THE OFFICIAL PATIENT'S SOURCEBOOK *on*

ACROMEGALY

JAMES N. PARKER, M.D.
AND PHILIP M. PARKER, PH.D., EDITORS

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.

Publisher's note: The ideas, procedures, and suggestions contained in this book are not intended as a substitute for consultation with your physician. All matters regarding your health require medical supervision. As new medical or scientific information becomes available from academic and clinical research, recommended treatments and drug therapies may undergo changes. The authors, editors, and publisher have attempted to make the information in this book up to date and accurate in accord with accepted standards at the time of publication. The authors, editors, and publisher are not responsible for errors or omissions or for consequences from application of the book, and make no warranty, expressed or implied, in regard to the contents of this book. Any practice described in this book should be applied by the reader in accordance with professional standards of care used in regard to the unique circumstances that may apply in each situation, in close consultation with a qualified physician. The reader is advised to always check product information (package inserts) for changes and new information regarding dose and contraindications before taking any drug or pharmacological product. Caution is especially urged when using new or infrequently ordered drugs, herbal remedies, vitamins and supplements, alternative therapies, complementary therapies and medicines, and integrative medical treatments.

Cataloging-in-Publication Data

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

The Official Patient's Sourcebook on Acromegaly: 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: 0-597-83366-4
1. Acromegaly-Popular works. I. Title.

Disclaimer

This publication is not intended to be used for the diagnosis or treatment of a health problem or as a substitute for consultation with licensed medical professionals. It is sold with the understanding that the publisher, editors, and authors are not engaging in the rendering of medical, psychological, financial, legal, or other professional services.

References to any entity, product, service, or source of information that may be contained in this publication should not be considered an endorsement, either direct or implied, by the publisher, editors or authors. ICON Group International, Inc., the editors, or the authors are not responsible for the content of any Web pages nor publications referenced in this publication.

Copyright Notice

Dedication

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

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 acromegaly. 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.

About the Editors

James N. Parker, M.D.

Dr. James N. Parker received his Bachelor of Science degree in Psychobiology from the University of California, Riverside and his M.D. from the University of California, San Diego. In addition to authoring numerous research publications, he has lectured at various academic institutions. Dr. Parker is the medical editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

Philip M. Parker, Ph.D.

Philip M. Parker is the Eli Lilly Chair Professor of Innovation, Business and Society at INSEAD (Fontainebleau, France and Singapore). Dr. Parker has also been Professor at the University of California, San Diego and has taught courses at Harvard University, the Hong Kong University of Science and Technology, the Massachusetts Institute of Technology, Stanford University, and UCLA. Dr. Parker is the associate editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

About ICON Health Publications

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

- The Official Patient's Sourcebook on Addison's Disease
- The Official Patient's Sourcebook on Asymptomatic Primary Hyperparathyroidism
- The Official Patient's Sourcebook on Cushing's Syndrome
- The Official Patient's Sourcebook on Cystic Fibrosis
- The Official Patient's Sourcebook on Diabetes
- The Official Patient's Sourcebook on Diabetes Insipidus
- The Official Patient's Sourcebook on Diabetes Mellitus
- The Official Patient's Sourcebook on Diabetic Neuropathy
- The Official Patient's Sourcebook on Gestational Diabetes
- The Official Patient's Sourcebook on Hyperparathyroidism
- The Official Patient's Sourcebook on Hypoglycemia
- The Official Patient's Sourcebook on Multiple Endocrine Neoplasia Type 1
- The Official Patient's Sourcebook on Prolactinoma

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:

ICON Group International, Inc.
4370 La Jolla Village Drive, Fourth Floor
San Diego, CA 92122 USA
Fax: 858-546-4341
Web site: **www.icongrouponline.com/health**

Table of Contents

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]

---

[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 Acromegaly* 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 acromegaly, 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 acromegaly.

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 acromegaly 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 acromegaly (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 acromegaly. It also gives you sources of information that can help you find a doctor in your local area specializing in treating acromegaly. Collectively, the material presented in Part I is a complete primer on basic research topics for patients with acromegaly.

Part II moves on to advanced research dedicated to acromegaly. 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 acromegaly. 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 acromegaly or related disorders. The appendices are dedicated to more pragmatic issues faced by many patients with acromegaly. 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 acromegaly.

Scope

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

- Acromegalia
- Eosinophilic Adenoma Syndrome
- Hyperpituitarism

- Marie Disease
- Marie's Disease

In addition to synonyms and related conditions, physicians may refer to acromegaly 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 acromegaly:[4]

- 253.0 acromegaly
- 253.0 acromegaly and gigantism

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 acromegaly. 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 acromegaly will log on to the Internet, type words into a search engine, and receive several

[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."

Web site listings which are mostly irrelevant or redundant. These patients are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with acromegaly 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 acromegaly is considered a relatively uncommon condition. Because of this, far less research is conducted on acromegaly 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 acromegaly, 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 acromegaly 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 acromegaly 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 acromegaly, 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

[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 "acromegaly support group" to find any active online support groups dedicated to acromegaly.

PART I: THE ESSENTIALS

ABOUT PART I

Part I has been edited to give you access to what we feel are "the essentials" on acromegaly. 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 acromegaly to you or even given you a pamphlet or brochure describing acromegaly. 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 ACROMEGALY: GUIDELINES

Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on acromegaly. 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 acromegaly 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 acromegaly. 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 acromegaly 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 acromegaly.

What Is Acromegaly?[8]

Acromegaly is a hormonal disorder that results when the pituitary gland produces excess growth hormone (GH). It most commonly affects middle-aged adults and can result in serious illness and premature death. Once recognized, acromegaly is treatable in most patients, but because of its slow and often insidious onset, it frequently is not diagnosed correctly.

The name acromegaly comes from the Greek words for "extremities" and "enlargement" and reflects one of its most common symptoms, the abnormal growth of the hands and feet. Soft tissue swelling of the hands and feet is often an early feature, with patients noticing a change in ring or shoe size. Gradually, bony changes alter the patient's facial features: the brow and lower jaw protrude, the nasal bone enlarges, and spacing of the teeth increases.

Overgrowth of bone and cartilage often leads to arthritis. When tissue thickens, it may trap nerves, causing carpal tunnel syndrome, characterized by numbness and weakness of the hands. Other symptoms of acromegaly include thick, coarse, oily skin; skin tags; enlarged lips, nose and tongue; deepening of the voice due to enlarged sinuses and vocal cords; snoring due to upper airway obstruction; excessive sweating and skin odor; fatigue and weakness; headaches; impaired vision; abnormalities of the menstrual cycle and sometimes breast discharge in women; and impotence in men. There may be enlargement of body organs, including the liver, spleen, kidneys and heart.

The most serious health consequences of acromegaly are diabetes mellitus, hypertension, and increased risk of cardiovascular disease. Patients with acromegaly are also at increased risk for polyps of the colon that can develop into cancer.

When GH-producing tumors occur in childhood, the disease that results is called gigantism rather than acromegaly. Fusion of the growth plates of the

---

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

long bones occurs after puberty so that development of excessive GH production in adults does not result in increased height. Prolonged exposure to excess GH before fusion of the growth plates causes increased growth of the long bones and increased height.

What Causes Acromegaly?

Acromegaly is caused by prolonged overproduction of GH by the pituitary gland. The pituitary is a small gland at the base of the brain that produces several important hormones to control body functions such as growth and development, reproduction, and metabolism. GH is part of a cascade of hormones that, as the name implies, regulates the physical growth of the body. This cascade begins in a part of the brain called the hypothalamus, which makes hormones that regulate the pituitary. One of these, growth hormone-releasing hormone (GHRH), stimulates the pituitary gland to produce GH.

Another hypothalamic hormone, somatostatin, inhibits GH production and release. Secretion of GH by the pituitary into the bloodstream causes the production of another hormone, called insulin-like growth factor 1 (IGF-1), in the liver. IGF-1 is the factor that actually causes the growth of bones and other tissues of the body. IGF-1, in turn, signals the pituitary to reduce GH production. GHRH, somatostatin, GH, and IGF-1 levels in the body are tightly regulated by each other and by sleep, exercise, stress, food intake and blood sugar levels. If the pituitary continues to make GH independent of the normal regulatory mechanisms, the level of IGF-1 continues to rise, leading to bone growth and organ enlargement. The excess GH also causes changes in sugar and lipid metabolism and can cause diabetes.

Pituitary Tumors

In over 90 percent of acromegaly patients, the overproduction of GH is caused by a benign tumor of the pituitary gland, called an adenoma. These tumors produce excess GH and, as they expand, compress surrounding brain tissues, such as the optic nerves. This expansion causes the headaches and visual disturbances that are often symptoms of acromegaly. In addition, compression of the surrounding normal pituitary tissue can alter production of other hormones, leading to changes in menstruation and breast discharge in women and impotence in men.

There is a marked variation in rates of GH production and the aggressiveness of the tumor. Some adenomas grow slowly and symptoms of GH excess are often not noticed for many years. Other adenomas grow rapidly and invade surrounding brain areas or the sinuses, which are located near the pituitary. In general, younger patients tend to have more aggressive tumors.

Most pituitary tumors arise spontaneously and are not genetically inherited. Many pituitary tumors arise from a genetic alteration in a single pituitary cell which leads to increased cell division and tumor formation. This genetic change, or mutation, is not present at birth, but is acquired during life. The mutation occurs in a gene that regulates the transmission of chemical signals within pituitary cells; it permanently switches on the signal that tells the cell to divide and secrete GH. The events within the cell that cause disordered pituitary cell growth and GH oversecretion currently are the subject of intensive research.

Non-Pituitary Tumors

In a few patients, acromegaly is caused not by pituitary tumors but by tumors of the pancreas, lungs, and adrenal glands. These tumors also lead to an excess of GH, either because they produce GH themselves or, more frequently, because they produce GHRH, the hormone that stimulates the pituitary to make GH. In these patients, the excess GHRH can be measured in the blood and establishes that the cause of the acromegaly is not due to a pituitary defect. When these non-pituitary tumors are surgically removed, GH levels fall and the symptoms of acromegaly improve.

In patients with GHRH-producing, non-pituitary tumors, the pituitary still may be enlarged and may be mistaken for a tumor. Therefore, it is important that physicians carefully analyze all "pituitary tumors" removed from patients with acromegaly in order not to overlook the possibility that a tumor elsewhere in the body is causing the disorder.

How Common Is Acromegaly?

Small pituitary adenomas are common. During autopsies, they are found in up to 25 percent of the U.S. population. However, these tumors rarely cause symptoms or produce excessive GH or other pituitary hormones. Scientists estimate that about 3 out of every million people develop acromegaly each year and that 40 to 60 out of every million people suffer from the disease at

any time. However, because the clinical diagnosis of acromegaly often is missed, these numbers probably underestimate the frequency of the disease.

How Is Acromegaly Diagnosed?

If a doctor suspects acromegaly, he or she can measure the GH level in the blood after a patient has fasted overnight to determine if it is elevated. However, a single measurement of an elevated blood GH level is not enough to diagnose acromegaly, because GH is secreted by the pituitary in spurts and its concentration in the blood can vary widely from minute to minute. At a given moment, a patient with acromegaly may have a normal GH level, whereas a GH level in a healthy person may be five times higher.

Because of these problems, more accurate information can be obtained when GH is measured under conditions in which GH secretion is normally suppressed. Physicians often use the oral glucose tolerance test to diagnose acromegaly, because ingestion of 75 g of the sugar glucose lowers blood GH levels less than 2 ng/ml in healthy people. In patients with GH overproduction, this reduction does not occur. The glucose tolerance test is the most reliable method of confirming a diagnosis of acromegaly.

Physicians also can measure IGF-1 levels in patients with suspected acromegaly. As mentioned earlier, elevated GH levels increase IGF-1 blood levels. Because IGF-1 levels are much more stable over the course of the day, they are often a more practical and reliable measure than GH levels. Elevated IGF-1 levels almost always indicate acromegaly. However, a pregnant woman's IGF-1 levels are two to three times higher than normal. In addition, physicians must be aware that IGF-1 levels decline in aging people and may be abnormally low in patients with poorly controlled diabetes mellitus.

After acromegaly has been diagnosed by measuring GH or IGF-1, imaging techniques, such as computed tomography (CT) scans or magnetic resonance imaging (MRI) scans of the pituitary are used to locate the tumor that causes the GH overproduction. Both techniques are excellent tools to visualize a tumor without surgery. If scans fail to detect a pituitary tumor, the physician should look for non-pituitary tumors in the chest, abdomen, or pelvis as the cause for excess GH. The presence of such tumors usually can be diagnosed by measuring GHRH in the blood and by a CT scan of possible tumor sites.

How Is Acromegaly Treated?

The goals of treatment are to reduce GH production to normal levels, to relieve the pressure that the growing pituitary tumor exerts on the surrounding brain areas, to preserve normal pituitary function, and to reverse or ameliorate the symptoms of acromegaly. Currently, treatment options include surgical removal of the tumor, drug therapy, and radiation therapy of the pituitary.

Surgery

Surgery is a rapid and effective treatment. The surgeon reaches the pituitary through an incision in the nose and, with special tools, removes the tumor tissue in a procedure called transsphenoidal surgery. This procedure promptly relieves the pressure on the surrounding brain regions and leads to a lowering of GH levels. If the surgery is successful, facial appearance and soft tissue swelling improve within a few days. Surgery is most successful in patients with blood GH levels below 40 ng/ml before the operation and with pituitary tumors no larger than 10 mm in diameter. Success depends on the skill and experience of the surgeon. The success rate also depends on what level of GH is defined as a cure. The best measure of surgical success is normalization of GH and IGF-1 levels. Ideally, GH should be less than 2 ng/ml after an oral glucose load. A review of GH levels in 1,360 patients worldwide immediately after surgery revealed that 60 percent had random GH levels below 5 ng/ml. Complications of surgery may include cerebrospinal fluid leaks, meningitis, or damage to the surrounding normal pituitary tissue, requiring lifelong pituitary hormone replacement.

Even when surgery is successful and hormone levels return to normal, patients must be carefully monitored for years for possible recurrence. More commonly, hormone levels may improve, but not return completely to normal. These patients may then require additional treatment, usually with medications.

Drug Therapy

Two medications currently are used to treat acromegaly. These drugs reduce both GH secretion and tumor size. Medical therapy is sometimes used to shrink large tumors before surgery. Bromocriptine (Parlodel®) in divided doses of about 20 mg daily reduces GH secretion from some pituitary tumors. Side effects include gastrointestinal upset, nausea, vomiting, light-

headedness when standing, and nasal congestion. These side effects can be reduced or eliminated if medication is started at a very low dose at bedtime, taken with food, and gradually increased to the full therapeutic dose.

Because bromocriptine can be taken orally, it is an attractive choice as primary drug or in combination with other treatments. However, bromocriptine lowers GH and IGF-1 levels and reduces tumor size in less than half of patients with acromegaly. Some patients report improvement in their symptoms although their GH and IGF-1 levels still are elevated.

The second medication used to treat acromegaly is octreotide (Sandostatin®). Octreotide is a synthetic form of a brain hormone, somatostatin, that stops GH production. This drug must be injected under the skin every 8 hours for effective treatment. Most patients with acromegaly respond to this medication. In many patients, GH levels fall within one hour and headaches improve within minutes after the injection. Several studies have shown that octreotide is effective for long-term treatment. Octreotide also has been used successfully to treat patients with acromegaly caused by non-pituitary tumors.

Because octreotide inhibits gastrointestinal and pancreatic function, long-term use causes digestive problems such as loose stools, nausea, and gas in one third of patients. In addition, approximately 25 percent of patients develop gallstones, which are usually asymptomatic. In rare cases, octreotide treatment can cause diabetes. On the other hand, scientists have found that in some acromegaly patients who already have diabetes, octreotide can reduce the need for insulin and improve blood sugar control.

Radiation Therapy

Radiation therapy has been used both as a primary treatment and combined with surgery or drugs. It is usually reserved for patients who have tumor remaining after surgery. These patients often also receive medication to lower GH levels. Radiation therapy is given in divided doses over four to six weeks. This treatment lowers GH levels by about 50 percent over 2 to 5 years. Patients monitored for more than 5 years show significant further improvement. Radiation therapy causes a gradual loss of production of other pituitary hormones with time. Loss of vision and brain injury, which have been reported, are very rare complications of radiation treatments.

No single treatment is effective for all patients. Treatment should be individualized depending on patient characteristics, such as age and tumor

size. If the tumor has not yet invaded surrounding brain tissues, removal of the pituitary adenoma by an experienced neurosurgeon is usually the first choice. After surgery, a patient must be monitored for a long time for increasing GH levels. If surgery does not normalize hormone levels or a relapse occurs, a doctor will usually begin additional drug therapy. The first choice should be bromocriptine because it is easy to administer; octreotide is the second alternative. With both medications, long-term therapy is necessary because their withdrawal can lead to rising GH levels and tumor re-expansion. Radiation therapy is generally used for patients whose tumors are not completely removed by surgery; for patients who are not good candidates for surgery because of other health problems; and for patients who do not respond adequately to surgery and medication.

Additional Resources

For more information, contact:

Pituitary Tumor Network Association
16350 Ventura Blvd., #231
Encino, CA 91436
(805) 499-9973
Fax: (805) 499-1523

More Guideline Sources

The guideline above on acromegaly 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 acromegaly. 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 acromegaly. 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**.

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 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 "acromegaly" or synonyms. The following was recently posted:

- **ACR Appropriateness Criteria™ for neuroendocrine imaging.**

  Source: American College of Radiology.; 1999; 9 pages

  http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=001674&sSearch_string=acromegaly

- **The management of diabetes mellitus in the primary care setting.**

  Source: Department of Defense/Veterans Health Administration.; 1999 December; 147 pages

  http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=001809&sSearch_string=acromegaly

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:

- **Pituitary Diseases: Disorders & Related Articles**

  Summary: This site contains symptoms and articles of specific diseases of the pituitary gland including cushings disease, acromegaly, addison's disease, growth hormone deficiency, hypothyroidism, hypogonadism

  Source: Pituitary Network Association

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=2646

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 acromegaly. 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**.

NORD (The National Organization of Rare Disorders, Inc.)

NORD provides an invaluable service to the public by publishing, for a nominal fee, short yet comprehensive guidelines on over 1,000 diseases. NORD primarily focuses on rare diseases that might not be covered by the previously listed sources. NORD's Web address is **www.rarediseases.org**. To see if a recent fact sheet has been published on acromegaly, simply go to the following hyperlink: **http://www.rarediseases.org/cgi-bin/nord/alphalist**. A complete guide on acromegaly can be purchased from NORD for a nominal fee.

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:

Adenoma: A benign epithelial tumour in which the cells form recognizable glandular structures or in which the cells are clearly derived from glandular epithelium. [EU]

Aggressiveness: The quality of being aggressive (= characterized by aggression; militant; enterprising; spreading with vigour; chemically active; variable and adaptable). [EU]

Agonist: In anatomy, a prime mover. In pharmacology, a drug that has affinity for and stimulates physiologic activity at cell receptors normally stimulated by naturally occurring substances. [EU]

Asymptomatic: No symptoms; no clear sign of disease present. [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]

Bromocriptine: A semisynthetic ergot alkaloid that is a dopamine D2 agonist. It suppresses prolactin secretion and is used to treat amenorrhea,

galactorrhea, and female infertility, and has been proposed for Parkinson disease. [NIH]

Cardiovascular: Pertaining to the heart and blood vessels. [EU]

Cerebrospinal: Pertaining to the brain and spinal cord. [EU]

Congestion: Excessive or abnormal accumulation of blood in a part. [EU]

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

Gastrointestinal: Pertaining to or communicating with the stomach and intestine, as a gastrointestinal fistula. [EU]

Gigantism: The condition of abnormal overgrowth or excessive size of the whole body or any of its parts. [NIH]

Glucose: D-glucose, a monosaccharide (hexose), C6H12O6, also known as dextrose (q.v.), found in certain foodstuffs, especially fruits, and in the normal blood of all animals. It is the end product of carbohydrate metabolism and is the chief source of energy for living organisms, its utilization being controlled by insulin. Excess glucose is converted to glycogen and stored in the liver and muscles for use as needed and, beyond that, is converted to fat and stored as adipose tissue. Glucose appears in the urine in diabetes mellitus. [EU]

Hematology: A subspecialty of internal medicine concerned with morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Hormones: Chemical substances having a specific regulatory effect on the activity of a certain organ or organs. The term was originally applied to substances secreted by various endocrine glands and transported in the bloodstream to the target organs. It is sometimes extended to include those substances that are not produced by the endocrine glands but that have similar effects. [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]

Hypogonadism: A condition resulting from or characterized by abnormally decreased functional activity of the gonads, with retardation of growth and sexual development. [EU]

Hypothalamus: Ventral part of the diencephalon extending from the region of the optic chiasm to the caudal border of the mammillary bodies and forming the inferior and lateral walls of the third ventricle. [NIH]

Hypothyroidism: Deficiency of thyroid activity. In adults, it is most common in women and is characterized by decrease in basal metabolic rate, tiredness and lethargy, sensitivity to cold, and menstrual disturbances. If untreated, it progresses to full-blown myxoedema. In infants, severe hypothyroidism leads to cretinism. In juveniles, the manifestations are intermediate, with less severe mental and developmental retardation and only mild symptoms of the adult form. When due to pituitary deficiency of thyrotropin secretion it is called secondary hypothyroidism. [EU]

Insulin: A protein hormone secreted by beta cells of the pancreas. Insulin plays a major role in the regulation of glucose metabolism, generally promoting the cellular utilization of glucose. It is also an important regulator of protein and lipid metabolism. Insulin is used as a drug to control insulin-dependent diabetes mellitus. [NIH]

Lipid: Any of a heterogeneous group of flats and fatlike substances characterized by being water-insoluble and being extractable by nonpolar (or fat) solvents such as alcohol, ether, chloroform, benzene, etc. All contain as a major constituent aliphatic hydrocarbons. The lipids, which are easily stored in the body, serve as a source of fuel, are an important constituent of cell structure, and serve other biological functions. Lipids may be considered to include fatty acids, neutral fats, waxes, and steroids. Compound lipids comprise the glycolipids, lipoproteins, and phospholipids. [EU]

Meningitis: Inflammation of the meninges. When it affects the dura mater, the disease is termed pachymeningitis; when the arachnoid and pia mater are involved, it is called leptomeningitis, or meningitis proper. [EU]

Menstruation: The cyclic, physiologic discharge through the vagina of blood and mucosal tissues from the nonpregnant uterus; it is under hormonal control and normally recurs, usually at approximately four-week intervals, in the absence of pregnancy during the reproductive period (puberty through menopause) of the female of the human and a few species of primates. It is the culmination of the menstrual cycle. [EU]

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

Nausea: An unpleasant sensation, vaguely referred to the epigastrium and abdomen, and often culminating in vomiting. [EU]

Octreotide: A potent, long-acting somatostatin octapeptide analog which has a wide range of physiological actions. It inhibits growth hormone secretion, is effective in the treatment of hormone-secreting tumors from various organs, and has beneficial effects in the management of many

pathological states including diabetes mellitus, orthostatic hypertension, hyperinsulinism, hypergastrinemia, and small bowel fistula. [NIH]

Oral: Pertaining to the mouth, taken through or applied in the mouth, as an oral medication or an oral thermometer. [EU]

Pancreas: An organ behind the lower part of the stomach that is about the size of a hand. It makes insulin so that the body can use glucose (sugar) for energy. It also makes enzymes that help the body digest food. Spread all over the pancreas are areas called the islets of Langerhans. The cells in these areas each have a special purpose. The alpha cells make glucagon, which raises the level of glucose in the blood; the beta cells make insulin; the delta cells make somatostatin. There are also the PP cells and the D1 cells, about which little is known. [NIH]

Puberty: The period during which the secondary sex characteristics begin to develop and the capability of sexual reproduction is attained. [EU]

Radiology: A specialty concerned with the use of x-ray and other forms of radiant energy in the diagnosis and treatment of disease. [NIH]

Recurrence: The return of a sign, symptom, or disease after a remission. [NIH]

Secretion: 1. the process of elaborating a specific product as a result of the activity of a gland; this activity may range from separating a specific substance of the blood to the elaboration of a new chemical substance. 2. any substance produced by secretion. [EU]

Snoring: Rough, noisy breathing during sleep, due to vibration of the uvula and soft palate. [NIH]

Somatostatin: A polypeptide hormone produced in the hypothalamus, and other tissues and organs. It inhibits the release of human growth hormone, and also modulates important physiological functions of the kidney, pancreas, and gastrointestinal tract. Somatostatin receptors are widely expressed throughout the body. Somatostatin also acts as a neurotransmitter in the central and peripheral nervous systems. [NIH]

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]

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]

Tomography: The recording of internal body images at a predetermined plane by means of the tomograph; called also body section roentgenography. [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]

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]

Withdrawal: 1. a pathological retreat from interpersonal contact and social involvement, as may occur in schizophrenia, depression, or schizoid avoidant and schizotypal personality disorders. 2. (DSM III-R) a substance-specific organic brain syndrome that follows the cessation of use or reduction in intake of a psychoactive substance that had been regularly used to induce a state of intoxication. [EU]

CHAPTER 2. SEEKING GUIDANCE

Overview

Some patients are comforted by the knowledge that a number of organizations dedicate their resources to helping people with acromegaly. 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 acromegaly. The chapter ends with a discussion on how to find a doctor that is right for you.

Associations and Acromegaly

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):

- **Brain and Pituitary Foundation of America**

  Address: Brain and Pituitary Foundation of America 281 East Moody Avenue, Fresno, CA 93720-1524

  Telephone: (209) 434-0610

  Background: The Brain and Pituitary Foundation of America is a not-for-profit voluntary health organization dedicated to assisting individuals with various brain and pituitary abnormalities such as Acromegaly, Prolactinoma, and Cushing's Syndrome. Established in 1984, this self-help organization also provides patient support and referrals for those seeking medical assistance. Educational materials produced by the organization include various brochures and disease specific literature.

  Relevant area(s) of interest: Acromegaly, Cushing's Syndrome, Prolactinoma

Finding 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 acromegaly. 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 "acromegaly" (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 "acromegaly". 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 "acromegaly" (or synonyms) into the "For these words:" box, you will only receive results on organizations dealing with acromegaly. 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 "acromegaly" (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.

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 acromegaly 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.
- 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

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

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 an Endocrinologist

The American Association of Clinical Endocrinologists (AACE) sponsors a Physician Finder database located at **http://www.aace.com/memsearch.php**. Physician Finder allows you to search for endocrinologists who are members of the AACE by specialty, city, state, or country. According to the AACE: "Members of AACE are physicians with special education, training and interest in the practice of clinical endocrinology. These physicians devote a significant part of their career to the evaluation and management of patients with endocrine disease. All members of AACE are physicians (M.D. or D.O.) and a majority is certified by Boards recognized by the American Board of Medical Specialties. Members of AACE are recognized clinicians, educators and scientists, many of whom are affiliated with medical schools and universities. Members of AACE contribute on a regular and continuing basis to the scientific literature on endocrine diseases and conduct medical education programs on this subject."[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.

---

[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.

[13] Quotation taken from the AACE's Web site: **http://www.aace.com/memsearch.php**.

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 acromegaly?
- 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 acromegaly?
- Spend enough time with me?

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.

---

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

- 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.
- 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 ACROMEGALY

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 acromegaly.

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 acromegaly 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 acromegaly.
- **Phase III.** Finally, researchers conduct Phase III trials to find out how new treatments for acromegaly 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 acromegaly 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 acromegaly. 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 acromegaly 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 acromegaly 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 acromegaly. 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 Acromegaly

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 acromegaly.[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.

- **Measurement of Outcome of Surgical Treatment in Patients With Acromegaly**

  Condition(s): Acromegaly

  Study Status: This study is currently recruiting patients.

  Sponsor(s): National Center for Research Resources (NCRR); Columbia University

  Purpose - Excerpt: Objectives: I. Compare growth hormone (GH) levels at baseline and after glucose suppression measured with both a polyclonal radioimmunoassay and a highly sensitive immunoradiometric assay (IRMA) in patients with acromegaly and normal volunteers. II. Measure the levels of IGF-I and its binding protein, IGFBP-3, in these cohorts. III. Determine any correlation between levels of IGF-I and IGFBP-3 and GH suppressibility as assessed by sensitive IRMA. IV. Determine if patients who demonstrate biochemical features of mild GH excess are at risk for progression to active disease.

  Study Type: Observational

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

Contact(s): New York; Columbia University College of Physicians and Surgeons, New York, New York, 10032, United States; Recruiting; Pamela U. Freda 212-305-3725. Study chairs or principal investigators: Pamela U. Freda, Study Chair; Columbia University

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00000606;jsessionid=A9F219605331D36698F5A034B9B4D062

- **Sandostatin LAR Depot vs. Surgery for Treating Acromegaly**

  Condition(s): Acromegaly; Pituitary Neoplasm

  Study Status: This study is currently recruiting patients.

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

  Purpose - Excerpt: The purpose of this study is to compare the efficacy of Sandostatin LAR(r) (Registered Trademark) Depot to transsphenoidal surgery in previously untreated acromegalic patients with macroadenomas. The primary goal is to normalize insulin-like growth factor-1 (IGF-1) levels. Secondary goals are to compare Sandostatin LAR(r) (Registered Trademark) Depot treatment and transsphenoidal surgery to achieve the following goals: suppress growth hormone levels to less than or equal to 2.5 ng/mL, relieve the clinical signs and symptoms of acromegaly, reduce the size of the macroadenomas, produce few side effects, assess the prognostic value of baseline pituitary adenoma size, extension and baseline growth hormone level on post-treatment growth hormone and IGF-1 levels, and assess the resource utilization of each treatment type.

  Phase(s): Phase II

  Study Type: Interventional

  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/NCT00000606;jsessionid=A9F219605331D36698F5A034B9B4D062

- **The Treatment and Natural History of Acromegaly**

  Condition(s): Acromegaly; Pituitary Neoplasm

  Study Status: This study is currently recruiting patients.

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

Purpose - Excerpt: This study is directed toward acromegaly and treatment of patients with acromegaly. Acromegaly is a condition due to high levels of growth hormone in the blood. Growth hormone is responsible for the regulation of the metabolism of sugar, fat, and protein. When growth hormone levels are elevated patients may experience symptoms such as fatigue, sweating, joint pain, enlargement of the hands and feet, growth of soft tissues, and changes in the bones of the face and skull. Most patient suffering from acromegaly have a tumor of the pituitary gland known as an adenoma. It can be treated surgically or destroyed by radiation. Occasionally drugs are used to treat acromegaly. Researchers have followed groups of patients with acromegaly for 25 years. The study will allow researchers to continue monitoring these patients and recruit new patients into the study. The patients will provide researchers with blood samples and pituitary gland tumor samples (when available through clinical care). These samples will be saved to provide future information about the disease. The study will provide researchers with information needed to better understand the causes and treatment of acromegaly.

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/NCT00000606;jsessionid=A9F219605331D36698F5A034B9B4D062

- **Study of the Effect of Growth Hormone-Releasing Hormone Antagonist on Growth Hormone Release in Acromegaly**

  Condition(s): Acromegaly

  Study Status: This study is completed.

  Sponsor(s): National Center for Research Resources (NCRR); University of Michigan

  Purpose - Excerpt: Objectives: I. Determine whether release of endogenous growth hormone (GH)-releasing hormone is involved in GH responses to clonidine, pyridostigmine, levodopa, arginine, GH-releasing peptide, insulin-induced hypoglycemia, and exercise in patients with

acromegaly. II. Determine whether endogenous GH-releasing hormone influences the maintenance of GH hypersecretion.

Study Type: Observational

Contact(s):. Study chairs or principal investigators: Ariel Barban, Study Chair; University of Michigan

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00000606;jsessionid=A9F219605331D36698F5A034B9B4D062

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 acromegaly. 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 acromegaly. In cases where certain diseases or disorders run in families, your participation may lead to better care or prevention for your family members.

[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.

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.

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 acromegaly? 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 "acromegaly" (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:

Arginine: An essential amino acid that is physiologically active in the L-form. [NIH]

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

Hypersecretion: Excessive secretion. [EU]

Levodopa: The naturally occurring form of dopa and the immediate precursor of dopamine. Unlike dopamine itself, it can be taken orally and crosses the blood-brain barrier. It is rapidly taken up by dopaminergic neurons and converted to dopamine. It is used for the treatment of parkinsonism and is usually given with agents that inhibit its conversion to dopamine outside of the central nervous system. [NIH]

Skull: The skeleton of the head including the bones of the face and the bones enclosing the brain. [NIH]

PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL

ABOUT PART II

In Part II, we introduce you to additional resources and advanced research on acromegaly. 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 acromegaly. In Part II, as in Part I, our objective is not to interpret the latest advances on acromegaly 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 acromegaly is suggested.

CHAPTER 4. STUDIES ON ACROMEGALY

Overview

Every year, academic studies are published on acromegaly 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 acromegaly. 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 acromegaly and teach you how to keep current on new studies as they are published or undertaken by the scientific community.

Federally-Funded Research on Acromegaly

The U.S. Government supports a variety of research studies relating to acromegaly and associated conditions. These studies are tracked by the Office of Extramural Research at the National Institutes of Health.[20] CRISP

[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

(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 acromegaly 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 acromegaly 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 acromegaly:

- **Project Title: 24-Hour Profiles of GH Secretion and GH Response to GHRP in Acromegaly**

  Principal Investigator & Institution: Thorner, Michael O.; University of Virginia Charlottesville Box 400195 Charlottesville, Va 22904

  Timing: Fiscal Year 2000

  Summary: This abstract is not available.

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

- **Project Title: B2036 Peg in Acromegaly Treatment**

  Principal Investigator & Institution: Kleinberg, David L.; Professor of Medicine; New York University School of Medicine 550 1St Ave New York, Ny 10016

  Timing: Fiscal Year 2000; Project Start 1-OCT-1975; Project End 0-NOV-2003

  Summary: Acromegaly is a hormonal disorder that occurs when a tumor in the pituitary gland produces excess growth hormone (GH). Excess growth hormone secretion leads to elevated levels of insulin-like growth factor 1 (IGF-1). Thus subjects with acromegaly have high levels of circulating GH and IGF-1. If GH is normalized, the mortality of subjects returns to normal. It is presumed that normalization of IGF-1 has the same effect. B2036-PEG is the first of a class of novel growth hormone receptor antagonists. The projected mechanism of action of B2036-PEG is the reversible binding to the GH receptor which will lead to blocking of

---

and Prevention (CDCP), Agency for Healthcare Research and Quality (AHRQ), and Office of Assistant Secretary of Health (OASH).

signal transduction and reductions in circulating IGF-1. The primary objective of this open-label extension study is to assess the long-term safety, tolerability, and efficacy of B2036-PEG in the treatment of acromegaly. The dose will be titrated in an attempt to normalize IGF-1 levels.

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

- **Project Title: Growth Hormone Releasing Hormone Antagonist on GH Release in Acromegaly**

  Principal Investigator & Institution: Jaffe, Craig A.; University of Michigan at Ann Arbor Ann Arbor, Mi 48109

  Timing: Fiscal Year 2000

  Summary: This abstract is not available.

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

- **Project Title: Ipstyl R for Treatment of Patients w/ Acromegaly**

  Principal Investigator & Institution: Snyder, Peter J.; Professor; University of Pennsylvania 3451 Walnut Philadelphia, Pa 19104

  Timing: Fiscal Year 2000

  Summary: The aim of this study is to determine if administration of the long-acting somatostatin analog, lanreotide, to patients who have acromegaly will improve the disease in terms of decreasing serum growth hormone and IGF-1 concentrations, decreasing the size of the pituitary adenoma, and improving symptoms and the nature and frequency of adverse effects.

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

- **Project Title: Open Label Trial of B2036 Peg in Treatment of Acromegaly**

  Principal Investigator & Institution: Vance, Mary L.; University of Virginia Charlottesville Box 400195 Charlottesville, Va 22904

  Timing: Fiscal Year 2000

  Summary: Somavert (B2036), a growth hormone receptor antagonist, therapy in patients with acromegaly will lower IGF-1 levels.

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

- **Project Title: Outcome of Surgical Therapy for Acromegaly**

  Principal Investigator & Institution: Freda, Pamela U.; Columbia University Health Sciences Ogc New York, Ny 10032

  Timing: Fiscal Year 2000

Summary: Acromegaly is a condition caused by excess secretion of growth hormone (GH). In almost all cases the excess GH is produced by a tumor of the anterior pituitary gland. Acromegaly is diagnosed by recognition of classic physical changes such as enlargement of the hands or feet, prominence of the jaw or brow, symptoms such as excess sweating or the development of hypertension or diabetes mellitus. The disease is confirmed by elevated GH levels, failure of GH to suppress after an oral glucose load and an elevated insulin like growth factor 1(IgF1) level. Standard initial treatment for acromegaly is surgical removal of the tumor. Recently, some studies have found that surgery for acromegaly is needed to better define the role of surgery in treatment of this disease. The purpose of this study is to establish the long term cure rate of pituitary surgery for acromegaly at this institution from 1980 to 1991. The study will consist of a retrospective chart review of 120 patients operated on during this period by one pituitary neurosurgeon and an assessment of these patients' current status by measurement of endocrine hormones.

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

- **Project Title: Safety and Efficacy of Somatostatin Analog - Lanreotide (Ipsstyl) for Acromegaly**

  Principal Investigator & Institution: Molitch, Mark E.; Northwestern University 303 E Chicago Ave Chicago, Il 60611

  Timing: Fiscal Year 2000

  Summary: Acromegaly causes well-known physical changes and carries an overall 2-3 fold increased mortality which can be decreased by treatment. Transsphenoidal surgery can cure only about two-thirds of patients. Medical therapy consists of bromocriptine and octreotide. Bromocriptine can reduce GH levels to normal in only about 10% of patients. Octreotide can reduce GH and IGF-I levels to normal in over 50% of patients, but must be given by subcutaneous injection 3 or more times daily. Lanreotide is a synthetic octapeptide analog of natural somatostatin with a prolonged half-life. In prior single dose studies with lanreotide in patients with acromegaly, GH levels fell rapidly within 2 hours and remained <5ng/ml for 10-14 days, with a return to pretreatment values by 23 days. It is the purpose of this study to evaluate lanreotide with respect to its efficacy and tolerability in patients who have never received lanreotide before. Of importance is the ability to take an injection once every 10-14 days rather than 3 times a day. This would promote patient adherence and compliance greatly.

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

- **Project Title: Somatostatin Analogue Lanreotide Ipstyl in Pts W/ Acromegaly**

  Principal Investigator & Institution: Katznelson, Laurence; Massachusetts General Hospital 55 Fruit St Boston, Ma 02114

  Timing: Fiscal Year 2000

  Summary: To investigate the long-term safety and efficacy of Lanreotide (Ipstyl)in controlling acromegaly in terms of normalization of growth hormone (GH) and Insulin-like Growth Factor-I (IGF-1) levels, as well as monitoring for tumor response, and ability of drug to control/reduce symptoms associated with acromegaly. Patients enrolled in this study will have previously completed SPID number 0384, a 3 month investigation of the benefits of Ipstyl for two management of acromegaly. This current protocol serves as a mechanism to continue administration of this medication to patients with acromegaly for an additional 52 weeks.

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

- **Project Title: Study of B2036-Ped in Treatment of Acromegaly**

  Principal Investigator & Institution: Clemmons, David R.; University of North Carolina Chapel Hill Box 2688, 910 Raleigh Rd Chapel Hill, Nc 27515

  Timing: Fiscal Year 2000

  Summary: The purpose of this research study is to determine the long term safety of an investigational drug, B2036-PEG, in patients with acromegaly which is caused by growth hormone secreting tumors. This drug blocks the actions of growth hormone. It may be more effective than the two previously available drugs because they work by different mechanisms which are only effective in selected patients. In contrast, all patients with acromegaly have high growth hormone levels and have growth hormone receptors. Therefore, this drug should have some effect in nearly all patients. Studies performed in animals and humans with this agent showed only a few minor side effects and a decrease in one of the blood proteins (IGF-1) that is responsible for many of the signs and symptoms seen in acromegaly. This study will determine the long term safety and effectiveness of B2036-PEG therapy at different daily doses.

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

- **Project Title: Dynamics of Growth Hormone Secretion in Pituitary Gland Dysfuntion**

  Principal Investigator & Institution: Arafah, Baha M.; Case Western Reserve University 10900 Euclid Ave Cleveland, Oh 44106

Timing: Fiscal Year 2000

Summary: Dynamics of growth hormone secretion are studied in patients with pituitary gland dysfunction before and on multiple occasions after therapeutic interventions. The emphasis is primarily on patients with acromegaly or gigantism. The project is now following patients longitudinally. The patients studied as children 15-20 years ago are being assessed annually as adults to evaluate the long term efficacy of the surgical intervention.

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

- **Project Title: Growth Hormone in Pituitary and Testicular Function**

  Principal Investigator & Institution: Chandrashekar, Varadaraj; Physiology; Southern Illinois University Carbondale at Carbondale Carbondale, Il 62901

  Timing: Fiscal Year 2000; Project Start 1-MAR-2000; Project End 8-FEB-2003

  Summary: Re production is adversely affected in human acromegaly due to excess GH secretion. Also in men, congenital GH resistance is due to mutated GH receptors (Laron syndrome) is associated with delay in sexual maturation, suggesting a role of GH in reproduction. However, it is not know whether these changes are mediated via the pituitary gland. To address this issue, pituitary and testicular functions will be evaluated in GH receptor knockout (GHR-KO mice; a model for Laron syndrom) and transgenic mice expressing the human GHRH gene (GHRH mice; a model for acromegaly). In GHR-KO male mice, the LH response to GnRH treatment is testosterone concentrations are increased, whereas the LH response to GnRH treatment is decreased. The specific aims are to assess why the pituitary and testicular functions are altered in these two lines of mice. To evaluate whether the alterations in pituitary and testicular function are due to lack of IGF-I secretion, GHR-KO mice will be treated with IGF-I or to determine whether the effects are due to hyper prolactinemia, prolactin secretion will be suppressed by treatment with a dopamine agonist. To examine whether the increased circulating testosterone levels in GHRH mice is due to increased IGF-I secretion, these animals will be treated with somatostatin to suppress IGF-I secretion. In these experiments, the pituitary function will be evaluated by measuring the gonadotropin response to GnRH treatment and assess LHbeta and FSHbeta mRNA expressions in the pituitary gland. The testicular function will be determined by evaluating the testosterone and the testosterone precursor responses to LH treatment. The long-term goals are to examine the long-term effects of exogenous GH on

reproduction in experimental animals. These studies may have some impact on the usage of GH in aging.

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

- **Project Title: Growth Hormone Releasing Hormone Antagonist Infusion In Acromegalics**

  Principal Investigator & Institution: Barkan, Ariel L.; University of Michigan at Ann Arbor Ann Arbor, Mi 48109

  Timing: Fiscal Year 2000

  Summary: Acromegaly is a disease caused by excessive growth hormone (GH) production. The majority of cases are due to pituitary gland tumors. There are two theories about the cause of these tumors formation: (1) A mutation in a chromosome of a cell leads to neoplastic transformation and subsequent formation of a tumor. (2) Excessive release of GH-releasing hormone (GHRH) (a factor produced by the hypothalamus that stimulates the growth and function of GH-secreting cells) stimulates GH-producing cells to multiply and produce large amounts of GH. Combinations of these two theories could be also functional. Moreover, GHRH can be produced by the pituitary tumor cells. Our hypothesis is that GHRH plays an important role in the formation of the pituitary tumors that cause acromegaly, and in maintaining the excessive GH secretion in acromegaly. We will attempt to answer this question by administering GHRH-antagonist (GHRH-Ant), a synthetic molecule that blocks the action of GHRH on the GH-producing cells, to patients with acromegaly. Two groups of patients will be studied: (a) Fifteen patients (group A) will have frequent blood sampling for plasma GH for 24 hours on 2 different occasions with the goal to show that without any intervention the GH secretion pattern in acromegaly does not change from day to day so that any changes that we could observe during administration of GHRH-Ant would be meaningful. (b) Ten patients recently diagnosed with acromegaly, who are scheduled to have pituitary surgery (group B) will receive intravenous (i.v.) infusion of GHRH-Ant for 7 days. Plasma GH will be measured every 10 min for 24 h, and the GH responses to factors that cause abnormal GH responses in acromegaly (i.v. thyrotropin-releasing hormone (TRH) and oral glucose) and to i.v. GHRH will be assessed before and at the end of the GHRH-Ant infusion. The effect of GHRH-Ant on the pituitary tumor size will be measured by pituitary MRI scans before and after the GHRH-Ant infusion. At the time of pituitary surgery, a pituitary tumor sample will be obtained to study the effects of GHRH-Ant on the GH production by the tumor cells in the laboratory. If the GHRH-Ant suppresses the secretion of GH and decreases the size of the pituitary tumors, we will

conclude that GHRH plays a role in the formation of the pituitary tumors that cause acromegaly and in maintaining abnormal GH secretion in this disease.

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 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 "acromegaly" (or synonyms) into the search box. This search gives you access to full-text articles.

The National Library of Medicine: PubMed

One of the quickest and most comprehensive ways to find academic studies in both English and other languages is to use PubMed, maintained by the National Library of Medicine. The advantage of PubMed over previously mentioned sources is that it covers a greater number of domestic and foreign references. It is also free to the public.[24] If the publisher has a Web site that 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.

---

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

[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 sites of participating publishers. Publishers that participate in PubMed supply NLM with their citations electronically prior to or at the time of publication.

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

- **Acromegaly and resulting myofascial pain and temporomandibular joint dysfunction: review of the literature and report of case.**
  Author(s): Hampton RE.
  Source: J Am Dent Assoc. 1987 May; 114(5): 625-31.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3474265&dopt=Abstract

- **Neurological features of acromegaly: a review and report of two cases.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1988 August; 11(4): 314-21. Review.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2844943&dopt=Abstract

- **Radiological features and diagnosis of acromegaly.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1988 June; 11(3): 206-13.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3392475&dopt=Abstract

Vocabulary Builder

Agar: A complex sulfated polymer of galactose units, extracted from Gelidium cartilagineum, Gracilaria confervoides, and related red algae. It is used as a gel in the preparation of solid culture media for microorganisms, as a bulk laxative, in making emulsions, and as a supporting medium for immunodiffusion and immunoelectrophoresis. [NIH]

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

Hyperplasia: The abnormal multiplication or increase in the number of normal cells in normal arrangement in a tissue. [EU]

Infusion: The therapeutic introduction of a fluid other than blood, as saline

solution, solution, into a vein. [EU]

Intravenous: Within a vein or veins. [EU]

LH: A small glycoprotein hormone secreted by the anterior pituitary. LH plays an important role in controlling ovulation and in controlling secretion of hormones by the ovaries and testes. [NIH]

Localization: 1. the determination of the site or place of any process or lesion. 2. restriction to a circumscribed or limited area. 3. prelocalization. [EU]

Neoplasms: New abnormal growth of tissue. Malignant neoplasms show a greater degree of anaplasia and have the properties of invasion and metastasis, compared to benign neoplasms. [NIH]

Neoplastic: Pertaining to or like a neoplasm (= any new and abnormal growth); pertaining to neoplasia (= the formation of a neoplasm). [EU]

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

Prolactinoma: A pituitary adenoma which secretes prolactin, leading to hyperprolactinemia. Clinical manifestations include amenorrhea; galactorrhea; impotence; headache; visual disturbances; and cerebrospinal fluid rhinorrhea. [NIH]

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

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]

Thyrotropin: A peptide hormone secreted by the anterior pituitary. It promotes the growth of the thyroid gland and stimulates the synthesis of thyroid hormones and the release of thyroxine by the thyroid gland. [NIH]

Xenopus: An aquatic genus of the family, Pipidae, occurring in Africa and distinguished by having black horny claws on three inner hind toes. [NIH]

CHAPTER 5. PATENTS ON ACROMEGALY

Overview

You can learn about innovations relating to acromegaly 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 acromegaly 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 acromegaly. 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 Acromegaly

By performing a patent search focusing on acromegaly, 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 acromegaly:

- **Treating acromegaly**

  Inventor(s): Lancranjan; Ioana (Basel, CH)

  Assignee(s): Sandoz Ltd. (Basel, CH)

  Patent Number: 4,122,190

  Date filed: October 3, 1977

  Abstract: .alpha.-Adrenoceptor agonists are useful in the treatment of acromegaly.

  Excerpt(s): These tablets and capsules (each containing the equivalent of 2 mg BS 100-141 as the free base) are useful in the treatment of acromegaly when administered 3 times a day.

  Web site: http://www.delphion.com/details?pn=US04122190__

Patent Applications on Acromegaly

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 acromegaly, you can access the U.S. Patent Office archive via the Internet at

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

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 "acromegaly" (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 acromegaly. You can also use this procedure to view pending patent applications concerning acromegaly. 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.

CHAPTER 6. BOOKS ON ACROMEGALY

Overview

This chapter provides bibliographic book references relating to acromegaly. You have many options to locate books on acromegaly. 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 acromegaly 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: 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 acromegaly (sorted alphabetically by title; follow the hyperlink to view more details at Amazon.com):

- **Acromegaly : an ultrastructural analysis of 51 adenomas and a clinical study in 80 patients treated by transanthrosphenoidal operation** by Jan Kinnman; ISBN: 9172220384;

http://www.amazon.com/exec/obidos/ASIN/9172220384/icongroupinterna

- **Acromegaly and its management** by A. G. Harris; ISBN: 0397518145; http://www.amazon.com/exec/obidos/ASIN/0397518145/icongroupinterna
- **Acromegaly: A Century of Scientific and Clinical Progress** by Richard J. Robbins (Editor) (1987); ISBN: 0306426188; http://www.amazon.com/exec/obidos/ASIN/0306426188/icongroupinterna
- **Acromegaly: Proceedings of the Symposium on Somatostatin Analogues (Hormone Research; Vol 33, Suppl.1, 1990)** by G. Michael Besser (Editor) (1990); ISBN: 3805552076; http://www.amazon.com/exec/obidos/ASIN/3805552076/icongroupinterna
- **Endocrinology '85: Proceedings of the International Congress Endocrinilogy '85, Torino, 5-8 June 1985 (International Congress Series, No 683)** by G.M. Molinatti, L. Martini (Editor); ISBN: 0444808116; http://www.amazon.com/exec/obidos/ASIN/0444808116/icongroupinterna
- **Growth Hormone, Growth Factors, Acromegaly (Progress in Endocrine Research and Therapy Volume 3)** by Dieter K. Ludecke, George Tolis (Editor) (1987); ISBN: 0881672998; http://www.amazon.com/exec/obidos/ASIN/0881672998/icongroupinterna
- **Handbook of Acromegaly** ; ISBN: 1901978117; http://www.amazon.com/exec/obidos/ASIN/1901978117/icongroupinterna
- **Sandostatin in the Treatment of Acromegaly: Consensus Round Table Amsterdam 1987** by Steven W.J. Lamberts (Editor) (1989); ISBN: 0387192697; http://www.amazon.com/exec/obidos/ASIN/0387192697/icongroupinterna
- **Treating Acromegaly: 100 Years on** by J. A. Wass (Editor) (1994); ISBN: 1898099057; http://www.amazon.com/exec/obidos/ASIN/1898099057/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 "acromegaly" (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]

- **Acromegaly: a century of scientific and clinical progress.** Author: edited by Richard J. Robbins and Shlomo Melmed; Year: 1987; New York: Plenum Press, c1987; ISBN: 0306426188 http://www.amazon.com/exec/obidos/ASIN/0306426188/icongroupinterna
- **Acromegaly and its management.** Author: Alan G. Harris; scientific editor, Adrian F. Daly; Year: 1996; Philadelphia: Lippincott-Raven, c1996; ISBN: 0397518145 http://www.amazon.com/exec/obidos/ASIN/0397518145/icongroupinterna
- **Acromegaly, a personal experience.** Author: Mark, Leonard Portal; Year: 1912; London, Baillière, Tindall and Cox, 1912
- **Acromegaly, by F. R. B. Atkinson ... with a foreword by Sir Arthur Keith.** Author: Atkinson, Frederick Richard Breeks; Year: 1932; London, J. Bale, sons & Danielsson, ltd., 1932
- **Acromegaly.** Author: Hinsdale, Guy, 1858-1948; Year: 1898; Detroit, Warren, 1898
- **Acromegaly.** Author: Sternberg, Maximilian, b. 1863; Year: 1899; London, 1899
- **Acromegaly; an ultrastructural analysis of 51 adenomas and a clinical study in 80 patients treated by transanthro-sphenoidal operation.** Author: Kinnman, Jan; Year: 1973; Stockholm, 1973; ISBN: 9172220384

---

[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 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/9172220384/icongroupinterna

- **Adjunctive medical therapy of acromegalic patients.** Author: J.W.R. Nortier; Year: 1984; Dordrecht, Holland; Cinnaminson, N.J., U.S.A.: Foris Publications, 1984; ISBN: 9067650935 (pbk.)
- **Bone remodelling and calcium, phosphate and collagen metabolism in acromegaly.** Author: by Johan Halse; Year: 1981; Oslo: [s.n.], 1981
- **Endocrine glands in acromegaly; a pathologic study of twenty-two cases.** Author: Beddow, R. M; Year: 1955; [Minneapolis] 1955
- **Essays on acromegaly, by P. Marie and Dr. Souza-Leite. With bibliography and appendix of cases by other authors.** Author: Marie, Pierre, 1853-1940; Year: 1891; London, 1891
- **Growth hormone, growth factors, and acromegaly.** Author: editors, Dieter K. Lüdecke, George Tolis; Year: 1987; New York: Raven Press, c1987; ISBN: 0881672998
  http://www.amazon.com/exec/obidos/ASIN/0881672998/icongroupinterna
- **Histopathologic study of pituitary adenomas associated with acromegaly.** Author: Young, Donald George, 1932-; Year: 1964; [Minneapolis] 1964
- **Morphological and histochemical study of the human costochondral junction in patients without growth disturbances and in acromegalic patients.** Author: Jones, Donald Richard, 1929-; Year: 1962; [Minneapolis] 1962
- **Pathophysiological studies in acromegaly pertaining to the extracellular water, renal function and basal metabolism.** Author: Ikkos, Denis; Year: 1956; Stockholm, 1956
- **Pituitary.** Author: edited by Shlomo Melmed; Year: 2002; Malden, Mass.: Blackwell Science, c2002; ISBN: 0632043571 (hardcover)
  http://www.amazon.com/exec/obidos/ASIN/0632043571/icongroupinterna
- **Sandostatin in the treatment of acromegaly: consensus round table, Amsterdam, 1987.** Author: editor, Steven W.J. Lamberts; Year: 1988; Berlin; New York: Springer-Verlag, c1988; ISBN: 0387192697 (U.S.)
  http://www.amazon.com/exec/obidos/ASIN/0387192697/icongroupinterna
- **Tumors of the nervous system. Edited by H. Gunter Seydel.** Author: Cancer Symposium (4th: 1973: American Oncologic Hospital, Philadelphia); Year: 1975; New York, Wiley [c1975]; ISBN: 0471778486

http://www.amazon.com/exec/obidos/ASIN/0471778486/icongroupinterna

Chapters on Acromegaly

Frequently, acromegaly will be discussed within a book, perhaps within a specific chapter. In order to find chapters that are specifically dealing with acromegaly, an excellent source of abstracts is the Combined Health Information Database. You will need to limit your search to book chapters and acromegaly 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 "acromegaly" (or synonyms) into the "For these words:" box, you will only receive results on chapters in books.

General Home References

In addition to references for acromegaly, 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):

- **Endocrine and Metabolic Disorders Sourcebook: Basic Information for the Layperson About Pancreatic and Insulin-Related Disorders** by Linda M. Shin (Editor), Linda M. Ross (Editor); Library Binding - 574 pages, 1st edition (July 1998), Omnigraphics, Inc.; ISBN: 0780802071; **http://www.amazon.com/exec/obidos/ASIN/0780802071/icongroupinterna**
- **Endocrine Secrets** by Michael T. McDermott, M.D.; 3rd edition (July 2001), Hanley & Belfus; ISBN: 1560534494; **http://www.amazon.com/exec/obidos/ASIN/1560534494/icongroupinterna**
- **How the Endocrine System Works** by J. Matthew Neal, M.D.; 104 pages -- 1st edition (June 15, 2001); Blackwell Science Inc.; ISBN: 0632045566; **http://www.amazon.com/exec/obidos/ASIN/0632045566/icongroupinterna**

Vocabulary Builder

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]

Pathologic: 1. indicative of or caused by a morbid condition. 2. pertaining to pathology (= branch of medicine that treats the essential nature of the disease, especially the structural and functional changes in tissues and organs of the body caused by the disease). [EU]

CHAPTER 7. 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**

---

[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 acromegaly, the following are particularly noteworthy.

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,

[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).

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 "acromegaly" (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	343187
Books / Periodicals / Audio Visual	2561
Consumer Health	292
Meeting Abstracts	3093
Other Collections	100
Total	349233

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 "acromegaly" (or synonyms) at the following Web site: **http://text.nlm.nih.gov**.

---

[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.

[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)

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 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**.

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.

- **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 Acromegaly

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 acromegaly. 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 "acromegaly" (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

[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.

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 acromegaly:

- **Acromegaly**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?102200
- **Pseudoacromegaly with Severe Insulin Resistance**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?602511

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. This Web site categorizes each disorder by the system of the body associated with it. 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**
- **Metabolism:** Food and energy.
  Examples: Adreno-leukodystrophy, Atherosclerosis, Best disease, Gaucher disease, Glucose galactose malabsorption, Gyrate atrophy, Juvenile onset diabetes, Obesity, Paroxysmal nocturnal hemoglobinuria, Phenylketonuria, Refsum disease, Tangier disease, Tay-Sachs disease.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Metabolism.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 "acromegaly" (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

---

[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 "acromegaly" (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 acromegaly (sorted alphabetically by title, hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Basic & Clinical Endocrinology** by Francis S. Greenspan, M.D. (Editor), David G. Gardner, M.D. (Editor); Paperback - 891 pages, 6th edition (November 2000), Appleton & Lange; ISBN: 083850597X; **http://www.amazon.com/exec/obidos/ASIN/083850597X/icongroupinterna**
- **Current Therapy in Endocrinology and Metabolism (Current Therapy Series)** by C. Wayne Bardin (Editor); Hardcover, 6th edition (April 1997), Mosby-Year Book; ISBN: 0815120168; **http://www.amazon.com/exec/obidos/ASIN/0815120168/icongroupinterna**
- **Endocrine Pathology** by Virginia A. Livolsi, et al; 640 pages -- 1st edition (January 25, 2002); Churchill Livingstone; ISBN: 0443065950; **http://www.amazon.com/exec/obidos/ASIN/0443065950/icongroupinterna**
- **Endocrinology Science and Medicine: A Review of Fundamental Principles** by E. Victor Adlin, M.D.; Paperback - 188 pages, 1st edition (March 15, 2001), Lippincott, Williams & Wilkins Publishers; ISBN: 0781719259; **http://www.amazon.com/exec/obidos/ASIN/0781719259/icongroupinterna**

- **Handbook of Physiology Sect 7: Rev Ed Endocrinology Vol 1: Cellular Endocrinology** by P. Michael Conn (Editor), H. Maurice Goodman (Editor); Hardcover - 601 pages, 1st edition, Vol. 1 (April 15, 1998), American Physiological Society; ISBN: 019510935X; **http://www.amazon.com/exec/obidos/ASIN/019510935X/icongroupinterna**
- **Textbook of Endocrine Physiology** James E. Griffin, M.D. (Editor); 4th edition (August 15, 2000), Oxford University Press; ISBN: 0195135415; **http://www.amazon.com/exec/obidos/ASIN/0195135415/icongroupinterna**
- **Williams Textbook of Endocrinology** by Jean D. Wilson (Editor), et al; Hardcover - 1819 pages, 9th edition (May 15, 1998), W B Saunders Co; ISBN: 0721661521; **http://www.amazon.com/exec/obidos/ASIN/0721661521/icongroupinterna**

CHAPTER 8. DISSERTATIONS ON ACROMEGALY

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 acromegaly. 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 Acromegaly

ProQuest Digital Dissertations is the largest archive of academic dissertations available. From this archive, we have compiled the following list covering dissertations devoted to acromegaly. 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 acromegaly:

- **Conformational Studies of Biologically Significant Peptide Structures (drug Design)** by Zhang, Li; Phd from University of California, San Diego, 2001, 203 pages
  http://wwwlib.umi.com/dissertations/fullcit/3001260

- **Growth Hormone and Gender: Studies in Healthy Adults and in Patients with Growth Hormone Disorders** by Eden Engstrom, Britt Margareta; Phd from Uppsala Universitet (sweden), 2001, 63 pages http://wwwlib.umi.com/dissertations/fullcit/f93505

Keeping Current

As previously mentioned, an effective way to stay current on dissertations dedicated to acromegaly 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.

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 acromegaly 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 acromegaly. 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 acromegaly. Research can give you information on the side effects, interactions, and limitations of prescription drugs used in the treatment of acromegaly. 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 acromegaly. 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 acromegaly 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 acromegaly. 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.

---

[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 acromegaly). 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 acromegaly. 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 (USP). It is important to read the disclaimer by the USP (**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 acromegaly. 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 acromegaly:

Bromocriptine

- **Systemic - U.S. Brands:** Parlodel
  http://www.nlm.nih.gov/medlineplus/druginfo/bromocriptinesystemic202094.html

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

Growth Hormone

- **Systemic - U.S. Brands:** Genotropin; Genotropin Miniquick; Humatrope; Norditropin; Nutropin; Nutropin AQ; Protropin; Saizen; Serostim
  http://www.nlm.nih.gov/medlineplus/druginfo/growthhormonesystemic202269.html

Insulin

- **Systemic - U.S. Brands:** Humulin 50/50; Humulin 70/30; Humulin 70/30 Pen; Humulin L; Humulin N; Humulin N Pen; Humulin R; Humulin R, Regular U-500 (Concentrated); Humulin U; Lente; Lente Iletin II; Novolin 70/30; Novolin 70/30 PenFill; Novolin 70/30 Prefilled; Novolin L; Novoli
  http://www.nlm.nih.gov/medlineplus/druginfo/insulinsystemic203298.html

Octreotide

- **Systemic - U.S. Brands:** Sandostatin
  http://www.nlm.nih.gov/medlineplus/druginfo/octreotidesystemic202421.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 acromegaly (including those with contraindications):[44]

- **Bromocriptine Mesylate**
  http://www.reutershealth.com/atoz/html/Bromocriptine_Mesylate.htm
- **Octreotide Acetate**
  http://www.reutershealth.com/atoz/html/Octreotide_Acetate.htm

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

- **Somatrem**
  http://www.reutershealth.com/atoz/html/Somatrem.htm
- **Somatropin**
  http://www.reutershealth.com/atoz/html/Somatropin.htm
- **Bromocriptine Mesylate**
  http://www.reutershealth.com/atoz/html/Bromocriptine_Mesylate.htm
- **Octreotide Acetate**
  http://www.reutershealth.com/atoz/html/Octreotide_Acetate.htm
- **Somatrem**
  http://www.reutershealth.com/atoz/html/Somatrem.htm
- **Somatropin**
  http://www.reutershealth.com/atoz/html/Somatropin.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 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 acromegaly--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 used to treat acromegaly or potentially create deleterious side effects in patients with acromegaly. 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 acromegaly. 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 acromegaly. The FDA warns patients to watch out for[45]:

- Secret formulas (real scientists share what they know)
- 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),

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

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:

Pharmacist: A person trained to prepare and distribute medicines and to give information about them. [NIH]

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

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 acromegaly. Finally, at the conclusion of this chapter, we will provide a list of readings on acromegaly 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 Acromegaly

Having read the previous discussion, you may be wondering which complementary or alternative treatments might be appropriate for acromegaly. 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 acromegaly 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 "acromegaly" (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 acromegaly:

- **Acromegaly and resulting myofascial pain and temporomandibular joint dysfunction: review of the literature and report of case.**
  Author(s): Hampton RE.

Source: J Am Dent Assoc. 1987 May; 114(5): 625-31.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3474265&dopt=Abstract

- **Hyperostosis of lumbar spinous process: a radiological feature in a young acromegalic.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1987 June; 10(3): 111-5.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3611984&dopt=Abstract

- **Manipulative treatment of backache in a young acromegalic: a case report.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1986 December; 9(4): 279-84.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2949039&dopt=Abstract

- **Measurement of free form of insulin-like growth factor I in human plasma.**
  Author(s): Hizuka N, Takano K, Asakawa K, Sukegawa I, Fukuda I, Demura H, Iwashita M, Adachi T, Shizume K.
  Source: Growth Regul. 1991 June; 1(2): 51-5.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1668800&dopt=Abstract

- **Neurological features of acromegaly: a review and report of two cases.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1988 August; 11(4): 314-21. Review.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2844943&dopt=Abstract

- **Postmyelographic cauda equina syndrome in an asymptomatic acquired spinal stenosis of a young acromegalic.**
  Author(s): Woo CC.

Source: Journal of Manipulative and Physiological Therapeutics. 1988 April; 11(2): 118-23.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3385339&dopt=Abstract

- **Radiological features and diagnosis of acromegaly.**
  Author(s): Woo CC.
  Source: Journal of Manipulative and Physiological Therapeutics. 1988 June; 11(3): 206-13.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3392475&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 acromegaly; 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:

- **Related Conditions**

  Arthritis, Osteo-
  Source: Integrative Medicine Communications; www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsConditions/Osteoarthritiscc.html

  Osteoarthritis
  Source: Integrative Medicine Communications; www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsConditions/Osteoarthritiscc.html

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
- **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:

Bradycardia: Slowness of the heart beat, as evidenced by slowing of the pulse rate to less than 60. [EU]

Lumbar: Pertaining to the loins, the part of the back between the thorax and the pelvis. [EU]

Stenosis: Narrowing or stricture of a duct or canal. [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 acromegaly. 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 acromegaly may be given different recommendations. Some recommendations may be directly related to acromegaly, 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 acromegaly. We will then show you how to find studies dedicated specifically to nutrition and acromegaly.

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

---

[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."

the use of plant products, in particular, has a long tradition. However, the 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 Acromegaly

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

[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.

periodically as this database is frequently updated. More studies can be 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 "acromegaly" (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 "acromegaly" (or a synonym):

- **Acromegaly and hyperprolactinemia in a patient with polyostotic fibrous dysplasia: dynamic endocrine studies and treatment with the somatostatin analogue octreotide.**
  Author(s): Department of Endocrinology, University Hospital Utrecht, The Netherlands.
  Source: Garcia, M B Koppeschaar, H P Lips, C J Thijssen, J H Krenning, E P J-Endocrinol-Invest. 1994 January; 17(1): 59-65 0391-4097
- **Acromegaly and transsphenoidal hypophysectomy: a case report.**
  Source: Baxter, M A AANA-J. 1994 April; 62(2): 182-5 0094-6354
- **Acromegaly.**
  Author(s): Department of Endicrinology, Nuclear Medicine Center, Lyon, France.
  Source: Sassolas, G Curr-Ther-Endocrinol-Metab. 1994; 544-8 0831-652X
- **ACTH secretion, circadian variations of salivary free and total serum cortisol and urinary 17-OHCS excretion in active acromegaly following bromocriptine treatment.**
  Author(s): Department of Pathophysiology and Clinical Biochemistry, Silesian Academy of Medicine, Zabrze, Poland.
  Source: Ostrowska, Z Zwirska Korzala, K Buntner, B Endocr-Regul. 1994 June; 28(2): 89-95 1210-0668
- **Assessment of growth hormone status in acromegaly: what biochemical markers to measure and how?**
  Author(s): Department of Endocrinology, St Bartholomew's Hospital, London, UK. C.Camacho-Hubner@mds.qmw.ac.uk
  Source: Camacho Hubner, C Growth-Horm-IGF-Res. 2000 April; 10 Suppl BS125-9 1096-6374
- **Bromocriptine treatment over 12 years in acromegaly: effect on glucose tolerance and insulin secretion.**
  Author(s): Abteilung fur Endokrinologie, Klinikum der Johann Wolfgang Goethe-Universitat, Frankfurt/Main.

Source: Rau, H Althoff, P H Schmidt, K Badenhoop, K Usadel, K H Clin-Investig. 1993 May; 71(5): 372-8 0941-0198

- **Cardiovascular effects of a single slow release lanreotide injection in patients with acromegaly and left ventricular hypertrophy.**
  Author(s): University of Brescia, Italy.
  Source: Manelli, F Desenzani, P Boni, E Bugari, G Negrini, F Romanelli, G Grassi, V Giustina, A Pituitary. 1999 November; 2(3): 205-10 1386-341X

- **Cardiovascular risk factors in acromegaly before and after normalization of serum IGF-I levels with the GH antagonist pegvisomant.**
  Author(s): Neuroendocrine Clinical Center, Massachusetts General Hospital and Harvard Medical School, Boston, Massachusetts 02114, USA.
  Source: Sesmilo, Gemma Fairfield, Wesley P Katznelson, Laurence Pulaski, Karen Freda, Pamela U Bonert, Vivien Dimaraki, Eleni Stavrou, Stavros Vance, Mary Lee Hayden, Douglas Klibanski, Anne J-Clin-Endocrinol-Metab. 2002 April; 87(4): 1692-9 0021-972X

- **Clinical significance of the growth hormone response to vasoactive intestinal peptide and gonadotropin-releasing hormone in acromegaly.**
  Author(s): Third Department of Internal Medicine, Hirosaki University School of Medicine, Aomori, Japan.
  Source: Watanobe, H Tamura, T Neuropeptides. 1995 February; 28(2): 115-24 0143-4179

- **Contradictory clinical implications between paradoxical growth hormone responses to thyrotropin-releasing hormone and those to vasoactive intestinal peptide and luteinizing hormone-releasing hormone in acromegaly.**
  Author(s): Third Department of Internal Medicine, Hirosaki University School of Medicine, Aomori, Japan.
  Source: Watanobe, H Tamura, T Sasaki, S Takebe, K Neuropeptides. 1993 December; 25(6): 363-75 0143-4179

- **Current management of acromegaly.**
  Author(s): Department of Endocrinology, Hospital La Paz, Madrid, Spain. mibarsd@infomed-dental.com
  Source: Diez, J J Iglesias, P Expert-Opin-Pharmacother. 2000 July; 1(5): 991-1006 1465-6566

- **Diabetic ketoacidosis in a patient with acromegaly.**
  Author(s): Department of Metabolic Diseases and Gastroenterology, Medical University of Lodz, ul. Kopcinskiego 22, 90-153 Lodz, Poland.
  Source: Kopff, B Mucha, S Wolffenbuttel, B H Drzewoski, J Med-Sci-Monit. 2001 Jan-February; 7(1): 142-7 1234-1010

- **Differential presentation of cortical and trabecular peripheral bone mineral density in acromegaly.**
  Author(s): Klinik II und Poliklinik f-ur Innere Medizin, Universit-at zu K-oln, Joseph-Stelzmann-Str. 9, K-oln D-50924, Germany.
  Source: Jockenhovel, F Rohrbach, S Deggerich, S Reinwein, D Reiners, C Eur-J-Med-Res. 1996 May 24; 1(8): 377-82 0949-2321

- **Effect of a six-month treatment with lanreotide on cardiovascular risk factors and arterial intima-media thickness in patients with acromegaly.**
  Author(s): Department of Molecular and Clinical Endocrinology and Oncology, 'Federico II' University of Naples, Via Sergio Pansini 5, 80131, Naples, Italy. colao@unina.it
  Source: Colao, Annamaria Marzullo, Paolo Lombardi, Gaetano Eur-J-Endocrinol. 2002 Mar; 146(3): 303-9 0804-4643

- **Efficacy and tolerability of the long-acting somatostatin analog lanreotide in acromegaly. A 12-month multicenter study of 58 acromegalic patients. French Multicenter Study Group on Lanreotide in Acromegaly.**
  Author(s): Service d'Endocrinologie et des Maladies de la Reproduction, CHU Bicetre, Le Kremlin-Bicetre, France. pchanson@club-internet.fr
  Source: Chanson, P Leselbaum, A Blumberg, J Schaison, G Pituitary. 2000 May; 2(4): 269-76 1386-341X

- **Evaluation of a repeatable depot-bromocriptine preparation(Parlodel LAR) for the treatment of acromegaly.**
  Author(s): Department of Internal Medicine, Klinikum Steglitz, Freie Universitat, Berlin, Germany.
  Source: Plockinger, U Quabbe, H J J-Endocrinol-Invest. 1991 December; 14(11): 943-8 0391-4097

- **Gonadotrophin and free alpha-subunit secretion in patients with acromegaly and clinically non-functioning pituitary tumors: anterior pituitary function and the effect of thyrotrophin-releasing hormone.**
  Author(s): Department of Neuroendocrinology, University of Belgrade, Serbia-SR, Yugoslavia.
  Source: Damjanovic, S S Popovic, V P Petakov, M S Nikolic Durovic, M M Doknic, M Z Gligorovic, M S J-Endocrinol-Invest. 1996 Nov; 19(10): 663-9 0391-4097

- **Hexarelin, a novel GHRP-6 analog, counteracts the inhibitory effect of hydrocortisone on growth hormone secretion in acromegaly.**
  Author(s): Cattedra di Clinica Medica, University of Brescia, Italy.
  Source: Giustina, A Bresciani, E Bugari, G Bussi, A R Deghenghi, R Imbimbo, B Giustina, G Endocr-Res. 1995 August; 21(3): 569-82 0743-5800

- **Lack of involvement of the cholinergic mechanism in vasoactive intestinal peptide- and peptide-histidine methionine-induced growth hormone (GH) responses in acromegaly: comparison with the GH responses to thyrotropin-releasing hormone and GH-releasing hormone.**
  Author(s): Third Department of Internal Medicine, Hirosaki University School of Medicine, Aomori, Japan.
  Source: Watanobe, H Habu, S Nasushita, R Takebe, K Neuropeptides. 1994 August; 27(2): 85-90 0143-4179
- **Long-acting octreotide LAR compared with lanreotide SR in the treatment of acromegaly.**
  Author(s): Department of Medicine, Medical School-University of Newcastle, Newcastle upon Tyne, U.K. pat.kendall-taylor@ncl.ac.uk
  Source: Kendall Taylor, P Miller, M Gebbie, J Turner, S al Maskari, M Pituitary. 2000 October; 3(2): 61-5 1386-341X

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:

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

Bacteria: Unicellular prokaryotic microorganisms which generally possess rigid cell walls, multiply by cell division, and exhibit three principal forms: round or coccal, rodlike or bacillary, and spiral or spirochetal. [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]

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]

Cholinergic: Resembling acetylcholine in pharmacological action; stimulated by or releasing acetylcholine or a related compound. [EU]

Cortical: Pertaining to or of the nature of a cortex or bark. [EU]

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

Diarrhea: Passage of excessively liquid or excessively frequent stools. [NIH]

Fats: One of the three main classes of foods and a source of energy in the body. Fats help the body use some vitamins and keep the skin healthy. They also serve as energy stores for the body. In food, there are two types of fats: saturated and unsaturated. [NIH]

Histidine: An essential amino acid important in a number of metabolic processes. It is required for the production of histamine. [NIH]

Hydrocortisone: The main glucocorticoid secreted by the adrenal cortex. Its synthetic counterpart is used, either as an injection or topically, in the treatment of inflammation, allergy, collagen diseases, asthma, adrenocortical deficiency, shock, and some neoplastic conditions. [NIH]

Hypertrophy: Nutrition) the enlargement or overgrowth of an organ or part due to an increase in size of its constituent cells. [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]

Methionine: A sulfur containing essential amino acid that is important in many body functions. It is a chelating agent for heavy metals. [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]

Neuroendocrinology: The study of the anatomical and functional relationships between the nervous system and the endocrine system. [NIH]

Neuropeptides: Peptides released by neurons as intercellular messengers. Many neuropeptides are also hormones released by non-neuronal cells. [NIH]

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]

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]

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]

Vasoactive: Exerting an effect upon the calibre of blood vessels. [EU]

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 acromegaly 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.

---

[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.

---

[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.

---

[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

---

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

Vocabulary Builder

17-Hydroxycorticosteroids: A group of hydroxycorticosteroids bearing a hydroxy group at the 17-position. Urinary excretion of these compounds is used as an index of adrenal function. They are used systemically in the free alcohol form, but with esterification of the hydroxy groups, topical effectiveness is increased. [NIH]

17-Ketosteroids: Steroids that contain a ketone group at position 17. [NIH]

Arthralgia: Pain in a joint. [EU]

Chronic: Persisting over a long period of time. [EU]

Hoarseness: An unnaturally deep or rough quality of voice. [NIH]

Shoulder Pain: Unilateral or bilateral pain of the shoulder. It is often caused by physical activities such as work or sports participation, but may also be pathologic in origin. [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 acromegaly and keep them on file. The NIH, in particular, suggests that patients with acromegaly visit the following Web sites in the ADAM Medical Encyclopedia:

- **Basic Guidelines for Acromegaly**

  Acromegaly
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000321.htm

- **Signs & Symptoms for Acromegaly**

  Ankle pain
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003167.htm

  Arthralgia
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003261.htm

  Double vision
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003029.htm

  Easy fatigue
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003088.htm

  Elbow pain
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003172.htm

  Excessive sweating
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003218.htm

  Fatigue
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003088.htm

  Foot pain
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003183.htm

Hair, excessive on females
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003148.htm

Headache
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003024.htm

High blood pressure
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003082.htm

Hip pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003179.htm

Hoarseness
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003054.htm

Joint pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003261.htm

Knee pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003187.htm

Muscle
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003193.htm

Muscle weakness
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003174.htm

Prognathism
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003026.htm

Shoulder pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003171.htm

Skin, abnormally dark or light
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003242.htm

Swelling
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003103.htm

Tongue problems
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003047.htm

Vision abnormalities
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003029.htm

Vomiting
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003117.htm

Weakness
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003174.htm

Weight gain (unintentional)
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003084.htm

Widely spaced teeth
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003063.htm

Wrist pain
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003175.htm

- **Diagnostics and Tests for Acromegaly**

17-hydroxycorticosteroids
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003459.htm

17-ketosteroids
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003460.htm

ALT
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003473.htm

Cranial CT scan
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003786.htm

Cranial MRI
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003791.htm

Creatinine
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003475.htm

Creatinine - urine
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003610.htm

CT
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003330.htm

ECT
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003324.htm

GH
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003706.htm

Growth hormone
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003706.htm

MRI
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003335.htm

Spine x-ray
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003806.htm

X-ray
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003337.htm

- **Background Topics for Acromegaly**

Anterior
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002232.htm

Cardiovascular
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002310.htm

Chronic
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002312.htm

Radiation therapy
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/001918.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**

ACROMEGALY 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.

17-Hydroxycorticosteroids: A group of hydroxycorticosteroids bearing a hydroxy group at the 17-position. Urinary excretion of these compounds is used as an index of adrenal function. They are used systemically in the free alcohol form, but with esterification of the hydroxy groups, topical effectiveness is increased. [NIH]

17-Ketosteroids: Steroids that contain a ketone group at position 17. [NIH]

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

ACTH: Adrenocorticotropic hormone. [EU]

Adenoma: A benign epithelial tumour in which the cells form recognizable glandular structures or in which the cells are clearly derived from glandular epithelium. [EU]

Agar: A complex sulfated polymer of galactose units, extracted from Gelidium cartilagineum, Gracilaria confervoides, and related red algae. It is used as a gel in the preparation of solid culture media for microorganisms, as a bulk laxative, in making emulsions, and as a supporting medium for immunodiffusion and immunoelectrophoresis. [NIH]

Aggressiveness: The quality of being aggressive (= characterized by aggression; militant; enterprising; spreading with vigour; chemically active; variable and adaptable). [EU]

Agonist: In anatomy, a prime mover. In pharmacology, a drug that has affinity for and stimulates physiologic activity at cell receptors normally stimulated by naturally occurring substances. [EU]

Arginine: An essential amino acid that is physiologically active in the L-form. [NIH]

Arthralgia: Pain in a joint. [EU]

Asymptomatic: No symptoms; no clear sign of disease present. [NIH]

Bacteria: Unicellular prokaryotic microorganisms which generally possess rigid cell walls, multiply by cell division, and exhibit three principal forms: round or coccal, rodlike or bacillary, and spiral or spirochetal. [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]

Bradycardia: Slowness of the heart beat, as evidenced by slowing of the pulse rate to less than 60. [EU]

Bromocriptine: A semisynthetic ergot alkaloid that is a dopamine D2 agonist. It suppresses prolactin secretion and is used to treat amenorrhea, galactorrhea, and female infertility, and has been proposed for Parkinson disease. [NIH]

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]

Cardiovascular: Pertaining to the heart and blood vessels. [EU]

Cerebrospinal: Pertaining to the brain and spinal cord. [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]

Cholinergic: Resembling acetylcholine in pharmacological action; stimulated by or releasing acetylcholine or a related compound. [EU]

Chromosomal: Pertaining to chromosomes. [EU]

Chronic: Persisting over a long period of time. [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]

Congestion: Excessive or abnormal accumulation of blood in a part. [EU]

Cortical: Pertaining to or of the nature of a cortex or bark. [EU]

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

Diarrhea: Passage of excessively liquid or excessively frequent stools. [NIH]

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

Endogenous: Developing or originating within the organisms or arising

from causes within the organism. [EU]

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

Extracellular: Outside a cell or cells. [EU]

Facial: Of or pertaining to the face. [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]

Fats: One of the three main classes of foods and a source of energy in the body. Fats help the body use some vitamins and keep the skin healthy. They also serve as energy stores for the body. In food, there are two types of fats: saturated and unsaturated. [NIH]

Gastrointestinal: Pertaining to or communicating with the stomach and intestine, as a gastrointestinal fistula. [EU]

Gigantism: The condition of abnormal overgrowth or excessive size of the whole body or any of its parts. [NIH]

Glucose: D-glucose, a monosaccharide (hexose), C6H12O6, also known as dextrose (q.v.), found in certain foodstuffs, especially fruits, and in the normal blood of all animals. It is the end product of carbohydrate metabolism and is the chief source of energy for living organisms, its utilization being controlled by insulin. Excess glucose is converted to glycogen and stored in the liver and muscles for use as needed and, beyond that, is converted to fat and stored as adipose tissue. Glucose appears in the urine in diabetes mellitus. [EU]

Hematology: A subspecialty of internal medicine concerned with morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Histidine: An essential amino acid important in a number of metabolic processes. It is required for the production of histamine. [NIH]

Hoarseness: An unnaturally deep or rough quality of voice. [NIH]

Hormonal: Pertaining to or of the nature of a hormone. [EU]

Hormones: Chemical substances having a specific regulatory effect on the activity of a certain organ or organs. The term was originally applied to substances secreted by various endocrine glands and transported in the bloodstream to the target organs. It is sometimes extended to include those substances that are not produced by the endocrine glands but that have similar effects. [NIH]

Hydrocortisone: The main glucocorticoid secreted by the adrenal cortex. Its synthetic counterpart is used, either as an injection or topically, in the

treatment of inflammation, allergy, collagen diseases, asthma, adrenocortical deficiency, shock, and some neoplastic conditions. [NIH]

Hyperplasia: The abnormal multiplication or increase in the number of normal cells in normal arrangement in a tissue. [EU]

Hypersecretion: Excessive secretion. [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]

Hypertrophy: Nutrition) the enlargement or overgrowth of an organ or part due to an increase in size of its constituent cells. [EU]

Hypogonadism: A condition resulting from or characterized by abnormally decreased functional activity of the gonads, with retardation of growth and sexual development. [EU]

Hypothalamus: Ventral part of the diencephalon extending from the region of the optic chiasm to the caudal border of the mammillary bodies and forming the inferior and lateral walls of the third ventricle. [NIH]

Hypothyroidism: Deficiency of thyroid activity. In adults, it is most common in women and is characterized by decrease in basal metabolic rate, tiredness and lethargy, sensitivity to cold, and menstrual disturbances. If untreated, it progresses to full-blown myxoedema. In infants, severe hypothyroidism leads to cretinism. In juveniles, the manifestations are intermediate, with less severe mental and developmental retardation and only mild symptoms of the adult form. When due to pituitary deficiency of thyrotropin secretion it is called secondary hypothyroidism. [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]

Insulin: A protein hormone secreted by beta cells of the pancreas. Insulin plays a major role in the regulation of glucose metabolism, generally promoting the cellular utilization of glucose. It is also an important regulator of protein and lipid metabolism. Insulin is used as a drug to control insulin-dependent diabetes mellitus. [NIH]

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]

Ketoacidosis: See: Diabetic ketoacidosis. [NIH]

Levodopa: The naturally occurring form of dopa and the immediate precursor of dopamine. Unlike dopamine itself, it can be taken orally and crosses the blood-brain barrier. It is rapidly taken up by dopaminergic neurons and converted to dopamine. It is used for the treatment of parkinsonism and is usually given with agents that inhibit its conversion to dopamine outside of the central nervous system. [NIH]

LH: A small glycoprotein hormone secreted by the anterior pituitary. LH plays an important role in controlling ovulation and in controlling secretion of hormones by the ovaries and testes. [NIH]

Lipid: Any of a heterogeneous group of flats and fatlike substances characterized by being water-insoluble and being extractable by nonpolar (or fat) solvents such as alcohol, ether, chloroform, benzene, etc. All contain as a major constituent aliphatic hydrocarbons. The lipids, which are easily stored in the body, serve as a source of fuel, are an important constituent of cell structure, and serve other biological functions. Lipids may be considered to include fatty acids, neutral fats, waxes, and steroids. Compound lipids comprise the glycolipids, lipoproteins, and phospholipids. [EU]

Localization: 1. the determination of the site or place of any process or lesion. 2. restriction to a circumscribed or limited area. 3. prelocalization. [EU]

Lumbar: Pertaining to the loins, the part of the back between the thorax and the pelvis. [EU]

Meningitis: Inflammation of the meninges. When it affects the dura mater, the disease is termed pachymeningitis; when the arachnoid and pia mater are involved, it is called leptomeningitis, or meningitis proper. [EU]

Menstruation: The cyclic, physiologic discharge through the vagina of blood and mucosal tissues from the nonpregnant uterus; it is under hormonal control and normally recurs, usually at approximately four-week intervals, in the absence of pregnancy during the reproductive period (puberty through menopause) of the female of the human and a few species of primates. It is the culmination of the menstrual cycle. [EU]

Methionine: A sulfur containing essential amino acid that is important in many body functions. It is a chelating agent for heavy metals. [NIH]

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

Nausea: An unpleasant sensation, vaguely referred to the epigastrium and abdomen, and often culminating in vomiting. [EU]

Neoplasms: New abnormal growth of tissue. Malignant neoplasms show a greater degree of anaplasia and have the properties of invasion and metastasis, compared to benign neoplasms. [NIH]

Neoplastic: Pertaining to or like a neoplasm (= any new and abnormal growth); pertaining to neoplasia (= the formation of a neoplasm). [EU]

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

Neuroendocrinology: The study of the anatomical and functional relationships between the nervous system and the endocrine system. [NIH]

Neuropeptides: Peptides released by neurons as intercellular messengers. Many neuropeptides are also hormones released by non-neuronal cells. [NIH]

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]

Octreotide: A potent, long-acting somatostatin octapeptide analog which has a wide range of physiological actions. It inhibits growth hormone secretion, is effective in the treatment of hormone-secreting tumors from various organs, and has beneficial effects in the management of many pathological states including diabetes mellitus, orthostatic hypertension, hyperinsulinism, hypergastrinemia, and small bowel fistula. [NIH]

Oral: Pertaining to the mouth, taken through or applied in the mouth, as an oral medication or an oral thermometer. [EU]

Pancreas: An organ behind the lower part of the stomach that is about the size of a hand. It makes insulin so that the body can use glucose (sugar) for energy. It also makes enzymes that help the body digest food. Spread all over the pancreas are areas called the islets of Langerhans. The cells in these areas each have a special purpose. The alpha cells make glucagon, which raises the level of glucose in the blood; the beta cells make insulin; the delta cells make somatostatin. There are also the PP cells and the D1 cells, about which little is known. [NIH]

Pathologic: 1. indicative of or caused by a morbid condition. 2. pertaining to pathology (= branch of medicine that treats the essential nature of the disease, especially the structural and functional changes in tissues and organs of the body caused by the disease). [EU]

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

Pharmacist: A person trained to prepare and distribute medicines and to give information about them. [NIH]

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]

Prolactinoma: A pituitary adenoma which secretes prolactin, leading to hyperprolactinemia. Clinical manifestations include amenorrhea; galactorrhea; impotence; headache; visual disturbances; and cerebrospinal fluid rhinorrhea. [NIH]

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

Puberty: The period during which the secondary sex characteristics begin to develop and the capability of sexual reproduction is attained. [EU]

Radiology: A specialty concerned with the use of x-ray and other forms of radiant energy in the diagnosis and treatment of disease. [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]

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]

Secretion: 1. the process of elaborating a specific product as a result of the activity of a gland; this activity may range from separating a specific substance of the blood to the elaboration of a new chemical substance. 2. any substance produced by secretion. [EU]

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]

Shoulder Pain: Unilateral or bilateral pain of the shoulder. It is often caused

by physical activities such as work or sports participation, but may also be pathologic in origin. [NIH]

Skull: The skeleton of the head including the bones of the face and the bones enclosing the brain. [NIH]

Snoring: Rough, noisy breathing during sleep, due to vibration of the uvula and soft palate. [NIH]

Somatostatin: A polypeptide hormone produced in the hypothalamus, and other tissues and organs. It inhibits the release of human growth hormone, and also modulates important physiological functions of the kidney, pancreas, and gastrointestinal tract. Somatostatin receptors are widely expressed throughout the body. Somatostatin also acts as a neurotransmitter in the central and peripheral nervous systems. [NIH]

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]

Stenosis: Narrowing or stricture of a duct or canal. [EU]

Thyrotropin: A peptide hormone secreted by the anterior pituitary. It promotes the growth of the thyroid gland and stimulates the synthesis of thyroid hormones and the release of thyroxine by the thyroid gland. [NIH]

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]

Tomography: The recording of internal body images at a predetermined plane by means of the tomograph; called also body section roentgenography. [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]

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

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]

Withdrawal: 1. a pathological retreat from interpersonal contact and social involvement, as may occur in schizophrenia, depression, or schizoid avoidant and schizotypal personality disorders. 2. (DSM III-R) a substance-

specific organic brain syndrome that follows the cessation of use or reduction in intake of a psychoactive substance that had been regularly used to induce a state of intoxication. [EU]

Xenopus: An aquatic genus of the family, Pipidae, occurring in Africa and distinguished by having black horny claws on three inner hind toes. [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**

INDEX