a Web-based system that lets users search simultaneously in multiple retrieval systems at the U.S. National Library of Medicine (NLM). It allows users of NLM services to initiate searches from one Web interface, providing "one-stop searching" for many of NLM's information resources or databases.[31] One target audience for the Gateway is the Internet user who is new to NLM's online resources and does not know what information is available or how best to search for it. This audience may include physicians and other healthcare providers, researchers, librarians, students, and, increasingly, patients, their families, and the public.[32] To use the NLM Gateway, simply go to the search site at **http://gateway.nlm.nih.gov/gw/Cmd**. Type "lupus nephritis" (or synonyms) into the search box and click "Search." The results will be presented in a tabular form, indicating the number of references in each database category.

Results Summary

Category	Items Found
Journal Articles	5040
Books / Periodicals / Audio Visual	18
Consumer Health	20
Meeting Abstracts	1
Other Collections	0
Total	5079

[30] Adapted from NLM: **http://gateway.nlm.nih.gov/gw/Cmd?Overview.x**.

[31] The NLM Gateway is currently being developed by the Lister Hill National Center for Biomedical Communications (LHNCBC) at the National Library of Medicine (NLM) of the National Institutes of Health (NIH).

[32] Other users may find the Gateway useful for an overall search of NLM's information resources. Some searchers may locate what they need immediately, while others will utilize the Gateway as an adjunct tool to other NLM search services such as PubMed® and MEDLINEplus®. The Gateway connects users with multiple NLM retrieval systems while also providing a search interface for its own collections. These collections include various types of information that do not logically belong in PubMed, LOCATORplus, or other established NLM retrieval systems (e.g., meeting announcements and pre-1966 journal citations). The Gateway will provide access to the information found in an increasing number of NLM retrieval systems in several phases.

HSTAT[33]

HSTAT is a free, Web-based resource that provides access to full-text documents used in healthcare decision-making.[34] HSTAT's audience includes healthcare providers, health service researchers, policy makers, insurance companies, consumers, and the information professionals who serve these groups. HSTAT provides access to a wide variety of publications, including clinical practice guidelines, quick-reference guides for clinicians, consumer health brochures, evidence reports and technology assessments from the Agency for Healthcare Research and Quality (AHRQ), as well as AHRQ's Put Prevention Into Practice.[35] Simply search by "lupus nephritis" (or synonyms) at the following Web site: **http://text.nlm.nih.gov**.

Coffee Break: Tutorials for Biologists[36]

Some patients may wish to have access to a general healthcare site that takes a scientific view of the news and covers recent breakthroughs in biology that may one day assist physicians in developing treatments. To this end, we recommend "Coffee Break," a collection of short reports on recent biological discoveries. Each report incorporates interactive tutorials that demonstrate how bioinformatics tools are used as a part of the research process. Currently, all Coffee Breaks are written by NCBI staff.[37] Each report is about 400 words and is usually based on a discovery reported in one or more articles from recently published, peer-reviewed literature.[38] This site has new

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[33] Adapted from HSTAT: **http://www.nlm.nih.gov/pubs/factsheets/hstat.html**.

[34] The HSTAT URL is **http://hstat.nlm.nih.gov/**.

[35] Other important documents in HSTAT include: the National Institutes of Health (NIH) Consensus Conference Reports and Technology Assessment Reports; the HIV/AIDS Treatment Information Service (ATIS) resource documents; the Substance Abuse and Mental Health Services Administration's Center for Substance Abuse Treatment (SAMHSA/CSAT) Treatment Improvement Protocols (TIP) and Center for Substance Abuse Prevention (SAMHSA/CSAP) Prevention Enhancement Protocols System (PEPS); the Public Health Service (PHS) Preventive Services Task Force's *Guide to Clinical Preventive Services*; the independent, nonfederal Task Force on Community Services *Guide to Community Preventive Services*; and the Health Technology Advisory Committee (HTAC) of the Minnesota Health Care Commission (MHCC) health technology evaluations.

[36] Adapted from **http://www.ncbi.nlm.nih.gov/Coffeebreak/Archive/FAQ.html**.

[37] The figure that accompanies each article is frequently supplied by an expert external to NCBI, in which case the source of the figure is cited. The result is an interactive tutorial that tells a biological story.

[38] After a brief introduction that sets the work described into a broader context, the report focuses on how a molecular understanding can provide explanations of observed biology and lead to therapies for diseases. Each vignette is accompanied by a figure and hypertext links that lead to a series of pages that interactively show how NCBI tools and resources are used in the research process.

articles every few weeks, so it can be considered an online magazine of sorts, and intended for general background information. You can access the Coffee Break Web site at **http://www.ncbi.nlm.nih.gov/Coffeebreak/**.

Other Commercial Databases

In addition to resources maintained by official agencies, other databases exist that are commercial ventures addressing medical professionals. Here are a few examples that may interest you:

- **CliniWeb International:** Index and table of contents to selected clinical information on the Internet; see **http://www.ohsu.edu/cliniweb/**.
- **Image Engine:** Multimedia electronic medical record system that integrates a wide range of digitized clinical images with textual data stored in the University of Pittsburgh Medical Center's MARS electronic medical record system; see the following Web site: **http://www.cml.upmc.edu/cml/imageengine/imageEngine.html**.
- **Medical World Search:** Searches full text from thousands of selected medical sites on the Internet; see **http://www.mwsearch.com/**.
- **MedWeaver:** Prototype system that allows users to search differential diagnoses for any list of signs and symptoms, to search medical literature, and to explore relevant Web sites; see **http://www.med.virginia.edu/~wmd4n/medweaver.html**.
- **Metaphrase:** Middleware component intended for use by both caregivers and medical records personnel. It converts the informal language generally used by caregivers into terms from formal, controlled vocabularies; see the following Web site: **http://www.lexical.com/Metaphrase.html**.

The Genome Project and Lupus Nephritis

With all the discussion in the press about the Human Genome Project, it is only natural that physicians, researchers, and patients want to know about how human genes relate to lupus nephritis. In the following section, we will discuss databases and references used by physicians and scientists who work in this area.

Online Mendelian Inheritance in Man (OMIM)

The Online Mendelian Inheritance in Man (OMIM) database is a catalog of human genes and genetic disorders authored and edited by Dr. Victor A. McKusick and his colleagues at Johns Hopkins and elsewhere. OMIM was developed for the World Wide Web by the National Center for Biotechnology Information (NCBI).[39] The database contains textual information, pictures, and reference information. It also contains copious links to NCBI's Entrez database of MEDLINE articles and sequence information.

Go to **http://www.ncbi.nlm.nih.gov/Omim/searchomim.html** to search the database. Type "lupus nephritis" (or synonyms) in the search box, and click "Submit Search." If too many results appear, you can narrow the search by adding the word "clinical." Each report will have additional links to related research and databases. By following these links, especially the link titled "Database Links," you will be exposed to numerous specialized databases that are largely used by the scientific community. These databases are overly technical and seldom used by the general public, but offer an abundance of information. The following is an example of the results you can obtain from the OMIM for lupus nephritis:

- **Complement Component 1, Q Subcomponent, Beta Polypeptide**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?120570
- **Complement Component 2 Deficiency**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?217000
- **Complement Component 3**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?120700
- **Complement Component 4b**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?120820

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[39] Adapted from **http://www.ncbi.nlm.nih.gov/**. Established in 1988 as a national resource for molecular biology information, NCBI creates public databases, conducts research in computational biology, develops software tools for analyzing genome data, and disseminates biomedical information--all for the better understanding of molecular processes affecting human health and disease.

- **Complement Component C1r Deficiency**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?216950
- **Fc Fragment of Igg, Low Affinity Iia, Receptor for**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?146790
- **Fk506-binding Protein 4**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?600611
- **Lupus Erythematosus, Systemic**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?152700
- **Peptide Ln1**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?601996
- **Phytanoyl-coa Hydroxylase**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?602026

Genes and Disease (NCBI - Map)

The Genes and Disease database is produced by the National Center for Biotechnology Information of the National Library of Medicine at the National Institutes of Health. Go to **http://www.ncbi.nlm.nih.gov/disease/**, and browse the system pages to have a full view of important conditions linked to human genes. Since this site is regularly updated, you may wish to re-visit it from time to time. The following systems and associated disorders are addressed:

- **Immune System:** Fights invaders.
  Examples: Asthma, autoimmune polyglandular syndrome, Crohn's disease, DiGeorge syndrome, familial Mediterranean fever, immunodeficiency with Hyper-IgM, severe combined immunodeficiency.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Immune.html**
- **Muscle and Bone:** Movement and growth.
  Examples: Duchenne muscular dystrophy, Ellis-van Creveld syndrome, Marfan syndrome, myotonic dystrophy, spinal muscular atrophy.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Muscle.html**
- **Signals:** Cellular messages.
  Examples: Ataxia telangiectasia, Baldness, Cockayne syndrome,

Glaucoma, SRY: sex determination, Tuberous sclerosis, Waardenburg syndrome, Werner syndrome.
Web site: **http://www.ncbi.nlm.nih.gov/disease/Signals.html**

- **Transporters:** Pumps and channels.
  Examples: Cystic Fibrosis, deafness, diastrophic dysplasia, Hemophilia A, long-QT syndrome, Menkes syndrome, Pendred syndrome, polycystic kidney disease, sickle cell anemia, Wilson's disease, Zellweger syndrome.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Transporters.html**

Entrez

Entrez is a search and retrieval system that integrates several linked databases at the National Center for Biotechnology Information (NCBI). These databases include nucleotide sequences, protein sequences, macromolecular structures, whole genomes, and MEDLINE through PubMed. Entrez provides access to the following databases:

- **PubMed:** Biomedical literature (PubMed),
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed**
- **Nucleotide Sequence Database (Genbank):**
  Web site:
  http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Nucleotide
- **Protein Sequence Database:**
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Protein**
- **Structure:** Three-dimensional macromolecular structures,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Structure**
- **Genome:** Complete genome assemblies,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Genome**
- **PopSet:** Population study data sets,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Popset**
- **OMIM:** Online Mendelian Inheritance in Man,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM**
- **Taxonomy:** Organisms in GenBank,
  Web site:
  http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Taxonomy
- **Books:** Online books,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=books**

- **ProbeSet:** Gene Expression Omnibus (GEO),
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=geo**
- **3D Domains:** Domains from Entrez Structure,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=geo**
- **NCBI's Protein Sequence Information Survey Results:**
  Web site: **http://www.ncbi.nlm.nih.gov/About/proteinsurvey/**

To access the Entrez system at the National Center for Biotechnology Information, go to **http://www.ncbi.nlm.nih.gov/entrez/**, and then select the database that you would like to search. The databases available are listed in the drop box next to "Search." In the box next to "for," enter "lupus nephritis" (or synonyms) and click "Go."

Jablonski's Multiple Congenital Anomaly/Mental Retardation (MCA/MR) Syndromes Database[40]

This online resource can be quite useful. It has been developed to facilitate the identification and differentiation of syndromic entities. Special attention is given to the type of information that is usually limited or completely omitted in existing reference sources due to space limitations of the printed form.

At **http://www.nlm.nih.gov/mesh/jablonski/syndrome_toc/toc_a.html** you can also search across syndromes using an alphabetical index**.** You can also search at **http://www.nlm.nih.gov/mesh/jablonski/syndrome_db.html**.

The Genome Database[41]

Established at Johns Hopkins University in Baltimore, Maryland in 1990, the Genome Database (GDB) is the official central repository for genomic mapping data resulting from the Human Genome Initiative. In the spring of 1999, the Bioinformatics Supercomputing Centre (BiSC) at the Hospital for Sick Children in Toronto, Ontario assumed the management of GDB. The Human Genome Initiative is a worldwide research effort focusing on structural analysis of human DNA to determine the location and sequence of the estimated 100,000 human genes. In support of this project, GDB stores

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[40] Adapted from the National Library of Medicine:
http://www.nlm.nih.gov/mesh/jablonski/about_syndrome.html.
[41] Adapted from the Genome Database:
http://gdbwww.gdb.org/gdb/aboutGDB.html#mission.

and curates data generated by researchers worldwide who are engaged in the mapping effort of the Human Genome Project (HGP). GDB's mission is to provide scientists with an encyclopedia of the human genome which is continually revised and updated to reflect the current state of scientific knowledge. Although GDB has historically focused on gene mapping, its focus will broaden as the Genome Project moves from mapping to sequence, and finally, to functional analysis.

To access the GDB, simply go to the following hyperlink: **http://www.gdb.org/**. Search "All Biological Data" by "Keyword." Type "lupus nephritis" (or synonyms) into the search box, and review the results. If more than one word is used in the search box, then separate each one with the word "and" or "or" (using "or" might be useful when using synonyms). This database is extremely technical as it was created for specialists. The articles are the results which are the most accessible to non-professionals and often listed under the heading "Citations." The contact names are also accessible to non-professionals.

Specialized References

The following books are specialized references written for professionals interested in lupus nephritis (sorted alphabetically by title, hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Adult and Pediatric Urology (3-Volume Set) (Includes a Card to Return to Receive the Free CD-ROM)** by Jay Y. Gillenwater, M.D. (Editor), et al; Hardcover - 2828 pages, 4th edition (January 15, 2002), Lippincott, Williams & Wilkins Publishers; ISBN: 0781732204; **http://www.amazon.com/exec/obidos/ASIN/0781732204/icongroupinterna**
- **Campbell's Urology (4-Volume Set)** by Meredith F. Campbell (Editor), et al; Hardcover, 8th edition (May 15, 2002), W B Saunders Co; ISBN: 0721690580; **http://www.amazon.com/exec/obidos/ASIN/0721690580/icongroupinterna**
- **Clinical Manual of Urology** by Philip M. Hanno, M.D. (Editor), et al; Paperback - 924 pages, 3rd edition (May 2, 2001), McGraw-Hill Professional Publishing; ISBN: 0071362010; **http://www.amazon.com/exec/obidos/ASIN/0071362010/icongroupinterna**
- **Comprehensive Urology** by George Weiss O'Reilly; Hardcover - 724 pages, 1st edition (January 15, 2001), Elsevier Science, Health Science Division; ISBN: 0723429499; **http://www.amazon.com/exec/obidos/ASIN/0723429499/icongroupinterna**

- **Manual of Urology: Diagnosis & Therapy** by Mike B. Siroky (Editor), et al; Spiral-bound - 362 pages, 2nd spiral edition (October 15, 1999), Lippincott, Williams & Wilkins Publishers; ISBN: 078171785X; **http://www.amazon.com/exec/obidos/ASIN/078171785X/icongroupinterna**
- **The Scientific Basis of Urology** by A.R. Mundy (Editor), et al; 531 pages - 1st edition (March 15, 1999), Isis Medical Media; ISBN: 1899066217; **http://www.amazon.com/exec/obidos/ASIN/1899066217/icongroupinterna**
- **Smith's General Urology** by Emil A. Tanagho (Editor), et al; Paperback - 888 pages, 15th edition (January 21, 2000), McGraw-Hill Professional Publishing; ISBN: 0838586074; **http://www.amazon.com/exec/obidos/ASIN/0838586074/icongroupinterna**
- **Urology (House Officer Series)** by Michael T. MacFarlane, M.D.; Paperback - 3rd edition (January 2001), Lippincott, Williams & Wilkins Publishers; ISBN: 0781731461; **http://www.amazon.com/exec/obidos/ASIN/0781731461/icongroupinterna**
- **Urology for Primary Care Physicians** by Unyime O. Nseyo (Editor), et al; Hardcover - 399 pages, 1st edition (July 15, 1999), W B Saunders Co; ISBN: 0721671489; **http://www.amazon.com/exec/obidos/ASIN/0721671489/icongroupinterna**

Vocabulary Builder

Polypeptide: A peptide which on hydrolysis yields more than two amino acids; called tripeptides, tetrapeptides, etc. according to the number of amino acids contained. [EU]

CHAPTER 10. DISSERTATIONS ON LUPUS NEPHRITIS

Overview

University researchers are active in studying almost all known diseases. The result of research is often published in the form of Doctoral or Master's dissertations. You should understand, therefore, that applied diagnostic procedures and/or therapies can take many years to develop after the thesis that proposed the new technique or approach was written.

In this chapter, we will give you a bibliography on recent dissertations relating to lupus nephritis. You can read about these in more detail using the Internet or your local medical library. We will also provide you with information on how to use the Internet to stay current on dissertations.

Dissertations on Lupus Nephritis

ProQuest Digital Dissertations is the largest archive of academic dissertations available. From this archive, we have compiled the following list covering dissertations devoted to lupus nephritis. You will see that the information provided includes the dissertation's title, its author, and the author's institution. To read more about the following, simply use the Internet address indicated. The following covers recent dissertations dealing with lupus nephritis:

- **Contributions to the Pathology of Kidney, Liver and Other Diseases (helicobacter Pylori)** by Sinniah, Rajalingam; Dsc from Queen's University of Belfast (northern Ireland), 2001
  http://wwwlib.umi.com/dissertations/fullcit/f461793

Keeping Current

As previously mentioned, an effective way to stay current on dissertations dedicated to lupus nephritis is to use the database called *ProQuest Digital Dissertations* via the Internet, located at the following Web address: **http://wwwlib.umi.com/dissertations.** The site allows you to freely access the last two years of citations and abstracts. Ask your medical librarian if the library has full and unlimited access to this database. From the library, you should be able to do more complete searches than with the limited 2-year access available to the general public.

Vocabulary Builder

Helicobacter: A genus of gram-negative, spiral-shaped bacteria that is pathogenic and has been isolated from the intestinal tract of mammals, including humans. [NIH]

PART III. APPENDICES

ABOUT PART III

Part III is a collection of appendices on general medical topics which may be of interest to patients with lupus nephritis and related conditions.

APPENDIX A. RESEARCHING YOUR MEDICATIONS

Overview

There are a number of sources available on new or existing medications which could be prescribed to patients with lupus nephritis. While a number of hard copy or CD-Rom resources are available to patients and physicians for research purposes, a more flexible method is to use Internet-based databases. In this chapter, we will begin with a general overview of medications. We will then proceed to outline official recommendations on how you should view your medications. You may also want to research medications that you are currently taking for other conditions as they may interact with medications for lupus nephritis. Research can give you information on the side effects, interactions, and limitations of prescription drugs used in the treatment of lupus nephritis. Broadly speaking, there are two sources of information on approved medications: public sources and private sources. We will emphasize free-to-use public sources.

Your Medications: The Basics[42]

The Agency for Health Care Research and Quality has published extremely useful guidelines on how you can best participate in the medication aspects of lupus nephritis. Taking medicines is not always as simple as swallowing a pill. It can involve many steps and decisions each day. The AHCRQ recommends that patients with lupus nephritis take part in treatment decisions. Do not be afraid to ask questions and talk about your concerns. By taking a moment to ask questions early, you may avoid problems later. Here are some points to cover each time a new medicine is prescribed**:**

- Ask about all parts of your treatment, including diet changes, exercise, and medicines.
- Ask about the risks and benefits of each medicine or other treatment you might receive.
- Ask how often you or your doctor will check for side effects from a given medication.

Do not hesitate to ask what is important to you about your medicines. You may want a medicine with the fewest side effects, or the fewest doses to take each day. You may care most about cost, or how the medicine might affect how you live or work. Or, you may want the medicine your doctor believes will work the best. Telling your doctor will help him or her select the best treatment for you.

Do not be afraid to "bother" your doctor with your concerns and questions about medications for lupus nephritis. You can also talk to a nurse or a pharmacist. They can help you better understand your treatment plan. Feel free to bring a friend or family member with you when you visit your doctor. Talking over your options with someone you trust can help you make better choices, especially if you are not feeling well. Specifically, ask your doctor the following:

- The name of the medicine and what it is supposed to do.
- How and when to take the medicine, how much to take, and for how long.
- What food, drinks, other medicines, or activities you should avoid while taking the medicine.
- What side effects the medicine may have, and what to do if they occur.
- If you can get a refill, and how often.

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[42] This section is adapted from AHCRQ: **http://www.ahcpr.gov/consumer/ncpiebro.htm**.

- About any terms or directions you do not understand.
- What to do if you miss a dose.
- If there is written information you can take home (most pharmacies have information sheets on your prescription medicines; some even offer large-print or Spanish versions).

Do not forget to tell your doctor about all the medicines you are currently taking (not just those for lupus nephritis). This includes prescription medicines and the medicines that you buy over the counter. Then your doctor can avoid giving you a new medicine that may not work well with the medications you take now. When talking to your doctor, you may wish to prepare a list of medicines you currently take, the reason you take them, and how you take them. Be sure to include the following information for each:

- Name of medicine
- Reason taken
- Dosage
- Time(s) of day

Also include any over-the-counter medicines, such as:

- Laxatives
- Diet pills
- Vitamins
- Cold medicine
- Aspirin or other pain, headache, or fever medicine
- Cough medicine
- Allergy relief medicine
- Antacids
- Sleeping pills
- Others (include names)

Learning More about Your Medications

Because of historical investments by various organizations and the emergence of the Internet, it has become rather simple to learn about the

medications your doctor has recommended for lupus nephritis. One such source is the United States Pharmacopeia. In 1820, eleven physicians met in Washington, D.C. to establish the first compendium of standard drugs for the United States. They called this compendium the "U.S. Pharmacopeia (USP)." Today, the USP is a non-profit organization consisting of 800 volunteer scientists, eleven elected officials, and 400 representatives of state associations and colleges of medicine and pharmacy. The USP is located in Rockville, Maryland, and its home page is located at **www.usp.org**. The USP currently provides standards for over 3,700 medications. The resulting USP DI® Advice for the Patient® can be accessed through the National Library of Medicine of the National Institutes of Health. The database is partially derived from lists of federally approved medications in the Food and Drug Administration's (FDA) Drug Approvals database.[43]

While the FDA database is rather large and difficult to navigate, the Phamacopeia is both user-friendly and free to use. It covers more than 9,000 prescription and over-the-counter medications. To access this database, simply type the following hyperlink into your Web browser: **http://www.nlm.nih.gov/medlineplus/druginformation.html**. To view examples of a given medication (brand names, category, description, preparation, proper use, precautions, side effects, etc.), simply follow the hyperlinks indicated within the United States Pharmacopoeia. It is important to read the disclaimer by the United States Pharmacopoeia (**http://www.nlm.nih.gov/medlineplus/drugdisclaimer.html**) before using the information provided.

Of course, we as editors cannot be certain as to what medications you are taking. Therefore, we have compiled a list of medications associated with the treatment of lupus nephritis. Once again, due to space limitations, we only list a sample of medications and provide hyperlinks to ample documentation (e.g. typical dosage, side effects, drug-interaction risks, etc.). The following drugs have been mentioned in the Pharmacopeia and other sources as being potentially applicable to lupus nephritis:

Corticosteroids

- **Dental - U.S. Brands:** Kenalog in Orabase; Orabase-HCA; Oracort; Oralone
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsdental202010.html

[43] Though cumbersome, the FDA database can be freely browsed at the following site: **www.fda.gov/cder/da/da.htm**.

- **Inhalation - U.S. Brands:** AeroBid; AeroBid-M; Azmacort; Beclovent; Decadron Respihaler; Pulmicort Respules; Pulmicort Turbuhaler; Vanceril; Vanceril 84 mcg Double Strength
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsinhalation202011.html
- **Nasal - U.S. Brands:** Beconase; Beconase AQ; Dexacort Turbinaire; Flonase; Nasacort; Nasacort AQ; Nasalide; Nasarel; Nasonex; Rhinocort; Vancenase; Vancenase AQ 84 mcg; Vancenase pockethaler
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsnasal202012.html
- **Ophthalmic - U.S. Brands:** AK-Dex; AK-Pred; AK-Tate; Baldex; Decadron; Dexair; Dexotic; Econopred; Econopred Plus; Eflone; Flarex; Fluor-Op; FML Forte; FML Liquifilm; FML S.O.P.; HMS Liquifilm; Inflamase Forte; Inflamase Mild; I-Pred; Lite Pred; Maxidex; Ocu-Dex; Ocu-Pred; Ocu-Pr
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsophthalmic202013.html
- **Otic - U.S. Brands:** Decadron
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsotic202014.html
- **Rectal - U.S. Brands:** Anucort-HC; Anu-Med HC; Anuprep HC; Anusol-HC; Anutone-HC; Anuzone-HC; Cort-Dome; Cortenema; Cortifoam; Hemorrhoidal HC; Hemril-HC Uniserts; Proctocort; Proctosol-HC; Rectosol-HC
  http://www.nlm.nih.gov/medlineplus/druginfo/corticosteroidsrectal203366.html

Commercial Databases

In addition to the medications listed in the USP above, a number of commercial sites are available by subscription to physicians and their institutions. You may be able to access these sources from your local medical library or your doctor's office.

Reuters Health Drug Database

The Reuters Health Drug Database can be searched by keyword at the hyperlink: **http://www.reutershealth.com/frame2/drug.html**. The following

medications are listed in the Reuters' database as associated with lupus nephritis (including those with contraindications):[44]

- **Quinidine**
  http://www.reutershealth.com/atoz/html/Quinidine.htm

Mosby's GenRx

Mosby's GenRx database (also available on CD-Rom and book format) covers 45,000 drug products including generics and international brands. It provides prescribing information, drug interactions, and patient information. Information in Mosby's GenRx database can be obtained at the following hyperlink: **http://www.genrx.com/Mosby/PhyGenRx/group.html**.

Physicians Desk Reference

The Physicians Desk Reference database (also available in CD-Rom and book format) is a full-text drug database. The database is searchable by brand name, generic name or by indication. It features multiple drug interactions reports. Information can be obtained at the following hyperlink: **http://physician.pdr.net/physician/templates/en/acl/psuser_t.htm**.

Other Web Sites

A number of additional Web sites discuss drug information. As an example, you may like to look at **www.drugs.com** which reproduces the information in the Pharmacopeia as well as commercial information. You may also want to consider the Web site of the Medical Letter, Inc. which allows users to download articles on various drugs and therapeutics for a nominal fee: **http://www.medletter.com/**.

Contraindications and Interactions (Hidden Dangers)

Some of the medications mentioned in the previous discussions can be problematic for patients with lupus nephritis--not because they are used in the treatment process, but because of contraindications, or side effects. Medications with contraindications are those that could react with drugs

[44] Adapted from *A to Z Drug Facts* by Facts and Comparisons.

used to treat lupus nephritis or potentially create deleterious side effects in patients with lupus nephritis. You should ask your physician about any contraindications, especially as these might apply to other medications that you may be taking for common ailments.

Drug-drug interactions occur when two or more drugs react with each other. This drug-drug interaction may cause you to experience an unexpected side effect. Drug interactions may make your medications less effective, cause unexpected side effects, or increase the action of a particular drug. Some drug interactions can even be harmful to you.

Be sure to read the label every time you use a nonprescription or prescription drug, and take the time to learn about drug interactions. These precautions may be critical to your health. You can reduce the risk of potentially harmful drug interactions and side effects with a little bit of knowledge and common sense.

Drug labels contain important information about ingredients, uses, warnings, and directions which you should take the time to read and understand. Labels also include warnings about possible drug interactions. Further, drug labels may change as new information becomes available. This is why it's especially important to read the label every time you use a medication. When your doctor prescribes a new drug, discuss all over-the-counter and prescription medications, dietary supplements, vitamins, botanicals, minerals and herbals you take as well as the foods you eat. Ask your pharmacist for the package insert for each prescription drug you take. The package insert provides more information about potential drug interactions.

A Final Warning

At some point, you may hear of alternative medications from friends, relatives, or in the news media. Advertisements may suggest that certain alternative drugs can produce positive results for patients with lupus nephritis. Exercise caution--some of these drugs may have fraudulent claims, and others may actually hurt you. The Food and Drug Administration (FDA) is the official U.S. agency charged with discovering which medications are likely to improve the health of patients with lupus nephritis. The FDA warns patients to watch out for[45]:

- Secret formulas (real scientists share what they know)

[45] This section has been adapted from **http://www.fda.gov/opacom/lowlit/medfraud.html**.

- Amazing breakthroughs or miracle cures (real breakthroughs don't happen very often; when they do, real scientists do not call them amazing or miracles)
- Quick, painless, or guaranteed cures
- If it sounds too good to be true, it probably isn't true.

If you have any questions about any kind of medical treatment, the FDA may have an office near you. Look for their number in the blue pages of the phone book. You can also contact the FDA through its toll-free number, 1-888-INFO-FDA (1-888-463-6332), or on the World Wide Web at **www.fda.gov**.

General References

In addition to the resources provided earlier in this chapter, the following general references describe medications (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Complete Guide to Prescription and Nonprescription Drugs 2001 (Complete Guide to Prescription and Nonprescription Drugs, 2001)** by H. Winter Griffith, Paperback 16th edition (2001), Medical Surveillance; ISBN: 0942447417; **http://www.amazon.com/exec/obidos/ASIN/039952634X/icongroupinterna**
- **The Essential Guide to Prescription Drugs, 2001** by James J. Rybacki, James W. Long; Paperback - 1274 pages (2001), Harper Resource; ISBN: 0060958162; **http://www.amazon.com/exec/obidos/ASIN/0060958162/icongroupinterna**
- **Handbook of Commonly Prescribed Drugs** by G. John Digregorio, Edward J. Barbieri; Paperback 16th edition (2001), Medical Surveillance; ISBN: 0942447417; **http://www.amazon.com/exec/obidos/ASIN/0942447417/icongroupinterna**
- **Johns Hopkins Complete Home Encyclopedia of Drugs 2nd ed.** by Simeon Margolis (Ed.), Johns Hopkins; Hardcover - 835 pages (2000), Rebus; ISBN: 0929661583; **http://www.amazon.com/exec/obidos/ASIN/0929661583/icongroupinterna**
- **Medical Pocket Reference: Drugs 2002** by Springhouse Paperback 1st edition (2001), Lippincott Williams & Wilkins Publishers; ISBN: 1582550964; **http://www.amazon.com/exec/obidos/ASIN/1582550964/icongroupinterna**

- **PDR** by Medical Economics Staff, Medical Economics Staff Hardcover - 3506 pages 55th edition (2000), Medical Economics Company; ISBN: 1563633752; **http://www.amazon.com/exec/obidos/ASIN/1563633752/icongroupinterna**
- **Pharmacy Simplified: A Glossary of Terms** by James Grogan; Paperback - 432 pages, 1st edition (2001), Delmar Publishers; ISBN: 0766828581; **http://www.amazon.com/exec/obidos/ASIN/0766828581/icongroupinterna**
- **Physician Federal Desk Reference** by Christine B. Fraizer; Paperback 2nd edition (2001), Medicode Inc; ISBN: 1563373971; **http://www.amazon.com/exec/obidos/ASIN/1563373971/icongroupinterna**
- **Physician's Desk Reference Supplements** Paperback - 300 pages, 53 edition (1999), ISBN: 1563632950; **http://www.amazon.com/exec/obidos/ASIN/1563632950/icongroupinterna**

Vocabulary Builder

The following vocabulary builder gives definitions of words used in this chapter that have not been defined in previous chapters:

Inhalation: The drawing of air or other substances into the lungs. [EU]

Liquifilm: A thin liquid layer of coating. [EU]

Quinidine: An optical isomer of quinine, extracted from the bark of the Cinchona tree and similar plant species. This alkaloid dampens the excitability of cardiac and skeletal muscles by blocking sodium and potassium currents across cellular membranes. It prolongs cellular action potential, and decreases automaticity. Quinidine also blocks muscarinic and alpha-adrenergic neurotransmission. [NIH]

APPENDIX B. RESEARCHING ALTERNATIVE MEDICINE

Overview

Complementary and alternative medicine (CAM) is one of the most contentious aspects of modern medical practice. You may have heard of these treatments on the radio or on television. Maybe you have seen articles written about these treatments in magazines, newspapers, or books. Perhaps your friends or doctor have mentioned alternatives.

In this chapter, we will begin by giving you a broad perspective on complementary and alternative therapies. Next, we will introduce you to official information sources on CAM relating to lupus nephritis. Finally, at the conclusion of this chapter, we will provide a list of readings on lupus nephritis from various authors. We will begin, however, with the National Center for Complementary and Alternative Medicine's (NCCAM) overview of complementary and alternative medicine.

What Is CAM?[46]

Complementary and alternative medicine (CAM) covers a broad range of healing philosophies, approaches, and therapies. Generally, it is defined as those treatments and healthcare practices which are not taught in medical schools, used in hospitals, or reimbursed by medical insurance companies. Many CAM therapies are termed "holistic," which generally means that the healthcare practitioner considers the whole person, including physical, mental, emotional, and spiritual health. Some of these therapies are also known as "preventive," which means that the practitioner educates and

[46] Adapted from the NCCAM: **http://nccam.nih.gov/nccam/fcp/faq/index.html#what-is**.

treats the person to prevent health problems from arising, rather than treating symptoms after problems have occurred.

People use CAM treatments and therapies in a variety of ways. Therapies are used alone (often referred to as alternative), in combination with other alternative therapies, or in addition to conventional treatment (sometimes referred to as complementary). Complementary and alternative medicine, or "integrative medicine," includes a broad range of healing philosophies, approaches, and therapies. Some approaches are consistent with physiological principles of Western medicine, while others constitute healing systems with non-Western origins. While some therapies are far outside the realm of accepted Western medical theory and practice, others are becoming established in mainstream medicine.

Complementary and alternative therapies are used in an effort to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. Some commonly used methods of complementary or alternative therapy include mind/body control interventions such as visualization and relaxation, manual healing including acupressure and massage, homeopathy, vitamins or herbal products, and acupuncture.

What Are the Domains of Alternative Medicine?[47]

The list of CAM practices changes continually. The reason being is that these new practices and therapies are often proved to be safe and effective, and therefore become generally accepted as "mainstream" healthcare practices. Today, CAM practices may be grouped within five major domains: (1) alternative medical systems, (2) mind-body interventions, (3) biologically-based treatments, (4) manipulative and body-based methods, and (5) energy therapies. The individual systems and treatments comprising these categories are too numerous to list in this sourcebook. Thus, only limited examples are provided within each.

Alternative Medical Systems

Alternative medical systems involve complete systems of theory and practice that have evolved independent of, and often prior to, conventional biomedical approaches. Many are traditional systems of medicine that are

[47] Adapted from the NCCAM: **http://nccam.nih.gov/nccam/fcp/classify/index.html**.

practiced by individual cultures throughout the world, including a number of venerable Asian approaches.

Traditional oriental medicine emphasizes the balance or disturbances of qi (pronounced chi) or vital energy in health and disease, respectively. Traditional oriental medicine consists of a group of techniques and methods including acupuncture, herbal medicine, oriental massage, and qi gong (a form of energy therapy). Acupuncture involves stimulating specific anatomic points in the body for therapeutic purposes, usually by puncturing the skin with a thin needle.

Ayurveda is India's traditional system of medicine. Ayurvedic medicine (meaning "science of life") is a comprehensive system of medicine that places equal emphasis on body, mind, and spirit. Ayurveda strives to restore the innate harmony of the individual. Some of the primary Ayurvedic treatments include diet, exercise, meditation, herbs, massage, exposure to sunlight, and controlled breathing.

Other traditional healing systems have been developed by the world's indigenous populations. These populations include Native American, Aboriginal, African, Middle Eastern, Tibetan, and Central and South American cultures. Homeopathy and naturopathy are also examples of complete alternative medicine systems.

Homeopathic medicine is an unconventional Western system that is based on the principle that "like cures like," i.e., that the same substance that in large doses produces the symptoms of an illness, in very minute doses cures it. Homeopathic health practitioners believe that the more dilute the remedy, the greater its potency. Therefore, they use small doses of specially prepared plant extracts and minerals to stimulate the body's defense mechanisms and healing processes in order to treat illness.

Naturopathic medicine is based on the theory that disease is a manifestation of alterations in the processes by which the body naturally heals itself and emphasizes health restoration rather than disease treatment. Naturopathic physicians employ an array of healing practices, including the following: diet and clinical nutrition, homeopathy, acupuncture, herbal medicine, hydrotherapy (the use of water in a range of temperatures and methods of applications), spinal and soft-tissue manipulation, physical therapies (such as those involving electrical currents, ultrasound, and light), therapeutic counseling, and pharmacology.

Mind-Body Interventions

Mind-body interventions employ a variety of techniques designed to facilitate the mind's capacity to affect bodily function and symptoms. Only a select group of mind-body interventions having well-documented theoretical foundations are considered CAM. For example, patient education and cognitive-behavioral approaches are now considered "mainstream." On the other hand, complementary and alternative medicine includes meditation, certain uses of hypnosis, dance, music, and art therapy, as well as prayer and mental healing.

Biological-Based Therapies

This category of CAM includes natural and biological-based practices, interventions, and products, many of which overlap with conventional medicine's use of dietary supplements. This category includes herbal, special dietary, orthomolecular, and individual biological therapies.

Herbal therapy employs an individual herb or a mixture of herbs for healing purposes. An herb is a plant or plant part that produces and contains chemical substances that act upon the body. Special diet therapies, such as those proposed by Drs. Atkins, Ornish, Pritikin, and Weil, are believed to prevent and/or control illness as well as promote health. Orthomolecular therapies aim to treat disease with varying concentrations of chemicals such as magnesium, melatonin, and mega-doses of vitamins. Biological therapies include, for example, the use of laetrile and shark cartilage to treat cancer and the use of bee pollen to treat autoimmune and inflammatory diseases.

Manipulative and Body-Based Methods

This category includes methods that are based on manipulation and/or movement of the body. For example, chiropractors focus on the relationship between structure and function, primarily pertaining to the spine, and how that relationship affects the preservation and restoration of health. Chiropractors use manipulative therapy as an integral treatment tool.

In contrast, osteopaths place particular emphasis on the musculoskeletal system and practice osteopathic manipulation. Osteopaths believe that all of the body's systems work together and that disturbances in one system may have an impact upon function elsewhere in the body. Massage therapists manipulate the soft tissues of the body to normalize those tissues.

Energy Therapies

Energy therapies focus on energy fields originating within the body (biofields) or those from other sources (electromagnetic fields). Biofield therapies are intended to affect energy fields (the existence of which is not yet experimentally proven) that surround and penetrate the human body. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in or through these fields. Examples include Qi gong, Reiki and Therapeutic Touch.

Qi gong is a component of traditional oriental medicine that combines movement, meditation, and regulation of breathing to enhance the flow of vital energy (qi) in the body, improve blood circulation, and enhance immune function. Reiki, the Japanese word representing Universal Life Energy, is based on the belief that, by channeling spiritual energy through the practitioner, the spirit is healed and, in turn, heals the physical body. Therapeutic Touch is derived from the ancient technique of "laying-on of hands." It is based on the premises that the therapist's healing force affects the patient's recovery and that healing is promoted when the body's energies are in balance. By passing their hands over the patient, these healers identify energy imbalances.

Bioelectromagnetic-based therapies involve the unconventional use of electromagnetic fields to treat illnesses or manage pain. These therapies are often used to treat asthma, cancer, and migraine headaches. Types of electromagnetic fields which are manipulated in these therapies include pulsed fields, magnetic fields, and alternating current or direct current fields.

Can Alternatives Affect My Treatment?

A critical issue in pursuing complementary alternatives mentioned thus far is the risk that these might have undesirable interactions with your medical treatment. It becomes all the more important to speak with your doctor who can offer advice on the use of alternatives. Official sources confirm this view. Though written for women, we find that the National Women's Health Information Center's advice on pursuing alternative medicine is appropriate for patients of both genders and all ages.[48]

[48] Adapted from **http://www.4woman.gov/faq/alternative.htm**.

Is It Okay to Want Both Traditional and Alternative Medicine?

Should you wish to explore non-traditional types of treatment, be sure to discuss all issues concerning treatments and therapies with your healthcare provider, whether a physician or practitioner of complementary and alternative medicine. Competent healthcare management requires knowledge of both conventional and alternative therapies you are taking for the practitioner to have a complete picture of your treatment plan.

The decision to use complementary and alternative treatments is an important one. Consider before selecting an alternative therapy, the safety and effectiveness of the therapy or treatment, the expertise and qualifications of the healthcare practitioner, and the quality of delivery. These topics should be considered when selecting any practitioner or therapy.

Finding CAM References on Lupus Nephritis

Having read the previous discussion, you may be wondering which complementary or alternative treatments might be appropriate for lupus nephritis. For the remainder of this chapter, we will direct you to a number of official sources which can assist you in researching studies and publications. Some of these articles are rather technical, so some patience may be required.

National Center for Complementary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health (**http://nccam.nih.gov**) has created a link to the National Library of Medicine's databases to allow patients to search for articles that specifically relate to lupus nephritis and complementary medicine. To search the database, go to the following Web site: **www.nlm.nih.gov/nccam/camonpubmed.html**. Select "CAM on PubMed." Enter "lupus nephritis" (or synonyms) into the search box. Click "Go." The following references provide information on particular aspects of complementary and alternative medicine (CAM) that are related to lupus nephritis:

- **A novel treatment for lupus nephritis: lignan precursor derived from flax.**
  Author(s): Clark WF, Muir AD, Westcott ND, Parbtani A.

Source: Lupus. 2000; 9(6): 429-36.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10981647&dopt=Abstract

- **Anti-DNA antibodies in the urine of lupus nephritis patients.**
  Author(s): Macanovic M, Hogarth MB, Lachmann PJ.
  Source: Nephrology, Dialysis, Transplantation : Official Publication of the European Dialysis and Transplant Association - European Renal Association. 1999 June; 14(6): 1418-24.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10383001&dopt=Abstract

- **Characterization of circulating immune complexes detected by monoclonal rheumatoid factor and conglutinin radioimmunoassays in SLE nephritis.**
  Author(s): Nishida SK, Alves MA, Ramos OL, Pereira AB.
  Source: J Clin Lab Immunol. 1988 December; 27(4): 163-9.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3251047&dopt=Abstract

- **Clinical trials in lupus nephritis.**
  Author(s): Ginzler EM.
  Source: Curr Rheumatol Rep. 2001 June; 3(3): 199-204. Review.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11352788&dopt=Abstract

- **Decreased pro-inflammatory cytokines and increased antioxidant enzyme gene expression by omega-3 lipids in murine lupus nephritis.**
  Author(s): Chandrasekar B, Fernandes G.
  Source: Biochemical and Biophysical Research Communications. 1994 April 29; 200(2): 893-8.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8179624&dopt=Abstract

- **Efficacy of a pure compound H1-A extracted from Cordyceps sinensis on autoimmune disease of MRL lpr/lpr mice.**
  Author(s): Yang LY, Chen A, Kuo YC, Lin CY.
  Source: The Journal of Laboratory and Clinical Medicine. 1999 November; 134(5): 492-500.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10560943&dopt=Abstract

- **Flaxseed in lupus nephritis: a two-year nonplacebo-controlled crossover study.**
  Author(s): Clark WF, Kortas C, Heidenheim AP, Garland J, Spanner E, Parbtani A.
  Source: J Am Coll Nutr. 2001 April; 20(2 Suppl): 143-8.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11349937&dopt=Abstract

- **Immunomodulating effect of a traditional Japanese medicine, hachimi-jio-gan (ba-wei-di-huang-wan), on Th1 predominance in autoimmune MRL/MP-lpr/lpr mice.**
  Author(s): Furuya Y, Kawakita T, Nomoto K.
  Source: International Immunopharmacology. 2001 March; 1(3): 551-9.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11367538&dopt=Abstract

- **Modulation of antioxidant enzymes and programmed cell death by n-3 fatty acids.**
  Author(s): Fernandes G, Chandrasekar B, Luan X, Troyer DA.
  Source: Lipids. 1996 March; 31 Suppl: S91-6.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8729101&dopt=Abstract

- **Nephrological research.**
  Author(s): Lin S.
  Source: Chin Med J (Engl). 1996 January; 109(1): 37-9. Review. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8758360&dopt=Abstract

- **Omega-3 fatty acid dietary supplementation in systemic lupus erythematosus.**
  Author(s): Clark WF, Parbtani A, Huff MW, Reid B, Holub BJ, Falardeau P.
  Source: Kidney International. 1989 October; 36(4): 653-60.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2811063&dopt=Abstract

- **Omega-3 fatty acid supplementation in clinical and experimental lupus nephritis.**
  Author(s): Clark WF, Parbtani A.

Source: American Journal of Kidney Diseases : the Official Journal of the National Kidney Foundation. 1994 May; 23(5): 644-7.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8172205&dopt=Abstract

- **Resolution of severe lupus nephritis associated with Tripterygium wilfordii hook F ingestion.**
  Author(s): Kao NL, Richmond GW, Moy JN.
  Source: Arthritis and Rheumatism. 1993 December; 36(12): 1751-2. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8250996&dopt=Abstract

- **Severe arthralgia and myalgia due to high-dose methylprednisolone pulse therapy cured by potassium infusion in a patient with diffuse proliferative lupus nephritis.**
  Author(s): Odabas AR, Cetinkaya R, Selcuk Y, Kaya H.
  Source: Nephron. 2001 January; 87(1): 95. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11174035&dopt=Abstract

- **The prognosis of biopsy-proven lupus nephritis in chinese patients: long term follow-up of 86 cases.**
  Author(s): Shen K, Yu Y, Tang Z, Liu Z, Li L.
  Source: Chin Med J (Engl). 1997 July; 110(7): 502-7.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9594205&dopt=Abstract

- **Unique therapeutic effects of the Japanese-Chinese herbal medicine, Sairei-to, on Th1/Th2 cytokines balance of the autoimmunity of MRL/lpr mice.**
  Author(s): Ito T, Seo N, Yagi H, Ohtani T, Tokura Y, Takigawa M, Furukawa F.
  Source: Journal of Dermatological Science. 2002 April; 28(3): 198-210.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11912007&dopt=Abstract

Additional Web Resources

A number of additional Web sites offer encyclopedic information covering CAM and related topics. The following is a representative sample:

- Alternative Medicine Foundation, Inc.: **http://www.herbmed.org/**
- AOL: **http://search.aol.com/cat.adp?id=169&layer=&from=subcats**
- Chinese Medicine: **http://www.newcenturynutrition.com/**
- drkoop.com®: **http://www.drkoop.com/InteractiveMedicine/IndexC.html**
- Family Village: **http://www.familyvillage.wisc.edu/med_altn.htm**
- Google: **http://directory.google.com/Top/Health/Alternative/**
- Healthnotes: **http://www.thedacare.org/healthnotes/**
- Open Directory Project: **http://dmoz.org/Health/Alternative/**
- TPN.com: **http://www.tnp.com/**
- Yahoo.com: **http://dir.yahoo.com/Health/Alternative_Medicine/**
- WebMD®Health: **http://my.webmd.com/drugs_and_herbs**
- WellNet: **http://www.wellnet.ca/herbsa-c.htm**
- WholeHealthMD.com: **http://www.wholehealthmd.com/reflib/0,1529,,00.html**

The following is a specific Web list relating to lupus nephritis; please note that any particular subject below may indicate either a therapeutic use, or a contraindication (potential danger), and does not reflect an official recommendation:

- **Herbs and Supplements**

  Flaxseed
  Alternative names: Linum usitatissimum, Linseed
  Source: Integrative Medicine Communications; www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsHerbs/Flaxseedch.html

  Linseed
  Source: Integrative Medicine Communications; www.onemedicine.com

Hyperlink:
http://www.drkoop.com/interactivemedicine/ConsHerbs/Flaxseedch.html

Linum usitatissimum
Source: Integrative Medicine Communications; www.onemedicine.com
Hyperlink:
http://www.drkoop.com/interactivemedicine/ConsHerbs/Flaxseedch.html

- **Related Conditions**

Systemic Lupus Erythematosus
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Concern/Lupus.htm

General References

A good place to find general background information on CAM is the National Library of Medicine. It has prepared within the MEDLINEplus system an information topic page dedicated to complementary and alternative medicine. To access this page, go to the MEDLINEplus site at: **www.nlm.nih.gov/medlineplus/alternativemedicine.html.** This Web site provides a general overview of various topics and can lead to a number of general sources. The following additional references describe, in broad terms, alternative and complementary medicine (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Alternative Medicine for Dummies** by James Dillard (Author); Audio Cassette, Abridged edition (1998), Harper Audio; ISBN: 0694520659; **http://www.amazon.com/exec/obidos/ASIN/0694520659/icongroupinterna**
- **Complementary and Alternative Medicine Secrets** by W. Kohatsu (Editor); Hardcover (2001), Hanley & Belfus; ISBN: 1560534400; **http://www.amazon.com/exec/obidos/ASIN/1560534400/icongroupinterna**
- **Dictionary of Alternative Medicine** by J. C. Segen; Paperback-2nd edition (2001), Appleton & Lange; ISBN: 0838516211; **http://www.amazon.com/exec/obidos/ASIN/0838516211/icongroupinterna**
- **Eat, Drink, and Be Healthy: The Harvard Medical School Guide to Healthy Eating** by Walter C. Willett, MD, et al; Hardcover - 352 pages

(2001), Simon & Schuster; ISBN: 0684863375;
http://www.amazon.com/exec/obidos/ASIN/0684863375/icongroupinterna

- **Encyclopedia of Natural Medicine, Revised 2nd Edition** by Michael T. Murray, Joseph E. Pizzorno; Paperback - 960 pages, 2nd Rev edition (1997), Prima Publishing; ISBN: 0761511571;
http://www.amazon.com/exec/obidos/ASIN/0761511571/icongroupinterna
- **Herbs for the Urinary Tract: Herbal Relief for Kidney Stones, Bladder Infections and Other Problems of the Urinary Tract** by Michael Moore; Paperback - 96 pages (June 1998), McGraw Hill - NTC; ISBN: 0879838159;
http://www.amazon.com/exec/obidos/ASIN/0879838159/icongroupinterna
- **Integrative Medicine: An Introduction to the Art & Science of Healing** by Andrew Weil (Author); Audio Cassette, Unabridged edition (2001), Sounds True; ISBN: 1564558541;
http://www.amazon.com/exec/obidos/ASIN/1564558541/icongroupinterna
- **New Encyclopedia of Herbs & Their Uses** by Deni Bown; Hardcover - 448 pages, Revised edition (2001), DK Publishing; ISBN: 078948031X;
http://www.amazon.com/exec/obidos/ASIN/078948031X/icongroupinterna
- **Textbook of Complementary and Alternative Medicine** by Wayne B. Jonas; Hardcover (2003), Lippincott, Williams & Wilkins; ISBN: 0683044370;
http://www.amazon.com/exec/obidos/ASIN/0683044370/icongroupinterna

For additional information on complementary and alternative medicine, ask your doctor or write to:

National Institutes of Health
National Center for Complementary and Alternative Medicine Clearinghouse
P. O. Box 8218
Silver Spring, MD 20907-8218

Vocabulary Builder

The following vocabulary builder gives definitions of words used in this chapter that have not been defined in previous chapters:

Filtration: The passage of a liquid through a filter, accomplished by gravity, pressure, or vacuum (suction). [EU]

APPENDIX C. RESEARCHING NUTRITION

Overview

Since the time of Hippocrates, doctors have understood the importance of diet and nutrition to patients' health and well-being. Since then, they have accumulated an impressive archive of studies and knowledge dedicated to this subject. Based on their experience, doctors and healthcare providers may recommend particular dietary supplements to patients with lupus nephritis. Any dietary recommendation is based on a patient's age, body mass, gender, lifestyle, eating habits, food preferences, and health condition. It is therefore likely that different patients with lupus nephritis may be given different recommendations. Some recommendations may be directly related to lupus nephritis, while others may be more related to the patient's general health. These recommendations, themselves, may differ from what official sources recommend for the average person.

In this chapter we will begin by briefly reviewing the essentials of diet and nutrition that will broadly frame more detailed discussions of lupus nephritis. We will then show you how to find studies dedicated specifically to nutrition and lupus nephritis.

Food and Nutrition: General Principles

What Are Essential Foods?

Food is generally viewed by official sources as consisting of six basic elements: (1) fluids, (2) carbohydrates, (3) protein, (4) fats, (5) vitamins, and (6) minerals. Consuming a combination of these elements is considered to be a healthy diet:

- **Fluids** are essential to human life as 80-percent of the body is composed of water. Water is lost via urination, sweating, diarrhea, vomiting, diuretics (drugs that increase urination), caffeine, and physical exertion.
- **Carbohydrates** are the main source for human energy (thermoregulation) and the bulk of typical diets. They are mostly classified as being either simple or complex. Simple carbohydrates include sugars which are often consumed in the form of cookies, candies, or cakes. Complex carbohydrates consist of starches and dietary fibers. Starches are consumed in the form of pastas, breads, potatoes, rice, and other foods. Soluble fibers can be eaten in the form of certain vegetables, fruits, oats, and legumes. Insoluble fibers include brown rice, whole grains, certain fruits, wheat bran and legumes.
- **Proteins** are eaten to build and repair human tissues. Some foods that are high in protein are also high in fat and calories. Food sources for protein include nuts, meat, fish, cheese, and other dairy products.
- **Fats** are consumed for both energy and the absorption of certain vitamins. There are many types of fats, with many general publications recommending the intake of unsaturated fats or those low in cholesterol.

Vitamins and minerals are fundamental to human health, growth, and, in some cases, disease prevention. Most are consumed in your diet (exceptions being vitamins K and D which are produced by intestinal bacteria and sunlight on the skin, respectively). Each vitamin and mineral plays a different role in health. The following outlines essential vitamins:

- **Vitamin A** is important to the health of your eyes, hair, bones, and skin; sources of vitamin A include foods such as eggs, carrots, and cantaloupe.
- **Vitamin B^1**, also known as thiamine, is important for your nervous system and energy production; food sources for thiamine include meat, peas, fortified cereals, bread, and whole grains.
- **Vitamin B^2**, also known as riboflavin, is important for your nervous system and muscles, but is also involved in the release of proteins from

nutrients; food sources for riboflavin include dairy products, leafy vegetables, meat, and eggs.

- **Vitamin B^3**, also known as niacin, is important for healthy skin and helps the body use energy; food sources for niacin include peas, peanuts, fish, and whole grains
- **Vitamin B^6**, also known as pyridoxine, is important for the regulation of cells in the nervous system and is vital for blood formation; food sources for pyridoxine include bananas, whole grains, meat, and fish.
- **Vitamin B^{12}** is vital for a healthy nervous system and for the growth of red blood cells in bone marrow; food sources for vitamin B^{12} include yeast, milk, fish, eggs, and meat.
- **Vitamin C** allows the body's immune system to fight various diseases, strengthens body tissue, and improves the body's use of iron; food sources for vitamin C include a wide variety of fruits and vegetables.
- **Vitamin D** helps the body absorb calcium which strengthens bones and teeth; food sources for vitamin D include oily fish and dairy products.
- **Vitamin E** can help protect certain organs and tissues from various degenerative diseases; food sources for vitamin E include margarine, vegetables, eggs, and fish.
- **Vitamin K** is essential for bone formation and blood clotting; common food sources for vitamin K include leafy green vegetables.
- **Folic Acid** maintains healthy cells and blood and, when taken by a pregnant woman, can prevent her fetus from developing neural tube defects; food sources for folic acid include nuts, fortified breads, leafy green vegetables, and whole grains.

It should be noted that one can overdose on certain vitamins which become toxic if consumed in excess (e.g. vitamin A, D, E and K).
Like vitamins, minerals are chemicals that are required by the body to remain in good health. Because the human body does not manufacture these chemicals internally, we obtain them from food and other dietary sources. The more important minerals include:

- **Calcium** is needed for healthy bones, teeth, and muscles, but also helps the nervous system function; food sources for calcium include dry beans, peas, eggs, and dairy products.
- **Chromium** is helpful in regulating sugar levels in blood; food sources for chromium include egg yolks, raw sugar, cheese, nuts, beets, whole grains, and meat.

- **Fluoride** is used by the body to help prevent tooth decay and to reinforce bone strength; sources of fluoride include drinking water and certain brands of toothpaste.
- **Iodine** helps regulate the body's use of energy by synthesizing into the hormone thyroxine; food sources include leafy green vegetables, nuts, egg yolks, and red meat.
- **Iron** helps maintain muscles and the formation of red blood cells and certain proteins; food sources for iron include meat, dairy products, eggs, and leafy green vegetables.
- **Magnesium** is important for the production of DNA, as well as for healthy teeth, bones, muscles, and nerves; food sources for magnesium include dried fruit, dark green vegetables, nuts, and seafood.
- **Phosphorous** is used by the body to work with calcium to form bones and teeth; food sources for phosphorous include eggs, meat, cereals, and dairy products.
- **Selenium** primarily helps maintain normal heart and liver functions; food sources for selenium include wholegrain cereals, fish, meat, and dairy products.
- **Zinc** helps wounds heal, the formation of sperm, and encourage rapid growth and energy; food sources include dried beans, shellfish, eggs, and nuts.

The United States government periodically publishes recommended diets and consumption levels of the various elements of food. Again, your doctor may encourage deviations from the average official recommendation based on your specific condition. To learn more about basic dietary guidelines, visit the Web site: **http://www.health.gov/dietaryguidelines/**. Based on these guidelines, many foods are required to list the nutrition levels on the food's packaging. Labeling Requirements are listed at the following site maintained by the Food and Drug Administration: **http://www.cfsan.fda.gov/~dms/lab-cons.html**. When interpreting these requirements, the government recommends that consumers become familiar with the following abbreviations before reading FDA literature:[49]

- **DVs (Daily Values):** A new dietary reference term that will appear on the food label. It is made up of two sets of references, DRVs and RDIs.
- **DRVs (Daily Reference Values):** A set of dietary references that applies to fat, saturated fat, cholesterol, carbohydrate, protein, fiber, sodium, and potassium.

[49] Adapted from the FDA: **http://www.fda.gov/fdac/special/foodlabel/dvs.html**.

- **RDIs (Reference Daily Intakes):** A set of dietary references based on the Recommended Dietary Allowances for essential vitamins and minerals and, in selected groups, protein. The name "RDI" replaces the term "U.S. RDA."
- **RDAs (Recommended Dietary Allowances):** A set of estimated nutrient allowances established by the National Academy of Sciences. It is updated periodically to reflect current scientific knowledge.

What Are Dietary Supplements?[50]

Dietary supplements are widely available through many commercial sources, including health food stores, grocery stores, pharmacies, and by mail. Dietary supplements are provided in many forms including tablets, capsules, powders, gel-tabs, extracts, and liquids. Historically in the United States, the most prevalent type of dietary supplement was a multivitamin/mineral tablet or capsule that was available in pharmacies, either by prescription or "over the counter." Supplements containing strictly herbal preparations were less widely available. Currently in the United States, a wide array of supplement products are available, including vitamin, mineral, other nutrients, and botanical supplements as well as ingredients and extracts of animal and plant origin.

The Office of Dietary Supplements (ODS) of the National Institutes of Health is the official agency of the United States which has the expressed goal of acquiring "new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold."[51] According to the ODS, dietary supplements can have an important impact on the prevention and management of disease and on the maintenance of health.[52] The ODS notes that considerable research on the effects of dietary supplements has been conducted in Asia and Europe where the use of plant products, in particular, has a long tradition. However, the

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[50] This discussion has been adapted from the NIH: **http://ods.od.nih.gov/whatare/whatare.html**.

[51] Contact: The Office of Dietary Supplements, National Institutes of Health, Building 31, Room 1B29, 31 Center Drive, MSC 2086, Bethesda, Maryland 20892-2086, Tel: (301) 435-2920, Fax: (301) 480-1845, E-mail: **ods@nih.gov**.

[52] Adapted from **http://ods.od.nih.gov/about/about.html**. The Dietary Supplement Health and Education Act defines dietary supplements as "a product (other than tobacco) intended to supplement the diet that bears or contains one or more of the following dietary ingredients: a vitamin, mineral, amino acid, herb or other botanical; or a dietary substance for use to supplement the diet by increasing the total dietary intake; or a concentrate, metabolite, constituent, extract, or combination of any ingredient described above; and intended for ingestion in the form of a capsule, powder, softgel, or gelcap, and not represented as a conventional food or as a sole item of a meal or the diet."

overwhelming majority of supplements have not been studied scientifically. To explore the role of dietary supplements in the improvement of health care, the ODS plans, organizes, and supports conferences, workshops, and symposia on scientific topics related to dietary supplements. The ODS often works in conjunction with other NIH Institutes and Centers, other government agencies, professional organizations, and public advocacy groups.

To learn more about official information on dietary supplements, visit the ODS site at **http://ods.od.nih.gov/whatare/whatare.html**. Or contact:

The Office of Dietary Supplements
National Institutes of Health
Building 31, Room 1B29
31 Center Drive, MSC 2086
Bethesda, Maryland 20892-2086
Tel: (301) 435-2920
Fax: (301) 480-1845
E-mail: ods@nih.gov

Finding Studies on Lupus Nephritis

The NIH maintains an office dedicated to patient nutrition and diet. The National Institutes of Health's Office of Dietary Supplements (ODS) offers a searchable bibliographic database called the IBIDS (International Bibliographic Information on Dietary Supplements). The IBIDS contains over 460,000 scientific citations and summaries about dietary supplements and nutrition as well as references to published international, scientific literature on dietary supplements such as vitamins, minerals, and botanicals.[53] IBIDS is available to the public free of charge through the ODS Internet page: **http://ods.od.nih.gov/databases/ibids.html**.

After entering the search area, you have three choices: (1) IBIDS Consumer Database, (2) Full IBIDS Database, or (3) Peer Reviewed Citations Only. We recommend that you start with the Consumer Database. While you may not find references for the topics that are of most interest to you, check back periodically as this database is frequently updated. More studies can be

[53] Adapted from **http://ods.od.nih.gov**. IBIDS is produced by the Office of Dietary Supplements (ODS) at the National Institutes of Health to assist the public, healthcare providers, educators, and researchers in locating credible, scientific information on dietary supplements. IBIDS was developed and will be maintained through an interagency partnership with the Food and Nutrition Information Center of the National Agricultural Library, U.S. Department of Agriculture.

found by searching the Full IBIDS Database. Healthcare professionals and researchers generally use the third option, which lists peer-reviewed citations. In all cases, we suggest that you take advantage of the "Advanced Search" option that allows you to retrieve up to 100 fully explained references in a comprehensive format. Type "lupus nephritis" (or synonyms) into the search box. To narrow the search, you can also select the "Title" field.

The following information is typical of that found when using the "Full IBIDS Database" when searching using "lupus nephritis" (or a synonym):

- **Beneficial effect of prostaglandin E1 in three cases of lupus nephritis with nephrotic syndrome.**
  Author(s): 2nd Department of Internal Medicine, Kyoto University Hospital, Japan.
  Source: Nagayama, Y Namura, Y Tamura, T Muso, R Ann-Allergy. 1988 October; 61(4): 289-95 0003-4738
- **Clinical implications of antineutrophil cytoplasmic antibody test in lupus nephritis.**
  Author(s): Division of Nephrology, College of Medicine, Seoul National University, Seoul, South Korea.
  Source: Chin, H J Ahn, C Lim, C S Chung, H K Lee, J G Song, Y W Lee, H S Han, J S Kim, S Lee, J S Am-J-Nephrol. 2000 Jan-February; 20(1): 57-63 0250-8095
- **Enhanced osteopontin expression and macrophage infiltration in MRL-Fas(lpr) mice with lupus nephritis.**
  Author(s): Division of Nephrology, University Hospital, and Institute of Physiology, University of Zurich-Irchel, Zurich, Switzerland. rpw@physiol.unizh.ch
  Source: Wuthrich, R P Fan, X Ritthaler, T Sibalic, V Yu, D J Loffing, J Kaissling, B Autoimmunity. 1998; 28(3): 139-50 0891-6934
- **Glucocorticoid receptor in patients with lupus nephritis: relationship between receptor levels in mononuclear leukocytes and effect of glucocorticoid therapy.**
  Author(s): Department of Internal Medicine, Keio University School of Medicine, Tokyo, Japan.
  Source: Tanaka, H Akama, H Ichikawa, Y Makino, I Homma, M J-Rheumatol. 1992 June; 19(6): 878-83 0315-162X
- **Improvement in lupus nephritis following treatment with a Chinese herbal preparation.**
  Author(s): Department of Pediatrics, National University of Singapore, Singapore.

Source: Yap, H K Ang, S G Lai, Y H Ramgolam, V Jordan, S C Arch-Pediatr-Adolesc-Med. 1999 August; 153(8): 850-2 1072-4710

- **Improvement in steroid and immunosuppressive drug resistant lupus nephritis by intravenous prostaglandin E1 therapy.**
  Author(s): Department of Medical Research, Veterans General Hospital, Taipei, Taiwan, Republic of China.
  Source: Lin, C Y Nephron. 1990; 55(3): 258-64 0028-2766

- **Lupus nephritis in children.**
  Author(s): Department of Nephrology, Postgraduate Medical Institute of Medical Education and Research, Chandigarh.
  Source: Gupta, K L Indian-J-Pediatr. 1999 Mar-April; 66(2): 215-23 0019-5456

- **Management of lupus nephritis at the Kenyatta National Hospital.**
  Author(s): Department of Medicine and Pathology, College of Health Sciences, University of Nairobi, Kenyatta National Hospital.
  Source: Otieno, L S McLigeyo, S O Kayima, J K Sitati, S East-Afr-Med-J. 1990 June; 67(6): 387-95 0012-835X

- **Physiologic role for enhanced renal thromboxane production in murine lupus nephritis.**
  Author(s): Department of Medicine, Duke University, Durham, North Carolina 27705.
  Source: Spurney, R F Bernstein, R J Ruiz, P Pisetsky, D S Coffman, T M Prostaglandins. 1991 July; 42(1): 15-28 0090-6980

- **Predictive value of clinical, laboratory, pathologic, and treatment variables in steroid/immunosuppressive resistant lupus nephritis.**
  Author(s): Department of Medicine, UCLA School of Medicine.
  Source: Wallace, D J Goldfinger, D Savage, G Nichols, S Goodman, D Fichman, M Stewart, M Klinenberg, J R J-Clin-Apheresis. 1988; 4(1): 30-4 0733-2459

- **Pregnancy in lupus nephritis and related disorders.**
  Source: Bobrie, G Liote, F Houillier, P Grunfeld, J P Jungers, P Am-J-Kidney-Dis. 1987 April; 9(4): 339-43 0272-6386

- **The effect of cyclophosphamide pulses on fertility in patients with lupus nephritis.**
  Author(s): Department of Internal Medicine F, Chaim Sheba Medical Center, Tel-Hashomer, Israel.
  Source: Langevitz, P Klein, L Pras, M Many, A Am-J-Reprod-Immunol. 1992 Oct-December; 28(3-4): 157-8 1046-7408

- **Thromboxane receptor blockade reduces renal injury in murine lupus nephritis.**
  Author(s): Department of Medicine, Duke University, Durham, North Carolina.
  Source: Spurney, R F Fan, P Y Ruiz, P Sanfilippo, F Pisetsky, D S Coffman, T M Kidney-Int. 1992 April; 41(4): 973-82 0085-2538
- **Treatment and outcome of lupus nephritis at the turn of the millennium.**
  Source: Uppal, S S J-Assoc-Physicians-India. 1999 September; 47(9): 857-61 0004-5772

Federal Resources on Nutrition

In addition to the IBIDS, the United States Department of Health and Human Services (HHS) and the United States Department of Agriculture (USDA) provide many sources of information on general nutrition and health. Recommended resources include:

- healthfinder®, HHS's gateway to health information, including diet and nutrition:
  http://www.healthfinder.gov/scripts/SearchContext.asp?topic=238&page=0
- The United States Department of Agriculture's Web site dedicated to nutrition information: **www.nutrition.gov**
- The Food and Drug Administration's Web site for federal food safety information: **www.foodsafety.gov**
- The National Action Plan on Overweight and Obesity sponsored by the United States Surgeon General:
  http://www.surgeongeneral.gov/topics/obesity/
- The Center for Food Safety and Applied Nutrition has an Internet site sponsored by the Food and Drug Administration and the Department of Health and Human Services: **http://vm.cfsan.fda.gov/**
- Center for Nutrition Policy and Promotion sponsored by the United States Department of Agriculture: **http://www.usda.gov/cnpp/**
- Food and Nutrition Information Center, National Agricultural Library sponsored by the United States Department of Agriculture: **http://www.nal.usda.gov/fnic/**
- Food and Nutrition Service sponsored by the United States Department of Agriculture: **http://www.fns.usda.gov/fns/**

Additional Web Resources

A number of additional Web sites offer encyclopedic information covering food and nutrition. The following is a representative sample:

- AOL: **http://search.aol.com/cat.adp?id=174&layer=&from=subcats**
- Family Village: **http://www.familyvillage.wisc.edu/med_nutrition.html**
- Google: **http://directory.google.com/Top/Health/Nutrition/**
- Healthnotes: **http://www.thedacare.org/healthnotes/**
- Open Directory Project: **http://dmoz.org/Health/Nutrition/**
- Yahoo.com: **http://dir.yahoo.com/Health/Nutrition/**
- WebMD®Health: **http://my.webmd.com/nutrition**
- WholeHealthMD.com: **http://www.wholehealthmd.com/reflib/0,1529,,00.html**

Vocabulary Builder

The following vocabulary builder defines words used in the references in this chapter that have not been defined in previous chapters:

Capsules: Hard or soft soluble containers used for the oral administration of medicine. [NIH]

Carbohydrate: An aldehyde or ketone derivative of a polyhydric alcohol, particularly of the pentahydric and hexahydric alcohols. They are so named because the hydrogen and oxygen are usually in the proportion to form water, (CH2O)n. The most important carbohydrates are the starches, sugars, celluloses, and gums. They are classified into mono-, di-, tri-, poly- and heterosaccharides. [EU]

Degenerative: Undergoing degeneration : tending to degenerate; having the character of or involving degeneration; causing or tending to cause degeneration. [EU]

Infiltration: The diffusion or accumulation in a tissue or cells of substances not normal to it or in amounts of the normal. Also, the material so accumulated. [EU]

Iodine: A nonmetallic element of the halogen group that is represented by the atomic symbol I, atomic number 53, and atomic weight of 126.90. It is a nutritionally essential element, especially important in thyroid hormone synthesis. In solution, it has anti-infective properties and is used topically. [NIH]

Neural: 1. pertaining to a nerve or to the nerves. 2. situated in the region of the spinal axis, as the neutral arch. [EU]

Niacin: Water-soluble vitamin of the B complex occurring in various animal and plant tissues. Required by the body for the formation of coenzymes NAD and NADP. Has pellagra-curative, vasodilating, and antilipemic properties. [NIH]

Overdose: 1. to administer an excessive dose. 2. an excessive dose. [EU]

Prostaglandins: A group of compounds derived from unsaturated 20-carbon fatty acids, primarily arachidonic acid, via the cyclooxygenase pathway. They are extremely potent mediators of a diverse group of physiological processes. [NIH]

Riboflavin: Nutritional factor found in milk, eggs, malted barley, liver, kidney, heart, and leafy vegetables. The richest natural source is yeast. It occurs in the free form only in the retina of the eye, in whey, and in urine; its principal forms in tissues and cells are as FMN and FAD. [NIH]

Selenium: An element with the atomic symbol Se, atomic number 34, and atomic weight 78.96. It is an essential micronutrient for mammals and other animals but is toxic in large amounts. Selenium protects intracellular structures against oxidative damage. It is an essential component of glutathione peroxidase. [NIH]

Thyroxine: An amino acid of the thyroid gland which exerts a stimulating effect on thyroid metabolism. [NIH]

APPENDIX D. FINDING MEDICAL LIBRARIES

Overview

At a medical library you can find medical texts and reference books, consumer health publications, specialty newspapers and magazines, as well as medical journals. In this Appendix, we show you how to quickly find a medical library in your area.

Preparation

Before going to the library, highlight the references mentioned in this sourcebook that you find interesting. Focus on those items that are not available via the Internet, and ask the reference librarian for help with your search. He or she may know of additional resources that could be helpful to you. Most importantly, your local public library and medical libraries have Interlibrary Loan programs with the National Library of Medicine (NLM), one of the largest medical collections in the world. According to the NLM, most of the literature in the general and historical collections of the National Library of Medicine is available on interlibrary loan to any library. NLM's interlibrary loan services are only available to libraries. If you would like to access NLM medical literature, then visit a library in your area that can request the publications for you.[54]

[54] Adapted from the NLM: **http://www.nlm.nih.gov/psd/cas/interlibrary.html**.

Finding a Local Medical Library

The quickest method to locate medical libraries is to use the Internet-based directory published by the National Network of Libraries of Medicine (NN/LM). This network includes 4626 members and affiliates that provide many services to librarians, health professionals, and the public. To find a library in your area, simply visit **http://nnlm.gov/members/adv.html** or call 1-800-338-7657.

Medical Libraries Open to the Public

In addition to the NN/LM, the National Library of Medicine (NLM) lists a number of libraries that are generally open to the public and have reference facilities. The following is the NLM's list plus hyperlinks to each library Web site. These Web pages can provide information on hours of operation and other restrictions. The list below is a small sample of libraries recommended by the National Library of Medicine (sorted alphabetically by name of the U.S. state or Canadian province where the library is located):[55]

- **Alabama:** Health InfoNet of Jefferson County (Jefferson County Library Cooperative, Lister Hill Library of the Health Sciences), **http://www.uab.edu/infonet/**
- **Alabama:** Richard M. Scrushy Library (American Sports Medicine Institute), **http://www.asmi.org/LIBRARY.HTM**
- **Arizona:** Samaritan Regional Medical Center: The Learning Center (Samaritan Health System, Phoenix, Arizona), **http://www.samaritan.edu/library/bannerlibs.htm**
- **California:** Kris Kelly Health Information Center (St. Joseph Health System), **http://www.humboldt1.com/~kkhic/index.html**
- **California:** Community Health Library of Los Gatos (Community Health Library of Los Gatos), **http://www.healthlib.org/orgresources.html**
- **California:** Consumer Health Program and Services (CHIPS) (County of Los Angeles Public Library, Los Angeles County Harbor-UCLA Medical Center Library) - Carson, CA, **http://www.colapublib.org/services/chips.html**
- **California:** Gateway Health Library (Sutter Gould Medical Foundation)
- **California:** Health Library (Stanford University Medical Center), **http://www-med.stanford.edu/healthlibrary/**

[55] Abstracted from **http://www.nlm.nih.gov/medlineplus/libraries.html**.

- **California:** Patient Education Resource Center - Health Information and Resources (University of California, San Francisco), **http://sfghdean.ucsf.edu/barnett/PERC/default.asp**
- **California:** Redwood Health Library (Petaluma Health Care District), **http://www.phcd.org/rdwdlib.html**
- **California:** San José PlaneTree Health Library, **http://planetreesanjose.org/**
- **California:** Sutter Resource Library (Sutter Hospitals Foundation), **http://go.sutterhealth.org/comm/resc-library/sac-resources.html**
- **California:** University of California, Davis. Health Sciences Libraries
- **California:** ValleyCare Health Library & Ryan Comer Cancer Resource Center (ValleyCare Health System), **http://www.valleycare.com/library.html**
- **California:** Washington Community Health Resource Library (Washington Community Health Resource Library), **http://www.healthlibrary.org/**
- **Colorado:** William V. Gervasini Memorial Library (Exempla Healthcare), **http://www.exempla.org/conslib.htm**
- **Connecticut:** Hartford Hospital Health Science Libraries (Hartford Hospital), **http://www.harthosp.org/library/**
- **Connecticut:** Healthnet: Connecticut Consumer Health Information Center (University of Connecticut Health Center, Lyman Maynard Stowe Library), **http://library.uchc.edu/departm/hnet/**
- **Connecticut:** Waterbury Hospital Health Center Library (Waterbury Hospital), **http://www.waterburyhospital.com/library/consumer.shtml**
- **Delaware:** Consumer Health Library (Christiana Care Health System, Eugene du Pont Preventive Medicine & Rehabilitation Institute), **http://www.christianacare.org/health_guide/health_guide_pmri_health_info.cfm**
- **Delaware:** Lewis B. Flinn Library (Delaware Academy of Medicine), **http://www.delamed.org/chls.html**
- **Georgia:** Family Resource Library (Medical College of Georgia), **http://cmc.mcg.edu/kids_families/fam_resources/fam_res_lib/frl.htm**
- **Georgia:** Health Resource Center (Medical Center of Central Georgia), **http://www.mccg.org/hrc/hrchome.asp**
- **Hawaii:** Hawaii Medical Library: Consumer Health Information Service (Hawaii Medical Library), **http://hml.org/CHIS/**

- **Idaho:** DeArmond Consumer Health Library (Kootenai Medical Center), **http://www.nicon.org/DeArmond/index.htm**
- **Illinois:** Health Learning Center of Northwestern Memorial Hospital (Northwestern Memorial Hospital, Health Learning Center), **http://www.nmh.org/health_info/hlc.html**
- **Illinois:** Medical Library (OSF Saint Francis Medical Center), **http://www.osfsaintfrancis.org/general/library/**
- **Kentucky:** Medical Library - Services for Patients, Families, Students & the Public (Central Baptist Hospital), **http://www.centralbap.com/education/community/library.htm**
- **Kentucky:** University of Kentucky - Health Information Library (University of Kentucky, Chandler Medical Center, Health Information Library), **http://www.mc.uky.edu/PatientEd/**
- **Louisiana:** Alton Ochsner Medical Foundation Library (Alton Ochsner Medical Foundation), **http://www.ochsner.org/library/**
- **Louisiana:** Louisiana State University Health Sciences Center Medical Library-Shreveport, **http://lib-sh.lsuhsc.edu/**
- **Maine:** Franklin Memorial Hospital Medical Library (Franklin Memorial Hospital), **http://www.fchn.org/fmh/lib.htm**
- **Maine:** Gerrish-True Health Sciences Library (Central Maine Medical Center), **http://www.cmmc.org/library/library.html**
- **Maine:** Hadley Parrot Health Science Library (Eastern Maine Healthcare), **http://www.emh.org/hll/hpl/guide.htm**
- **Maine:** Maine Medical Center Library (Maine Medical Center), **http://www.mmc.org/library/**
- **Maine:** Parkview Hospital, **http://www.parkviewhospital.org/communit.htm#Library**
- **Maine:** Southern Maine Medical Center Health Sciences Library (Southern Maine Medical Center), **http://www.smmc.org/services/service.php3?choice=10**
- **Maine:** Stephens Memorial Hospital Health Information Library (Western Maine Health), **http://www.wmhcc.com/hil_frame.html**
- **Manitoba, Canada:** Consumer & Patient Health Information Service (University of Manitoba Libraries), **http://www.umanitoba.ca/libraries/units/health/reference/chis.html**
- **Manitoba, Canada:** J.W. Crane Memorial Library (Deer Lodge Centre), **http://www.deerlodge.mb.ca/library/libraryservices.shtml**

- **Maryland:** Health Information Center at the Wheaton Regional Library (Montgomery County, Md., Dept. of Public Libraries, Wheaton Regional Library), **http://www.mont.lib.md.us/healthinfo/hic.asp**
- **Massachusetts:** Baystate Medical Center Library (Baystate Health System), **http://www.baystatehealth.com/1024/**
- **Massachusetts:** Boston University Medical Center Alumni Medical Library (Boston University Medical Center), **http://med-libwww.bu.edu/library/lib.html**
- **Massachusetts:** Lowell General Hospital Health Sciences Library (Lowell General Hospital), **http://www.lowellgeneral.org/library/HomePageLinks/WWW.htm**
- **Massachusetts:** Paul E. Woodard Health Sciences Library (New England Baptist Hospital), **http://www.nebh.org/health_lib.asp**
- **Massachusetts:** St. Luke's Hospital Health Sciences Library (St. Luke's Hospital), **http://www.southcoast.org/library/**
- **Massachusetts:** Treadwell Library Consumer Health Reference Center (Massachusetts General Hospital), **http://www.mgh.harvard.edu/library/chrcindex.html**
- **Massachusetts:** UMass HealthNet (University of Massachusetts Medical School), **http://healthnet.umassmed.edu/**
- **Michigan:** Botsford General Hospital Library - Consumer Health (Botsford General Hospital, Library & Internet Services), **http://www.botsfordlibrary.org/consumer.htm**
- **Michigan:** Helen DeRoy Medical Library (Providence Hospital and Medical Centers), **http://www.providence-hospital.org/library/**
- **Michigan:** Marquette General Hospital - Consumer Health Library (Marquette General Hospital, Health Information Center), **http://www.mgh.org/center.html**
- **Michigan:** Patient Education Resouce Center - University of Michigan Cancer Center (University of Michigan Comprehensive Cancer Center), **http://www.cancer.med.umich.edu/learn/leares.htm**
- **Michigan:** Sladen Library & Center for Health Information Resources - Consumer Health Information, **http://www.sladen.hfhs.org/library/consumer/index.html**
- **Montana:** Center for Health Information (St. Patrick Hospital and Health Sciences Center), **http://www.saintpatrick.org/chi/librarydetail.php3?ID=41**

- **National:** Consumer Health Library Directory (Medical Library Association, Consumer and Patient Health Information Section), **http://caphis.mlanet.org/directory/index.html**
- **National:** National Network of Libraries of Medicine (National Library of Medicine) - provides library services for health professionals in the United States who do not have access to a medical library, **http://nnlm.gov/**
- **National:** NN/LM List of Libraries Serving the Public (National Network of Libraries of Medicine), **http://nnlm.gov/members/**
- **Nevada:** Health Science Library, West Charleston Library (Las Vegas Clark County Library District), **http://www.lvccld.org/special_collections/medical/index.htm**
- **New Hampshire:** Dartmouth Biomedical Libraries (Dartmouth College Library), **http://www.dartmouth.edu/~biomed/resources.htmld/conshealth.htmld/**
- **New Jersey:** Consumer Health Library (Rahway Hospital), **http://www.rahwayhospital.com/library.htm**
- **New Jersey:** Dr. Walter Phillips Health Sciences Library (Englewood Hospital and Medical Center), **http://www.englewoodhospital.com/links/index.htm**
- **New Jersey:** Meland Foundation (Englewood Hospital and Medical Center), **http://www.geocities.com/ResearchTriangle/9360/**
- **New York:** Choices in Health Information (New York Public Library) - NLM Consumer Pilot Project participant, **http://www.nypl.org/branch/health/links.html**
- **New York:** Health Information Center (Upstate Medical University, State University of New York), **http://www.upstate.edu/library/hic/**
- **New York:** Health Sciences Library (Long Island Jewish Medical Center), **http://www.lij.edu/library/library.html**
- **New York:** ViaHealth Medical Library (Rochester General Hospital), **http://www.nyam.org/library/**
- **Ohio:** Consumer Health Library (Akron General Medical Center, Medical & Consumer Health Library), **http://www.akrongeneral.org/hwlibrary.htm**
- **Oklahoma:** Saint Francis Health System Patient/Family Resource Center (Saint Francis Health System), **http://www.sfh-tulsa.com/patientfamilycenter/default.asp**

- **Oregon:** Planetree Health Resource Center (Mid-Columbia Medical Center), **http://www.mcmc.net/phrc/**
- **Pennsylvania:** Community Health Information Library (Milton S. Hershey Medical Center), **http://www.hmc.psu.edu/commhealth/**
- **Pennsylvania:** Community Health Resource Library (Geisinger Medical Center), **http://www.geisinger.edu/education/commlib.shtml**
- **Pennsylvania:** HealthInfo Library (Moses Taylor Hospital), **http://www.mth.org/healthwellness.html**
- **Pennsylvania:** Hopwood Library (University of Pittsburgh, Health Sciences Library System), **http://www.hsls.pitt.edu/chi/hhrcinfo.html**
- **Pennsylvania:** Koop Community Health Information Center (College of Physicians of Philadelphia), **http://www.collphyphil.org/kooppg1.shtml**
- **Pennsylvania:** Learning Resources Center - Medical Library (Susquehanna Health System), **http://www.shscares.org/services/lrc/index.asp**
- **Pennsylvania:** Medical Library (UPMC Health System), **http://www.upmc.edu/passavant/library.htm**
- **Quebec, Canada:** Medical Library (Montreal General Hospital), **http://ww2.mcgill.ca/mghlib/**
- **South Dakota:** Rapid City Regional Hospital - Health Information Center (Rapid City Regional Hospital, Health Information Center), **http://www.rcrh.org/education/LibraryResourcesConsumers.htm**
- **Texas:** Houston HealthWays (Houston Academy of Medicine-Texas Medical Center Library), **http://hhw.library.tmc.edu/**
- **Texas:** Matustik Family Resource Center (Cook Children's Health Care System), **http://www.cookchildrens.com/Matustik_Library.html**
- **Washington:** Community Health Library (Kittitas Valley Community Hospital), **http://www.kvch.com/**
- **Washington:** Southwest Washington Medical Center Library (Southwest Washington Medical Center), **http://www.swmedctr.com/Home/**

APPENDIX E. YOUR RIGHTS AND INSURANCE

Overview

Any patient with lupus nephritis faces a series of issues related more to the healthcare industry than to the medical condition itself. This appendix covers two important topics in this regard: your rights and responsibilities as a patient, and how to get the most out of your medical insurance plan.

Your Rights as a Patient

The President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has created the following summary of your rights as a patient.[56]

Information Disclosure

Consumers have the right to receive accurate, easily understood information. Some consumers require assistance in making informed decisions about health plans, health professionals, and healthcare facilities. Such information includes:

- ***Health plans.*** Covered benefits, cost-sharing, and procedures for resolving complaints, licensure, certification, and accreditation status, comparable measures of quality and consumer satisfaction, provider network composition, the procedures that govern access to specialists and emergency services, and care management information.

[56]Adapted from Consumer Bill of Rights and Responsibilities: **http://www.hcqualitycommission.gov/press/cbor.html#head1**.

- ***Health professionals.*** Education, board certification, and recertification, years of practice, experience performing certain procedures, and comparable measures of quality and consumer satisfaction.
- ***Healthcare facilities.*** Experience in performing certain procedures and services, accreditation status, comparable measures of quality, worker, and consumer satisfaction, and procedures for resolving complaints.
- ***Consumer assistance programs.*** Programs must be carefully structured to promote consumer confidence and to work cooperatively with health plans, providers, payers, and regulators. Desirable characteristics of such programs are sponsorship that ensures accountability to the interests of consumers and stable, adequate funding.

Choice of Providers and Plans

Consumers have the right to a choice of healthcare providers that is sufficient to ensure access to appropriate high-quality healthcare. To ensure such choice, the Commission recommends the following:

- ***Provider network adequacy.*** All health plan networks should provide access to sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay -- including access to emergency services 24 hours a day and 7 days a week. If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers.
- ***Women's health services.*** Women should be able to choose a qualified provider offered by a plan -- such as gynecologists, certified nurse midwives, and other qualified healthcare providers -- for the provision of covered care necessary to provide routine and preventative women's healthcare services.
- ***Access to specialists.*** Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.
- ***Transitional care.*** Consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of a pregnancy) at the time they involuntarily change health

plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days (or through completion of postpartum care) to allow for transition of care.

- ***Choice of health plans.*** Public and private group purchasers should, wherever feasible, offer consumers a choice of high-quality health insurance plans.

Access to Emergency Services

Consumers have the right to access emergency healthcare services when and where the need arises. Health plans should provide payment when a consumer presents to an emergency department with acute symptoms of sufficient severity--including severe pain--such that a "prudent layperson" could reasonably expect the absence of medical attention to result in placing that consumer's health in serious jeopardy, serious impairment to bodily functions, or serious dysfunction of any bodily organ or part.

Participation in Treatment Decisions

Consumers have the right and responsibility to fully participate in all decisions related to their healthcare. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators. Physicians and other health professionals should:

- Provide patients with sufficient information and opportunity to decide among treatment options consistent with the informed consent process.
- Discuss all treatment options with a patient in a culturally competent manner, including the option of no treatment at all.
- Ensure that persons with disabilities have effective communications with members of the health system in making such decisions.
- Discuss all current treatments a consumer may be undergoing.
- Discuss all risks, benefits, and consequences to treatment or nontreatment.
- Give patients the opportunity to refuse treatment and to express preferences about future treatment decisions.

- Discuss the use of advance directives -- both living wills and durable powers of attorney for healthcare -- with patients and their designated family members.
- Abide by the decisions made by their patients and/or their designated representatives consistent with the informed consent process.

Health plans, health providers, and healthcare facilities should:

- Disclose to consumers factors -- such as methods of compensation, ownership of or interest in healthcare facilities, or matters of conscience -- that could influence advice or treatment decisions.
- Assure that provider contracts do not contain any so-called "gag clauses" or other contractual mechanisms that restrict healthcare providers' ability to communicate with and advise patients about medically necessary treatment options.
- Be prohibited from penalizing or seeking retribution against healthcare professionals or other health workers for advocating on behalf of their patients.

Respect and Nondiscrimination

Consumers have the right to considerate, respectful care from all members of the healthcare industry at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality healthcare system. To assure that right, the Commission recommends the following:

- Consumers must not be discriminated against in the delivery of healthcare services consistent with the benefits covered in their policy, or as required by law, based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.
- Consumers eligible for coverage under the terms and conditions of a health plan or program, or as required by law, must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Confidentiality of Health Information

Consumers have the right to communicate with healthcare providers in confidence and to have the confidentiality of their individually identifiable

healthcare information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

Complaints and Appeals

Consumers have the right to a fair and efficient process for resolving differences with their health plans, healthcare providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review. A free copy of the Patient's Bill of Rights is available from the American Hospital Association.[57]

Patient Responsibilities

Treatment is a two-way street between you and your healthcare providers. To underscore the importance of finance in modern healthcare as well as your responsibility for the financial aspects of your care, the President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has proposed that patients understand the following "Consumer Responsibilities."[58] In a healthcare system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume certain responsibilities. Greater individual involvement by the consumer in his or her care increases the likelihood of achieving the best outcome and helps support a quality-oriented, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing healthy habits such as exercising, not smoking, and eating a healthy diet.
- Work collaboratively with healthcare providers in developing and carrying out agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use your health insurance plan's internal complaint and appeal processes to address your concerns.
- Avoid knowingly spreading disease.

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[57] To order your free copy of the Patient's Bill of Rights, telephone 312-422-3000 or visit the American Hospital Association's Web site: **http://www.aha.org**. Click on "Resource Center," go to "Search" at bottom of page, and then type in "Patient's Bill of Rights." The Patient's Bill of Rights is also available from Fax on Demand, at 312-422-2020, document number 471124.

[58] Adapted from **http://www.hcqualitycommission.gov/press/cbor.html#head1**.

- Recognize the reality of risks, the limits of the medical science, and the human fallibility of the healthcare professional.
- Be aware of a healthcare provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- Become knowledgeable about your health plan's coverage and options (when available) including all covered benefits, limitations, and exclusions, rules regarding use of network providers, coverage and referral rules, appropriate processes to secure additional information, and the process to appeal coverage decisions.
- Show respect for other patients and health workers.
- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, healthcare providers, and Government health benefit programs.

Choosing an Insurance Plan

There are a number of official government agencies that help consumers understand their healthcare insurance choices.[59] The U.S. Department of Labor, in particular, recommends ten ways to make your health benefits choices work best for you.[60]

1. Your options are important. There are many different types of health benefit plans. Find out which one your employer offers, then check out the plan, or plans, offered. Your employer's human resource office, the health plan administrator, or your union can provide information to help you match your needs and preferences with the available plans. The more information you have, the better your healthcare decisions will be.

2. Reviewing the benefits available. Do the plans offered cover preventive care, well-baby care, vision or dental care? Are there deductibles? Answers to these questions can help determine the out-of-pocket expenses you may face. Matching your needs and those of your family members will result in the best possible benefits. Cheapest may not always be best. Your goal is high quality health benefits.

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[59] More information about quality across programs is provided at the following AHRQ Web site:
http://www.ahrq.gov/consumer/qntascii/qnthplan.htm.

[60] Adapted from the Department of Labor:
http://www.dol.gov/dol/pwba/public/pubs/health/top10-text.html.

3. Look for quality. The quality of healthcare services varies, but quality can be measured. You should consider the quality of healthcare in deciding among the healthcare plans or options available to you. Not all health plans, doctors, hospitals and other providers give the highest quality care. Fortunately, there is quality information you can use right now to help you compare your healthcare choices. Find out how you can measure quality. Consult the U.S. Department of Health and Human Services publication "Your Guide to Choosing Quality Health Care" on the Internet at **www.ahcpr.gov/consumer**.

4. Your plan's summary plan description (SPD) provides a wealth of information. Your health plan administrator can provide you with a copy of your plan's SPD. It outlines your benefits and your legal rights under the Employee Retirement Income Security Act (ERISA), the federal law that protects your health benefits. It should contain information about the coverage of dependents, what services will require a co-pay, and the circumstances under which your employer can change or terminate a health benefits plan. Save the SPD and all other health plan brochures and documents, along with memos or correspondence from your employer relating to health benefits.

5. Assess your benefit coverage as your family status changes. Marriage, divorce, childbirth or adoption, and the death of a spouse are all life events that may signal a need to change your health benefits. You, your spouse and dependent children may be eligible for a special enrollment period under provisions of the Health Insurance Portability and Accountability Act (HIPAA). Even without life-changing events, the information provided by your employer should tell you how you can change benefits or switch plans, if more than one plan is offered. If your spouse's employer also offers a health benefits package, consider coordinating both plans for maximum coverage.

6. Changing jobs and other life events can affect your health benefits. Under the Consolidated Omnibus Budget Reconciliation Act (COBRA), you, your covered spouse, and your dependent children may be eligible to purchase extended health coverage under your employer's plan if you lose your job, change employers, get divorced, or upon occurrence of certain other events. Coverage can range from 18 to 36 months depending on your situation. COBRA applies to most employers with 20 or more workers and requires your plan to notify you of your rights. Most plans require eligible individuals to make their COBRA election within 60 days of the plan's notice. Be sure to follow up with your plan sponsor if you don't receive notice, and make sure you respond within the allotted time.

7. HIPAA can also help if you are changing jobs, particularly if you have a medical condition. HIPAA generally limits pre-existing condition exclusions to a maximum of 12 months (18 months for late enrollees). HIPAA also requires this maximum period to be reduced by the length of time you had prior "creditable coverage." You should receive a certificate documenting your prior creditable coverage from your old plan when coverage ends.

8. Plan for retirement. Before you retire, find out what health benefits, if any, extend to you and your spouse during your retirement years. Consult with your employer's human resources office, your union, the plan administrator, and check your SPD. Make sure there is no conflicting information among these sources about the benefits you will receive or the circumstances under which they can change or be eliminated. With this information in hand, you can make other important choices, like finding out if you are eligible for Medicare and Medigap insurance coverage.

9. Know how to file an appeal if your health benefits claim is denied. Understand how your plan handles grievances and where to make appeals of the plan's decisions. Keep records and copies of correspondence. Check your health benefits package and your SPD to determine who is responsible for handling problems with benefit claims. Contact PWBA for customer service assistance if you are unable to obtain a response to your complaint.

10. You can take steps to improve the quality of the healthcare and the health benefits you receive. Look for and use things like Quality Reports and Accreditation Reports whenever you can. Quality reports may contain consumer ratings -- how satisfied consumers are with the doctors in their plan, for instance-- and clinical performance measures -- how well a healthcare organization prevents and treats illness. Accreditation reports provide information on how accredited organizations meet national standards, and often include clinical performance measures. Look for these quality measures whenever possible. Consult "Your Guide to Choosing Quality Health Care" on the Internet at **www.ahcpr.gov/consumer**.

Medicare and Medicaid

Illness strikes both rich and poor families. For low-income families, Medicaid is available to defer the costs of treatment. The Health Care Financing Administration (HCFA) administers Medicare, the nation's largest health insurance program, which covers 39 million Americans. In the following pages, you will learn the basics about Medicare insurance as well as useful

contact information on how to find more in-depth information about Medicaid.[61]

Who is Eligible for Medicare?

Generally, you are eligible for Medicare if you or your spouse worked for at least 10 years in Medicare-covered employment and you are 65 years old and a citizen or permanent resident of the United States. You might also qualify for coverage if you are under age 65 but have a disability or End-Stage Renal disease (permanent kidney failure requiring dialysis or transplant). Here are some simple guidelines:

You can get Part A at age 65 without having to pay premiums if:

- You are already receiving retirement benefits from Social Security or the Railroad Retirement Board.
- You are eligible to receive Social Security or Railroad benefits but have not yet filed for them.
- You or your spouse had Medicare-covered government employment.

If you are under 65, you can get Part A without having to pay premiums if:

- You have received Social Security or Railroad Retirement Board disability benefit for 24 months.
- You are a kidney dialysis or kidney transplant patient.

Medicare has two parts:

- Part A (Hospital Insurance). Most people do not have to pay for Part A.
- Part B (Medical Insurance). Most people pay monthly for Part B.

Part A (Hospital Insurance)

Helps Pay For: Inpatient hospital care, care in critical access hospitals (small facilities that give limited outpatient and inpatient services to people in rural areas) and skilled nursing facilities, hospice care, and some home healthcare.

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[61] This section has been adapted from the Official U.S. Site for Medicare Information: **http://www.medicare.gov/Basics/Overview.asp**.

Cost: Most people get Part A automatically when they turn age 65. You do not have to pay a monthly payment called a premium for Part A because you or a spouse paid Medicare taxes while you were working.

If you (or your spouse) did not pay Medicare taxes while you were working and you are age 65 or older, you still may be able to buy Part A. If you are not sure you have Part A, look on your red, white, and blue Medicare card. It will show "Hospital Part A" on the lower left corner of the card. You can also call the Social Security Administration toll free at 1-800-772-1213 or call your local Social Security office for more information about buying Part A. If you get benefits from the Railroad Retirement Board, call your local RRB office or 1-800-808-0772. For more information, call your Fiscal Intermediary about Part A bills and services. The phone number for the Fiscal Intermediary office in your area can be obtained from the following Web site: **http://www.medicare.gov/Contacts/home.asp**.

Part B (Medical Insurance)

Helps Pay For: Doctors, services, outpatient hospital care, and some other medical services that Part A does not cover, such as the services of physical and occupational therapists, and some home healthcare. Part B helps pay for covered services and supplies when they are medically necessary.

Cost: As of 2001, you pay the Medicare Part B premium of $50.00 per month. In some cases this amount may be higher if you did not choose Part B when you first became eligible at age 65. The cost of Part B may go up 10% for each 12-month period that you were eligible for Part B but declined coverage, except in special cases. You will have to pay the extra 10% cost for the rest of your life.

Enrolling in Part B is your choice. You can sign up for Part B anytime during a 7-month period that begins 3 months before you turn 65. Visit your local Social Security office, or call the Social Security Administration at 1-800-772-1213 to sign up. If you choose to enroll in Part B, the premium is usually taken out of your monthly Social Security, Railroad Retirement, or Civil Service Retirement payment. If you do not receive any of the above payments, Medicare sends you a bill for your part B premium every 3 months. You should receive your Medicare premium bill in the mail by the 10th of the month. If you do not, call the Social Security Administration at 1-800-772-1213, or your local Social Security office. If you get benefits from the Railroad Retirement Board, call your local RRB office or 1-800-808-0772. For more information, call your Medicare carrier about bills and services. The

phone number for the Medicare carrier in your area can be found at the following Web site: **http://www.medicare.gov/Contacts/home.asp**. You may have choices in how you get your healthcare including the Original Medicare Plan, Medicare Managed Care Plans (like HMOs), and Medicare Private Fee-for-Service Plans.

Medicaid

Medicaid is a joint federal and state program that helps pay medical costs for some people with low incomes and limited resources. Medicaid programs vary from state to state. People on Medicaid may also get coverage for nursing home care and outpatient prescription drugs which are not covered by Medicare. You can find more information about Medicaid on the HCFA.gov Web site at **http://www.hcfa.gov/medicaid/medicaid.htm**.

States also have programs that pay some or all of Medicare's premiums and may also pay Medicare deductibles and coinsurance for certain people who have Medicare and a low income. To qualify, you must have:

- Part A (Hospital Insurance),
- Assets, such as bank accounts, stocks, and bonds that are not more than $4,000 for a single person, or $6,000 for a couple, and
- A monthly income that is below certain limits.

For more information on these programs, look at the Medicare Savings Programs brochure, **http://www.medicare.gov/Library/PDFNavigation/PDFInterim.asp?Language=English&Type=Pub&PubID=10126**. There are also Prescription Drug Assistance Programs available. Find information on these programs which offer discounts or free medications to individuals in need at **http://www.medicare.gov/Prescription/Home.asp**.

NORD's Medication Assistance Programs

Finally, the National Organization for Rare Disorders, Inc. (NORD) administers medication programs sponsored by humanitarian-minded pharmaceutical and biotechnology companies to help uninsured or under-insured individuals secure life-saving or life-sustaining drugs.[62] NORD

[62] Adapted from NORD: **http://www.rarediseases.org/cgi-bin/nord/progserv#patient?id=rPIzL9oD&mv_pc=30**.

programs ensure that certain vital drugs are available "to those individuals whose income is too high to qualify for Medicaid but too low to pay for their prescribed medications." The program has standards for fairness, equity, and unbiased eligibility. It currently covers some 14 programs for nine pharmaceutical companies. NORD also offers early access programs for investigational new drugs (IND) under the approved "Treatment INDs" programs of the Food and Drug Administration (FDA). In these programs, a limited number of individuals can receive investigational drugs that have yet to be approved by the FDA. These programs are generally designed for rare diseases or disorders. For more information, visit **www.rarediseases.org**.

Additional Resources

In addition to the references already listed in this chapter, you may need more information on health insurance, hospitals, or the healthcare system in general. The NIH has set up an excellent guidance Web site that addresses these and other issues. Topics include:[63]

- Health Insurance:
  http://www.nlm.nih.gov/medlineplus/healthinsurance.html
- Health Statistics:
  http://www.nlm.nih.gov/medlineplus/healthstatistics.html
- HMO and Managed Care:
  http://www.nlm.nih.gov/medlineplus/managedcare.html
- Hospice Care: **http://www.nlm.nih.gov/medlineplus/hospicecare.html**
- Medicaid: **http://www.nlm.nih.gov/medlineplus/medicaid.html**
- Medicare: **http://www.nlm.nih.gov/medlineplus/medicare.html**
- Nursing Homes and Long-term Care:
  http://www.nlm.nih.gov/medlineplus/nursinghomes.html
- Patient's Rights, Confidentiality, Informed Consent, Ombudsman Programs, Privacy and Patient Issues:
  http://www.nlm.nih.gov/medlineplus/patientissues.html
- Veteran's Health, Persian Gulf War, Gulf War Syndrome, Agent Orange:
  http://www.nlm.nih.gov/medlineplus/veteranshealth.html

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[63] You can access this information at:
http://www.nlm.nih.gov/medlineplus/healthsystem.html.

Vocabulary Builder

Auscultation: The act of listening for sounds within the body, chiefly for ascertaining the condition of the lungs, heart, pleura, abdomen and other organs, and for the detection of pregnancy. [EU]

Chest Pain: Pressure, burning, or numbness in the chest. [NIH]

Fatigue: The state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond to stimuli. [NIH]

ONLINE GLOSSARIES

The Internet provides access to a number of free-to-use medical dictionaries and glossaries. The National Library of Medicine has compiled the following list of online dictionaries:

- ADAM Medical Encyclopedia (A.D.A.M., Inc.), comprehensive medical reference: **http://www.nlm.nih.gov/medlineplus/encyclopedia.html**
- MedicineNet.com Medical Dictionary (MedicineNet, Inc.): **http://www.medterms.com/Script/Main/hp.asp**
- Merriam-Webster Medical Dictionary (Inteli-Health, Inc.): **http://www.intelihealth.com/IH/**
- Multilingual Glossary of Technical and Popular Medical Terms in Eight European Languages (European Commission) - Danish, Dutch, English, French, German, Italian, Portuguese, and Spanish: **http://allserv.rug.ac.be/~rvdstich/eugloss/welcome.html**
- On-line Medical Dictionary (CancerWEB): **http://www.graylab.ac.uk/omd/**
- Technology Glossary (National Library of Medicine) - Health Care Technology: **http://www.nlm.nih.gov/nichsr/ta101/ta10108.htm**
- Terms and Definitions (Office of Rare Diseases): **http://rarediseases.info.nih.gov/ord/glossary_a-e.html**

Beyond these, MEDLINEplus contains a very user-friendly encyclopedia covering every aspect of medicine (licensed from A.D.A.M., Inc.). The ADAM Medical Encyclopedia Web site address is **http://www.nlm.nih.gov/medlineplus/encyclopedia.html**. ADAM is also available on commercial Web sites such as Web MD (**http://my.webmd.com/adam/asset/adam_disease_articles/a_to_z/a)** and drkoop.com (**http://www.drkoop.com/**). Topics of interest can be researched by using keywords before continuing elsewhere, as these basic definitions and concepts will be useful in more advanced areas of research. You may choose to print various pages specifically relating to lupus nephritis and keep them on file. The NIH, in particular, suggests that patients with lupus nephritis visit the following Web sites in the ADAM Medical Encyclopedia:

- **Basic Guidelines for Lupus Nephritis**

  Hypertension
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000468.htm

  Lupus nephritis
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000481.htm

  SLE
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000435.htm

  Systemic lupus erythematosus
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000435.htm

- **Signs & Symptoms for Lupus Nephritis**

  Blood in the urine
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003138.htm

  Chest pain
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003079.htm

  Cough
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003072.htm

  Decreased urine output
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003147.htm

  Edema
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003103.htm

Erythema
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003220.htm

Fatigue
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003088.htm

Fever
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003090.htm

Hematuria
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003138.htm

Joint pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003261.htm

Joint swelling
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003262.htm

Rash
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003220.htm

Seizures
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003200.htm

Swelling
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003103.htm

- **Diagnostics and Tests for Lupus Nephritis**

ALT
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003473.htm

ANA
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003535.htm

Antinuclear antibody
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003535.htm

Biopsy
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003416.htm

Blood pressure
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003398.htm

BUN
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003474.htm

Casts
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003586.htm

Complement
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003456.htm

Complement component 3
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003539.htm

Creatinine
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003475.htm

Dialysis
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003421.htm

Kidney biopsy
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003907.htm

Urinalysis
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003579.htm

Urine immunoglobulin light chain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003597.htm

- **Nutrition for Lupus Nephritis**

Protein
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002467.htm

- **Surgery and Procedures for Lupus Nephritis**

Kidney transplant
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003005.htm

- **Background Topics for Lupus Nephritis**

Acute
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002215.htm

Antibodies
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002223.htm

Auscultation
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002226.htm

Incidence
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002387.htm

Inflammatory response
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/000821.htm

Renal
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002289.htm

Systemic
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002294.htm

Titer
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002328.htm

Online Dictionary Directories

The following are additional online directories compiled by the National Library of Medicine, including a number of specialized medical dictionaries and glossaries:

- Medical Dictionaries: Medical & Biological (World Health Organization): **http://www.who.int/hlt/virtuallibrary/English/diction.htm#Medical**
- MEL-Michigan Electronic Library List of Online Health and Medical Dictionaries (Michigan Electronic Library): **http://mel.lib.mi.us/health/health-dictionaries.html**
- Patient Education: Glossaries (DMOZ Open Directory Project): **http://dmoz.org/Health/Education/Patient_Education/Glossaries/**
- Web of Online Dictionaries (Bucknell University): **http://www.yourdictionary.com/diction5.html#medicine**

LUPUS NEPHRITIS GLOSSARY

The following is a complete glossary of terms used in this sourcebook. The definitions are derived from official public sources including the National Institutes of Health [NIH] and the European Union [EU]. After this glossary, we list a number of additional hardbound and electronic glossaries and dictionaries that you may wish to consult.

Abdomen: That portion of the body that lies between the thorax and the pelvis. [NIH]

Acidosis: A pathologic condition resulting from accumulation of acid or depletion of the alkaline reserve (bicarbonate content) in the blood and body tissues, and characterized by an increase in hydrogen ion concentration. [EU]

Alkalosis: A pathologic condition resulting from accumulation of base, or from loss of acid without comparable loss of base in the body fluids, and characterized by decrease in hydrogen ion concentration (increase in pH). [EU]

Alleles: Mutually exclusive forms of the same gene, occupying the same locus on homologous chromosomes, and governing the same biochemical and developmental process. [NIH]

Amenorrhea: Absence or abnormal stoppage of the menses; called also amenia. [EU]

Angiitis: Inflammation of a vessel, chiefly of a blood or a lymph vessel; called also vasculitis. [EU]

Antibody: An immunoglobulin molecule that has a specific amino acid sequence by virtue of which it interacts only with the antigen that induced its synthesis in cells of the lymphoid series (especially plasma cells), or with antigen closely related to it. Antibodies are classified according to their ode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

Antigen: Any substance which is capable, under appropriate conditions, of inducing a specific immune response and of reacting with the products of that response, that is, with specific antibody or specifically sensitized T-lymphocytes, or both. Antigens may be soluble substances, such as toxins and foreign proteins, or particulate, such as bacteria and tissue cells; however, only the portion of the protein or polysaccharide molecule known as the antigenic determinant (q.v.) combines with antibody or a specific receptor on a lymphocyte. Abbreviated Ag. [EU]

Antihypertensive: An agent that reduces high blood pressure. [EU]

Antioxidant: One of many widely used synthetic or natural substances added to a product to prevent or delay its deterioration by action of oxygen in the air. Rubber, paints, vegetable oils, and prepared foods commonly contain antioxidants. [EU]

Assay: Determination of the amount of a particular constituent of a mixture, or of the biological or pharmacological potency of a drug. [EU]

Asymptomatic: Showing or causing no symptoms. [EU]

Atrophy: A wasting away; a diminution in the size of a cell, tissue, organ, or part. [EU]

Auscultation: The act of listening for sounds within the body, chiefly for ascertaining the condition of the lungs, heart, pleura, abdomen and other organs, and for the detection of pregnancy. [EU]

Autoimmunity: Process whereby the immune system reacts against the body's own tissues. Autoimmunity may produce or be caused by autoimmune diseases. [NIH]

Benign: Not malignant; not recurrent; favourable for recovery. [EU]

Biochemical: Relating to biochemistry; characterized by, produced by, or involving chemical reactions in living organisms. [EU]

Biopsy: The removal and examination, usually microscopic, of tissue from the living body, performed to establish precise diagnosis. [EU]

Calculi: An abnormal concretion occurring mostly in the urinary and biliary tracts, usually composed of mineral salts. Also called stones. [NIH]

Capillary: Any one of the minute vessels that connect the arterioles and venules, forming a network in nearly all parts of the body. Their walls act as semipermeable membranes for the interchange of various substances, including fluids, between the blood and tissue fluid; called also vas capillare. [EU]

Capsules: Hard or soft soluble containers used for the oral administration of medicine. [NIH]

Captopril: A potent and specific inhibitor of peptidyl-dipeptidase A. It blocks the conversion of angiotensin I to angiotensin II, a vasoconstrictor and important regulator of arterial blood pressure. Captopril acts to suppress the renin-angiotensin system and inhibits pressure responses to exogenous angiotensin. [NIH]

Carbohydrate: An aldehyde or ketone derivative of a polyhydric alcohol, particularly of the pentahydric and hexahydric alcohols. They are so named because the hydrogen and oxygen are usually in the proportion to form water, (CH2O)n. The most important carbohydrates are the starches, sugars, celluloses, and gums. They are classified into mono-, di-, tri-, poly- and heterosaccharides. [EU]

Cataract: An opacity, partial or complete, of one or both eyes, on or in the lens or capsule, especially an opacity impairing vision or causing blindness. The many kinds of cataract are classified by their morphology (size, shape, location) or etiology (cause and time of occurrence). [EU]

Chemotherapy: The treatment of disease by means of chemicals that have a specific toxic effect upon the disease - producing microorganisms or that selectively destroy cancerous tissue. [EU]

Cholesterol: The principal sterol of all higher animals, distributed in body tissues, especially the brain and spinal cord, and in animal fats and oils. [NIH]

Collagen: The protein substance of the white fibres (collagenous fibres) of skin, tendon, bone, cartilage, and all other connective tissue; composed of molecules of tropocollagen (q.v.), it is converted into gelatin by boiling. collagenous pertaining to collagen; forming or producing collagen. [EU]

Coronary: Encircling in the manner of a crown; a term applied to vessels; nerves, ligaments, etc. The term usually denotes the arteries that supply the heart muscle and, by extension, a pathologic involvement of them. [EU]

Cyclophosphamide: Precursor of an alkylating nitrogen mustard antineoplastic and immunosuppressive agent that must be activated in the liver to form the active aldophosphamide. It is used in the treatment of lymphomas, leukemias, etc. Its side effect, alopecia, has been made use of in defleecing sheep. Cyclophosphamide may also cause sterility, birth defects, mutations, and cancer. [NIH]

Cytokines: Non-antibody proteins secreted by inflammatory leukocytes and some non-leukocytic cells, that act as intercellular mediators. They differ from classical hormones in that they are produced by a number of tissue or cell types rather than by specialized glands. They generally act locally in a paracrine or autocrine rather than endocrine manner. [NIH]

Cytoplasm: The protoplasm of a cell exclusive of that of the nucleus; it consists of a continuous aqueous solution (cytosol) and the organelles and inclusions suspended in it (phaneroplasm), and is the site of most of the chemical activities of the cell. [EU]

Cytotoxic: Pertaining to or exhibiting cytotoxicity. [EU]

Degenerative: Undergoing degeneration : tending to degenerate; having the character of or involving degeneration; causing or tending to cause degeneration. [EU]

Dermatology: A medical specialty concerned with the skin, its structure, functions, diseases, and treatment. [NIH]

Diarrhea: Passage of excessively liquid or excessively frequent stools. [NIH]

Distal: Remote; farther from any point of reference; opposed to proximal. In dentistry, used to designate a position on the dental arch farther from the

median line of the jaw. [EU]

Eczema: A pruritic papulovesicular dermatitis occurring as a reaction to many endogenous and exogenous agents, characterized in the acute stage by erythema, edema associated with a serous exudate between the cells of the epidermis (spongiosis) and an inflammatory infiltrate in the dermis, oozing and vesiculation, and crusting and scaling; and in the more chronic stages by lichenification or thickening or both, signs of excoriations, and hyperpigmentation or hypopigmentation or both. Atopic dermatitis is the most common type of dermatitis. Called also eczematous dermatitis. [EU]

Edema: Excessive amount of watery fluid accumulated in the intercellular spaces, most commonly present in subcutaneous tissue. [NIH]

Electrolyte: A substance that dissociates into ions when fused or in solution, and thus becomes capable of conducting electricity; an ionic solute. [EU]

Empyema: Accumulation of pus in a cavity of the body; when used without a descriptive qualifier, it refers to thoracic empyema (q.v.). [EU]

Endogenous: Developing or originating within the organisms or arising from causes within the organism. [EU]

Enzyme: A protein molecule that catalyses chemical reactions of other substances without itself being destroyed or altered upon completion of the reactions. Enzymes are classified according to the recommendations of the Nomenclature Committee of the International Union of Biochemistry. Each enzyme is assigned a recommended name and an Enzyme Commission (EC) number. They are divided into six main groups; oxidoreductases, transferases, hydrolases, lyases, isomerases, and ligases. [EU]

Exogenous: Developed or originating outside the organism, as exogenous disease. [EU]

Exudate: Material, such as fluid, cells, or cellular debris, which has escaped from blood vessels and has been deposited in tissues or on tissue surfaces, usually as a result of inflammation. An exudate, in contrast to a transudate, is characterized by a high content of protein, cells, or solid materials derived from cells. [EU]

Fatigue: The state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond to stimuli. [NIH]

Fibrosis: The formation of fibrous tissue; fibroid or fibrous degeneration [EU]

Filtration: The passage of a liquid through a filter, accomplished by gravity, pressure, or vacuum (suction). [EU]

Fistula: An abnormal passage or communication, usually between two internal organs, or leading from an internal organ to the surface of the body; frequently designated according to the organs or parts with which it

communicates, as anovaginal, brochocutaneous, hepatopleural, pulmonoperitoneal, rectovaginal, urethrovaginal, and the like. Such passages are frequently created experimentally for the purpose of obtaining body secretions for physiologic study. [EU]

Genotype: The genetic constitution of the individual; the characterization of the genes. [NIH]

Glomerulonephritis: A variety of nephritis characterized by inflammation of the capillary loops in the glomeruli of the kidney. It occurs in acute, subacute, and chronic forms and may be secondary to haemolytic streptococcal infection. Evidence also supports possible immune or autoimmune mechanisms. [EU]

Helicobacter: A genus of gram-negative, spiral-shaped bacteria that is pathogenic and has been isolated from the intestinal tract of mammals, including humans. [NIH]

Hematology: A subspecialty of internal medicine concerned with morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Heredity: 1. the genetic transmission of a particular quality or trait from parent to offspring. 2. the genetic constitution of an individual. [EU]

Humoral: Of, relating to, proceeding from, or involving a bodily humour - now often used of endocrine factors as opposed to neural or somatic. [EU]

Hyperlipidemia: An excess of lipids in the blood. [NIH]

Hypertension: Persistently high arterial blood pressure. Various criteria for its threshold have been suggested, ranging from 140 mm. Hg systolic and 90 mm. Hg diastolic to as high as 200 mm. Hg systolic and 110 mm. Hg diastolic. Hypertension may have no known cause (essential or idiopathic h.) or be associated with other primary diseases (secondary h.). [EU]

Hypotension: Abnormally low blood pressure; seen in shock but not necessarily indicative of it. [EU]

Iatrogenic: Resulting from the activity of physicians. Originally applied to disorders induced in the patient by autosuggestion based on the physician's examination, manner, or discussion, the term is now applied to any adverse condition in a patient occurring as the result of treatment by a physician or surgeon, especially to infections acquired by the patient during the course of treatment. [EU]

Idiopathic: Of the nature of an idiopathy; self-originated; of unknown causation. [EU]

Indicative: That indicates; that points out more or less exactly; that reveals fairly clearly. [EU]

Induction: The act or process of inducing or causing to occur, especially the production of a specific morphogenetic effect in the developing embryo through the influence of evocators or organizers, or the production of anaesthesia or unconsciousness by use of appropriate agents. [EU]

Infiltration: The diffusion or accumulation in a tissue or cells of substances not normal to it or in amounts of the normal. Also, the material so accumulated. [EU]

Inflammation: A pathological process characterized by injury or destruction of tissues caused by a variety of cytologic and chemical reactions. It is usually manifested by typical signs of pain, heat, redness, swelling, and loss of function. [NIH]

Infusion: The therapeutic introduction of a fluid other than blood, as saline solution, solution, into a vein. [EU]

Ingestion: The act of taking food, medicines, etc., into the body, by mouth. [EU]

Inhalation: The drawing of air or other substances into the lungs. [EU]

Interstitial: Pertaining to or situated between parts or in the interspaces of a tissue. [EU]

Intrinsic: Situated entirely within or pertaining exclusively to a part. [EU]

Iodine: A nonmetallic element of the halogen group that is represented by the atomic symbol I, atomic number 53, and atomic weight of 126.90. It is a nutritionally essential element, especially important in thyroid hormone synthesis. In solution, it has anti-infective properties and is used topically. [NIH]

Lesion: Any pathological or traumatic discontinuity of tissue or loss of function of a part. [EU]

Ligation: Application of a ligature to tie a vessel or strangulate a part. [NIH]

Lupus: A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

Mediator: An object or substance by which something is mediated, such as (1) a structure of the nervous system that transmits impulses eliciting a specific response; (2) a chemical substance (transmitter substance) that induces activity in an excitable tissue, such as nerve or muscle; or (3) a substance released from cells as the result of the interaction of antigen with antibody or by the action of antigen with a sensitized lymphocyte. [EU]

Membrane: A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ. [EU]

Microscopy: The application of microscope magnification to the study of materials that cannot be properly seen by the unaided eye. [NIH]

Molecular: Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

Monocytes: Large, phagocytic mononuclear leukocytes produced in the vertebrate bone marrow and released into the blood; contain a large, oval or somewhat indented nucleus surrounded by voluminous cytoplasm and numerous organelles. [NIH]

Mutagenesis: Process of generating genetic mutations. It may occur spontaneously or be induced by mutagens. [NIH]

Necrosis: The sum of the morphological changes indicative of cell death and caused by the progressive degradative action of enzymes; it may affect groups of cells or part of a structure or an organ. [EU]

Nephritis: Inflammation of the kidney; a focal or diffuse proliferative or destructive process which may involve the glomerulus, tubule, or interstitial renal tissue. [EU]

Nephrology: A subspecialty of internal medicine concerned with the anatomy, physiology, and pathology of the kidney. [NIH]

Nephrons: The functional units of the kidney, consisting of the glomerulus and the attached tubule. [NIH]

Nephropathy: Disease of the kidneys. [EU]

Niacin: Water-soluble vitamin of the B complex occurring in various animal and plant tissues. Required by the body for the formation of coenzymes NAD and NADP. Has pellagra-curative, vasodilating, and antilipemic properties. [NIH]

Nitrogen: An element with the atomic symbol N, atomic number 7, and atomic weight 14. Nitrogen exists as a diatomic gas and makes up about 78% of the earth's atmosphere by volume. It is a constituent of proteins and nucleic acids and found in all living cells. [NIH]

Osteoporosis: Reduction in the amount of bone mass, leading to fractures after minimal trauma. [EU]

Overdose: 1. to administer an excessive dose. 2. an excessive dose. [EU]

Paradoxical: Occurring at variance with the normal rule. [EU]

Pediatrics: A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

Phagocytosis: Endocytosis of particulate material, such as microorganisms or cell fragments. The material is taken into the cell in membrane-bound vesicles (phagosomes) that originate as pinched off invaginations of the plasma membrane. Phagosomes fuse with lysosomes, forming phagolysosomes in which the engulfed material is killed and digested. [EU]

Phenotype: The outward appearance of the individual. It is the product of

interactions between genes and between the genotype and the environment. This includes the killer phenotype, characteristic of yeasts. [NIH]

Plasmapheresis: Procedure whereby plasma is separated and extracted from anticoagulated whole blood and the red cells retransfused to the donor. Plasmapheresis is also employed for therapeutic use. [NIH]

Poisoning: A condition or physical state produced by the ingestion, injection or inhalation of, or exposure to a deleterious agent. [NIH]

Polypeptide: A peptide which on hydrolysis yields more than two amino acids; called tripeptides, tetrapeptides, etc. according to the number of amino acids contained. [EU]

Potassium: An element that is in the alkali group of metals. It has an atomic symbol K, atomic number 19, and atomic weight 39.10. It is the chief cation in the intracellular fluid of muscle and other cells. Potassium ion is a strong electrolyte and it plays a significant role in the regulation of fluid volume and maintenance of the water-electrolyte balance. [NIH]

Precursor: Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

Prednisone: A synthetic anti-inflammatory glucocorticoid derived from cortisone. It is biologically inert and converted to prednisolone in the liver. [NIH]

Preeclampsia: A toxaemia of late pregnancy characterized by hypertension, edema, and proteinuria, when convulsions and coma are associated, it is called eclampsia. [EU]

Prevalence: The total number of cases of a given disease in a specified population at a designated time. It is differentiated from incidence, which refers to the number of new cases in the population at a given time. [NIH]

Prostaglandins: A group of compounds derived from unsaturated 20-carbon fatty acids, primarily arachidonic acid, via the cyclooxygenase pathway. They are extremely potent mediators of a diverse group of physiological processes. [NIH]

Protease: Proteinase (= any enzyme that catalyses the splitting of interior peptide bonds in a protein). [EU]

Proteins: Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

Pulse: The rhythmical expansion and contraction of an artery produced by waves of pressure caused by the ejection of blood from the left ventricle of the heart as it contracts. [NIH]

Puromycin: An antibiotic from Streptomyces alboniger that inhibits protein

synthesis by binding to RNA. It is a antineoplastic and antitrypanosomal agent and is used in research as an inhibitor of protein synthesis. [NIH]

Purpura: Purplish or brownish red discoloration, easily visible through the epidermis, caused by hemorrhage into the tissues. [NIH]

Quinidine: An optical isomer of quinine, extracted from the bark of the Cinchona tree and similar plant species. This alkaloid dampens the excitability of cardiac and skeletal muscles by blocking sodium and potassium currents across cellular membranes. It prolongs cellular action potential, and decreases automaticity. Quinidine also blocks muscarinic and alpha-adrenergic neurotransmission. [NIH]

Receptor: 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

Recombinant: 1. a cell or an individual with a new combination of genes not found together in either parent; usually applied to linked genes. [EU]

Reconstitution: 1. a type of regeneration in which a new organ forms by the rearrangement of tissues rather than from new formation at an injured surface. 2. the restoration to original form of a substance previously altered for preservation and storage, as the restoration to a liquid state of blood serum or plasma that has been dried and stored. [EU]

Rectal: Pertaining to the rectum (= distal portion of the large intestine). [EU]

Remission: A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

Respiratory: Pertaining to respiration. [EU]

Retina: The ten-layered nervous tissue membrane of the eye. It is continuous with the optic nerve and receives images of external objects and transmits visual impulses to the brain. Its outer surface is in contact with the choroid and the inner surface with the vitreous body. The outer-most layer is pigmented, whereas the inner nine layers are transparent. [NIH]

Riboflavin: Nutritional factor found in milk, eggs, malted barley, liver, kidney, heart, and leafy vegetables. The richest natural source is yeast. It occurs in the free form only in the retina of the eye, in whey, and in urine; its principal forms in tissues and cells are as FMN and FAD. [NIH]

Sclerosis: A induration, or hardening; especially hardening of a part from inflammation and in diseases of the interstitial substance. The term is used chiefly for such a hardening of the nervous system due to hyperplasia of the

connective tissue or to designate hardening of the blood vessels. [EU]

Seizures: Clinical or subclinical disturbances of cortical function due to a sudden, abnormal, excessive, and disorganized discharge of brain cells. Clinical manifestations include abnormal motor, sensory and psychic phenomena. Recurrent seizures are usually referred to as epilepsy or "seizure disorder." [NIH]

Selenium: An element with the atomic symbol Se, atomic number 34, and atomic weight 78.96. It is an essential micronutrient for mammals and other animals but is toxic in large amounts. Selenium protects intracellular structures against oxidative damage. It is an essential component of glutathione peroxidase. [NIH]

Serum: The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

Spectrum: A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

Stimulant: 1. producing stimulation; especially producing stimulation by causing tension on muscle fibre through the nervous tissue. 2. an agent or remedy that produces stimulation. [EU]

Stomach: An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

Thrombosis: The formation, development, or presence of a thrombus. [EU]

Thyroxine: An amino acid of the thyroid gland which exerts a stimulating effect on thyroid metabolism. [NIH]

Tolerance: 1. the ability to endure unusually large doses of a drug or toxin. 2. acquired drug tolerance; a decreasing response to repeated constant doses of a drug or the need for increasing doses to maintain a constant response. [EU]

Toxemia: A generalized intoxication produced by toxins and other substances elaborated by an infectious agent. [NIH]

Toxicity: The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

Toxicology: The science concerned with the detection, chemical composition, and pharmacologic action of toxic substances or poisons and the treatment and prevention of toxic manifestations. [NIH]

Transplantation: The grafting of tissues taken from the patient's own body

or from another. [EU]

Urinalysis: Examination of urine by chemical, physical, or microscopic means. Routine urinalysis usually includes performing chemical screening tests, determining specific gravity, observing any unusual color or odor, screening for bacteriuria, and examining the sediment microscopically. [NIH]

Urology: A surgical specialty concerned with the study, diagnosis, and treatment of diseases of the urinary tract in both sexes and the genital tract in the male. It includes the specialty of andrology which addresses both male genital diseases and male infertility. [NIH]

Vasculitis: Inflammation of a vessel, angiitis. [EU]

Viruses: Minute infectious agents whose genomes are composed of DNA or RNA, but not both. They are characterized by a lack of independent metabolism and the inability to replicate outside living host cells. [NIH]

Vitiligo: A disorder consisting of areas of macular depigmentation, commonly on extensor aspects of extremities, on the face or neck, and in skin folds. Age of onset is often in young adulthood and the condition tends to progress gradually with lesions enlarging and extending until a quiescent state is reached. [NIH]

General Dictionaries and Glossaries

While the above glossary is essentially complete, the dictionaries listed here cover virtually all aspects of medicine, from basic words and phrases to more advanced terms (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Dictionary of Medical Acronymns & Abbreviations** by Stanley Jablonski (Editor), Paperback, 4th edition (2001), Lippincott Williams & Wilkins Publishers, ISBN: 1560534605, **http://www.amazon.com/exec/obidos/ASIN/1560534605/icongroupinterna**
- **Dictionary of Medical Terms : For the Nonmedical Person (Dictionary of Medical Terms for the Nonmedical Person, Ed 4)** by Mikel A. Rothenberg, M.D, et al, Paperback - 544 pages, 4th edition (2000), Barrons Educational Series, ISBN: 0764112015, **http://www.amazon.com/exec/obidos/ASIN/0764112015/icongroupinterna**
- **A Dictionary of the History of Medicine** by A. Sebastian, CD-Rom edition (2001), CRC Press-Parthenon Publishers, ISBN: 185070368X, **http://www.amazon.com/exec/obidos/ASIN/185070368X/icongroupinterna**
- **Dorland's Illustrated Medical Dictionary (Standard Version)** by Dorland, et al, Hardcover - 2088 pages, 29th edition (2000), W B Saunders Co, ISBN:

0721662544,
http://www.amazon.com/exec/obidos/ASIN/0721662544/icongroupinterna

- **Dorland's Electronic Medical Dictionary** by Dorland, et al, Software, 29th Book & CD-Rom edition (2000), Harcourt Health Sciences, ISBN: 0721694934,
http://www.amazon.com/exec/obidos/ASIN/0721694934/icongroupinterna
- **Dorland's Pocket Medical Dictionary (Dorland's Pocket Medical Dictionary, 26th Ed)** Hardcover - 912 pages, 26th edition (2001), W B Saunders Co, ISBN: 0721682812,
http://www.amazon.com/exec/obidos/ASIN/0721682812/icongroupinterna/103-4193558-7304618
- **Melloni's Illustrated Medical Dictionary (Melloni's Illustrated Medical Dictionary, 4th Ed)** by Melloni, Hardcover, 4th edition (2001), CRC Press-Parthenon Publishers, ISBN: 85070094X,
http://www.amazon.com/exec/obidos/ASIN/85070094X/icongroupinterna
- **Stedman's Electronic Medical Dictionary Version 5.0 (CD-ROM for Windows and Macintosh, Individual)** by Stedmans, CD-ROM edition (2000), Lippincott Williams & Wilkins Publishers, ISBN: 0781726328,
http://www.amazon.com/exec/obidos/ASIN/0781726328/icongroupinterna
- **Stedman's Medical Dictionary** by Thomas Lathrop Stedman, Hardcover - 2098 pages, 27th edition (2000), Lippincott, Williams & Wilkins, ISBN: 068340007X,
http://www.amazon.com/exec/obidos/ASIN/068340007X/icongroupinterna
- **Tabers Cyclopedic Medical Dictionary (Thumb Index)** by Donald Venes (Editor), et al, Hardcover - 2439 pages, 19th edition (2001), F A Davis Co, ISBN: 0803606540,
http://www.amazon.com/exec/obidos/ASIN/0803606540/icongroupinterna

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