

THE OFFICIAL  
PATIENT'S SOURCEBOOK  
*on*

OCULAR  
HISTOPLASMOSIS  
SYNDROME



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

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## Dedication

To the healthcare professionals dedicating their time and efforts to the study of ocular histoplasmosis syndrome.

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

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- The Official Patient's Sourcebook on Ocular Herpes
- The Official Patient's Sourcebook on Presbyopia
- The Official Patient's Sourcebook on Pterygium
- The Official Patient's Sourcebook on Retinal Detachment

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## INTRODUCTION

### Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, “The best prescription is knowledge.”<sup>1</sup> 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.<sup>2</sup>

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.<sup>3</sup>

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<sup>1</sup> Quotation from <http://www.drkoop.com>.

<sup>2</sup> The Agency for Healthcare Research and Quality (AHRQ):  
<http://www.ahrq.gov/consumer/diaginfo.htm>.

<sup>3</sup> 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 Ocular Histoplasmosis Syndrome* 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 ocular histoplasmosis syndrome, 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 ocular histoplasmosis syndrome.

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

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

## Scope

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

- Histoplasmosis with Retinitis
- Ocular Histoplasmosis

In addition to synonyms and related conditions, physicians may refer to ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome:<sup>4</sup>

- 115.90 histoplasmosis
- 115.92 histoplasmosis with retinitis

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 ocular histoplasmosis syndrome. 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.

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<sup>4</sup> 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."

Why “Internet age”? All too often, patients diagnosed with ocular histoplasmosis syndrome will log on to the Internet, type words into a search engine, and receive several Web site listings which are mostly irrelevant or redundant. These patients are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with ocular histoplasmosis syndrome 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.

While we focus on the more scientific aspects of ocular histoplasmosis syndrome, 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*



# **PART I: THE ESSENTIALS**

## **ABOUT PART I**

Part I has been edited to give you access to what we feel are “the essentials” on ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome to you or even given you a pamphlet or brochure describing ocular histoplasmosis syndrome. 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 OCULAR HISTOPLASMOSIS SYNDROME: GUIDELINES

### Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome 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)<sup>5</sup>

The National Institutes of Health (NIH) is the first place to search for relatively current patient guidelines and fact sheets on ocular histoplasmosis syndrome. 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.

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<sup>5</sup> Adapted from the NIH: <http://www.nih.gov/about/NIHoverview.html>.

Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

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 ocular histoplasmosis syndrome and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at **<http://www.nih.gov/health/consumer/conkey.htm>**
- National Eye Institute (NEI); guidelines available at **<http://www.nei.nih.gov/publications/publications.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>**

Among those listed above, the National Eye Institute is especially noteworthy. Established by Congress in 1968 to protect and prolong the vision of the American people, the National Eye Institute (NEI), one of the Federal government's National Institutes of Health (NIH), conducts and supports research that helps prevent and treat eye diseases and other disorders of vision.<sup>6</sup> Vision research is supported by the NEI through approximately 1600 research grants and training awards made to scientists at more than 250 medical centers, hospitals, universities, and other institutions across the country and around the world. The NEI also conducts laboratory and patient-oriented research at its own facilities located on the NIH campus in Bethesda, Maryland. This research leads to sight-saving treatments, reduces visual impairment and blindness, and improves the quality of life for people of all ages. NEI-supported research has advanced our knowledge of how the eye functions in health and disease. Another part of the NEI

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<sup>6</sup> Throughout the sourcebook, some of the text has been "adapted" from various official or governmental sources. Adapted signifies "reproduced" or "reproduced with minor editorial adjustments." This paragraph has been adapted from the NEI: **<http://www.nei.nih.gov/about/mission.htm>**; the NEI has also established the National Eye Health Education Program (NEHEP), a partnership of about 60 professional, civic, and voluntary organizations and government agencies concerned with eye health. The program represents a natural extension of the NEI's support of vision research -- a final step in the research continuum, where results are disseminated to health professionals, patients, and the public. Other NEI public education activities include a traveling exhibit, which have been viewed by more than 3.8 million people nationwide; and a school curriculum on vision for grades 4-8.

mission is to conduct public and professional education programs that help prevent blindness, reduce visual impairment, and increase awareness of services and devices that are available for people with low vision.

The National Institutes of Health has recently published the following guideline for ocular histoplasmosis syndrome:

### **What Is Histoplasmosis?<sup>7</sup>**

Histoplasmosis is a disease caused when airborne spores of the fungus *Histoplasma capsulatum* are inhaled into the lungs, the primary infection site. This microscopic fungus, which is found throughout the world in river valleys and soil where bird or bat droppings accumulate, is released into the air when soil is disturbed by plowing fields, sweeping chicken coops, or digging holes.

Histoplasmosis is often so mild that it produces no apparent symptoms. Any symptoms that might occur are often similar to those from a common cold. In fact, if you had histoplasmosis symptoms, you might dismiss them as those from a cold or flu, since the body's immune system normally overcomes the infection in a few days without treatment.

However, histoplasmosis, even mild cases, can later cause a serious eye disease called ocular histoplasmosis syndrome (OHS), a leading cause of vision loss in Americans ages 20 to 40.

### **How Does Histoplasmosis Cause Ocular Histoplasmosis Syndrome?**

Scientists believe that *Histoplasma capsulatum* (histo) spores spread from the lungs to the eye, lodging in the choroid, a layer of blood vessels that provides blood and nutrients to the retina. The retina is the light-sensitive layer of tissue that lines the back of the eye. Scientists have not yet been able to detect any trace of the histo fungus in the eyes of patients with ocular histoplasmosis syndrome. Nevertheless, there is good reason to suspect the histo organism as the cause of OHS.

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<sup>7</sup> Adapted from the National Eye Institute:  
<http://www.nei.nih.gov/health/histoplasmosis/index.htm>.

## **How Does OHS Develop?**

OHS develops when fragile, abnormal blood vessels grow underneath the retina. These abnormal blood vessels form a lesion known as choroidal neovascularization (CNV). If left untreated, the CNV lesion can turn into scar tissue and replace the normal retinal tissue in the macula. The macula is the central part of the retina that provides the sharp, central vision that allows us to read a newspaper or drive a car. When this scar tissue forms, visual messages from the retina to the brain are affected, and vision loss results.

Vision is also impaired when these abnormal blood vessels leak fluid and blood into the macula. If these abnormal blood vessels grow toward the center of the macula, they may affect a tiny depression called the fovea. The fovea is the region of the retina with the highest concentration of special retinal nerve cells, called cones, that produce sharp, daytime vision. Damage to the fovea and the cones can severely impair, and even destroy, this straight-ahead vision. Early treatment of OHS is essential; if the abnormal blood vessels have affected the fovea, controlling the disease will be more difficult. Since OHS rarely affects side, or peripheral vision, the disease does not cause total blindness.

## **What Are the Symptoms of OHS?**

OHS usually has no symptoms in its early stages; the initial OHS infection usually subsides without the need for treatment. This is true for other histo infections; in fact, often the only evidence that the inflammation ever occurred are tiny scars called “histo spots,” which remain at the infection sites. Histo spots do not generally affect vision, but for reasons that are still not well understood, they can result in complications years--sometimes even decades--after the original eye infection. Histo spots have been associated with the growth of the abnormal blood vessels underneath the retina.

In later stages, OHS symptoms may appear if the abnormal blood vessels cause changes in vision. For example, straight lines may appear crooked or wavy, or a blind spot may appear in the field of vision. Because these symptoms indicate that OHS has already progressed enough to affect vision, anyone who has been exposed to histoplasmosis and perceives even slight changes in vision should consult an eye care professional.

## **Who Is at Risk For OHS?**

Although only a tiny fraction of the people infected with the histo fungus ever develops OHS, any person who has had histoplasmosis should be alert for any changes in vision similar to those described above. Studies have shown the OHS patients usually test positive for previous exposure to histoplasmosis.

In the United States, the highest incidence of histoplasmosis occurs in a region often referred to as the “Histo Belt,” where up to 90 percent of the adult population has been infected by histoplasmosis. This region includes all of Arkansas, Kentucky, Missouri, Tennessee, and West Virginia as well as large portions of Alabama, Illinois, Indiana, Iowa, Kansas, Louisiana, Maryland, Mississippi, Nebraska, Ohio, Oklahoma, Texas, and Virginia. Since most cases of histoplasmosis are undiagnosed, anyone who has ever lived in an area known to have a high rate of histoplasmosis should consider having their eyes examined for histo spots.

## **How Is OHS Diagnosed?**

An eye care professional will usually diagnose OHS if a careful eye examination reveals two conditions: (1) The presence of histo spots, which indicate previous exposure to the histo fungus spores; and (2) Swelling of the retina, which signals the growth of new, abnormal blood vessels. To confirm the diagnosis, a dilated eye examination must be performed. This means that the pupils are enlarged temporarily with special drops, allowing the eye care professional to better examine the retina.

If fluid, blood, or abnormal blood vessels are present, an eye care professional may want to perform a diagnostic procedure called fluorescein angiography. In this procedure, a dye, injected into the patient's arm, travels to the blood vessels of the retina. The dye allows a better view of the CNV lesion, and photographs can document the location and extent to which it has spread. Particular attention is paid to how close the abnormal blood vessels are to the fovea.

## **How Is OHS Treated?**

The only proven treatment for OHS is a form of laser surgery called photocoagulation. A small, powerful beam of light destroys the fragile,

abnormal blood vessels, as well as a small amount of the overlying retinal tissue. Although the destruction of retinal tissue during the procedure can itself cause some loss of vision, this is done in the hope of protecting the fovea and preserving the finely-tuned vision it provides.

## **How Effective Is Laser Surgery?**

Controlled clinical trials, sponsored by the National Eye Institute, have shown that photocoagulation can reduce future vision loss from OHS by more than half. The treatment is most effective when:

The CNV has not grown into the center of the fovea, where it can affect vision. The eye care professional is able to identify and destroy the entire area of CNV.

## **Does Laser Surgery Restore Lost Vision?**

Laser photocoagulation usually does not restore lost vision. However, it does reduce the chance of further CNV growth and any resulting vision loss.

## **Does Laser Surgery Cure OHS?**

No. OHS cannot be cured. Once contracted, OHS remains a threat to a person's sight for their lifetime.

People with OHS who experience one bout of abnormal blood vessel growth may have recurrent CNV. Each recurrence can damage vision and may require additional laser therapy. It is crucial to detect and treat OHS as early as possible before it causes significant visual impairment.

## **Is There a Way to Check for Signs of OHS Damage?**

Yes. A person can check for signs of damage to the macula by looking at a printed pattern called an Amsler grid. If the macula has been damaged, the vertical and horizontal lines of the grid may appear curved, or a blank spot may seem to appear.

Many eye care professionals advise patients who have received treatment for OHS, as well as those with histo spots, to check their vision daily with the

Amsler grid one eye at a time. Patients with OHS in one eye are likely to develop it in the other.

## **What Help Is Available?**

Scientists and engineers have developed many useful devices to help people with severe visual impairment in both eyes. These devices, called low vision aids, use special lenses or electronics to create enlarged visual images. An eye care professional can suggest sources that provide information on counseling, training, and special services for people with low vision. Many organizations for people who are blind also serve those with low vision.

## **What Research Is Being Conducted on OHS?**

The National Eye Institute (NEI) supports research aimed at learning more about the relationship between histoplasmosis and OHS and how to treat OHS effectively. One such multicenter clinical study is called the Submacular Surgery Trials (SST). This clinical study is examining whether CNV in the fovea, which cannot be treated by laser photocoagulation, can be successfully removed through traditional surgery. Patients with OHS who would like to receive more information about the Submacular Surgery Trials should call the SST Chairman's Office toll-free at 1-888-554-0412. Information on the Submacular Surgery Trials is also available on the NEI web site at <http://www.nei.nih.gov/neitrials/index.htm>.

## **Where Can I Obtain Information?**

Information on systemic histoplasmosis can be obtained from:

### **The National Institute of Allergy and Infectious Diseases (NIAID)**

The National Institutes of Health

Building 31, Room 7A50

31 Center Drive, MSC 2520

Bethesda, MD, 20892-2520

Telephone: 301-496-5717

Website: <http://www.niaid.nih.gov>

## More Guideline Sources

The guideline above on ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome. 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 the following: <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 “ocular histoplasmosis syndrome” or synonyms. The following was recently posted:



- **2001 USPHS/IDSA guidelines for the prevention of opportunistic infections in persons infected with human immunodeficiency virus.**

Source: Centers for Disease Control and Prevention/Infectious Diseases Society of America/Public Health Service (U.S.); 1999 August (updated 2001 November 28); 64 pages

[http://www.guideline.gov/FRAMESETS/guideline\\_fs.asp?guideline=002306&sSearch\\_string=ocular+histoplasmosis+syndrome](http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=002306&sSearch_string=ocular+histoplasmosis+syndrome)

### **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:

- **Facts About Histoplasmosis**

Summary: This fact sheet provides information about presumed ocular histoplasmosis syndrome (POHS) -- a serious eye disease that is a leading cause of vision loss.

Source: National Eye Institute, National Institutes of Health

<http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=1175>

### **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 ocular histoplasmosis syndrome. The drawbacks of this approach are that the information is not organized by theme and that the references are often a mix of information for professionals and patients. Nevertheless, a large number of the listed Web sites provide useful background information. We can only recommend this route, therefore, for relatively rare or specific disorders, or when using highly targeted searches. To use the NIH search utility, visit the following Web page: **<http://search.nih.gov/index.html>**.

### Additional Web Sources

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

- AOL: <http://search.aol.com/cat.adp?id=168&layer=&from=subcats>
- drkoop.com<sup>®</sup>: <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/](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/](http://dmoz.org/Health/Conditions_and_Diseases/)
- Yahoo.com: [http://dir.yahoo.com/Health/Diseases\\_and\\_Conditions/](http://dir.yahoo.com/Health/Diseases_and_Conditions/)
- WebMD<sup>®</sup>Health: [http://my.webmd.com/health\\_topics](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:

**Angiography:** Radiography of blood vessels after injection of a contrast medium. [NIH]

**Blindness:** The inability to see or the loss or absence of perception of visual stimuli. This condition may be the result of eye diseases; optic nerve diseases; optic chiasm diseases; or brain diseases affecting the visual pathways or occipital lobe. [NIH]

**Choroid:** The layer filled with blood vessels that nourishes the retina; part of the uvea. [NIH]

**Cones:** One type of specialized light-sensitive cells (photoreceptors) in the retina that provide sharp central vision and color vision. [NIH]

**Fovea:** The central part of the macula that provides the sharpest vision. [NIH]

**Fungus:** A general term used to denote a group of eukaryotic protists, including mushrooms, yeasts, rusts, moulds, smuts, etc., which are characterized by the absence of chlorophyll and by the presence of a rigid cell wall composed of chitin, mannans, and sometimes cellulose. They are

usually of simple morphological form or show some reversible cellular specialization, such as the formation of pseudoparenchymatous tissue in the fruiting body of a mushroom. The dimorphic fungi grow, according to environmental conditions, as moulds or yeasts. [EU]

**Histoplasma:** A mitosporic Onygenales fungal species causing histoplasmosis in humans and animals. *Histoplasma capsulatum* and its teleomorph *Ajellomyces capsulatus* are the offending species. [NIH]

**Inflammation:** The body's reaction to trauma, infection, or a foreign substance, often associated with pain, heat, redness, swelling, and/or loss of function. [NIH]

**Lenses:** Pieces of glass or other transparent materials used for magnification or increased visual acuity. [NIH]

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

**Macula:** The small, sensitive area of the central retina; provides vision for fine work and reading. [NIH]

**Pupil:** The adjustable opening at the center of the iris that allows varying amounts of light to enter the eye. [NIH]

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

**Retina:** The light-sensitive layer of tissue that lines the back of the eyeball; sends visual messages through the optic nerve to the brain. [NIH]

**Spores:** The reproductive elements of lower organisms, such as protozoa, fungi, and cryptogamic plants. [NIH]

**Systemic:** Pertaining to or affecting the body as a whole. [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 ocular histoplasmosis syndrome. 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.<sup>8</sup> 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 ocular histoplasmosis syndrome. The chapter ends with a discussion on how to find a doctor that is right for you.

### Associations and Ocular Histoplasmosis Syndrome

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.<sup>9</sup> 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

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<sup>8</sup> Churches, synagogues, and other houses of worship might also have groups that can offer you the social support you need.

<sup>9</sup> 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. 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, 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 ocular histoplasmosis syndrome. 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 "ocular histoplasmosis syndrome" (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 "ocular histoplasmosis syndrome". 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 “ocular histoplasmosis syndrome” (or synonyms) into the “For these words:” box, you will only receive results on organizations dealing with ocular histoplasmosis syndrome. 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 “ocular histoplasmosis syndrome” (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 as service at their Web site: **<http://boards.webmd.com/roundtable>**. These online self-help communities can help you connect with a network of people whose concerns are similar to yours. Online support groups are places where people can talk informally. If you read about a novel approach, consult with your doctor or other healthcare providers, as the treatments or discoveries you hear about may not be scientifically proven to be safe and effective. The following maybe of particular interest:

- **In The Blink of an Eye**  
<http://home.golden.net/~blink/index.shtml>

### **Finding an Eye Care Professional<sup>10</sup>**

The National Eye Institute does not provide referrals nor recommend specific eye care professionals. However, you may wish to consider the following ways of finding a professional to provide your eye care. You can:

- Ask family members and friends about eye care professionals they use.
- Ask your family doctor for the name of a local eye care specialist.

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<sup>10</sup> This section has been adapted from **<http://www.nei.nih.gov/health/findprofessional.htm>**.

- Call the department of ophthalmology or optometry at a nearby hospital or university medical center.
- Contact a state or county association of ophthalmologists or optometrists. These groups, usually called academies or societies, may have lists of eye care professionals with specific information on specialty and experience.
- Contact your insurance company or health plan to learn whether it has a list of eye care professionals that are covered under your plan.
- At a bookstore or library, check on available journals and books about choosing physicians and medical treatments. Here are some examples:
  - Most large libraries have the reference set *The ABMS Compendium of Certified Medical Professionals*, which lists board-certified ophthalmologists, each with a small amount of biographical information. A library reference specialist can also help you identify other books on finding healthcare professionals or help you seek additional information about local eye physicians using the Internet.
  - Each year, usually in August, the magazine *U.S. News and World Report* features an article that rates hospitals in the United States.

For more specific information, the following sources may prove useful:

- The American Academy of Ophthalmology coordinates an online listing called **Find an Ophthalmologist** that contains information on member ophthalmologists practicing in the United States and abroad. This service is designed to help the general public locate ophthalmologists within a specific region. Web site: <http://www.eyenet.org/>.
- The **International Society of Refractive Surgery** maintains a comprehensive directory of surgeons around the world who are currently performing refractive surgery. Telephone: (407) 786-7446. E-mail: [isrshq@isrs.org](mailto:isrshq@isrs.org). Web site: <http://www.isrs.org>.
- The **Blue Book of Optometrists** and the **Red Book of Ophthalmologists**, now available online, can be used to find doctors in the U.S., Puerto Rico, and Canada. This resource is helpful when you know the doctor's name, but need contact information. Web site: <http://www.eyefind.com/>.
- Administrators in Medicine and the Association of State Medical Board Executive Directors have launched **DocFinder**, an online database that helps consumers learn whether any malpractice actions have been taken against a particular doctor. The site provides links to the licensing boards in the participating states. Web site: <http://www.docboard.org/>.
- The **American Association of Eye and Ear Hospitals (AAEEH)** is comprised of the premier centers for specialized eye and ear procedures in the world. Association members are major referral centers that offer



some of the most innovative teaching programs, and routinely treat the most severely ill eye and ear patients. Telephone: (202) 347-1993. Web site: <http://www.aaeeh.org/locations.html>.

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

- Check with the associations listed earlier in this chapter.
- Information on doctors in some states is available on the Internet at <http://www.docboard.org>. This Web site is run by “Administrators in Medicine,” a group of state medical board directors.
- The American Board of Medical Specialties can tell you if your doctor is board certified. “Certified” means that the doctor has completed a training program in a specialty and has passed an exam, or “board,” to assess his or her knowledge, skills, and experience to provide quality patient care in that specialty. Primary care doctors may also be certified as specialists. The AMBS Web site is located at <http://www.abms.org/newsearch.asp>.<sup>11</sup> 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>.

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

## Selecting Your Doctor<sup>12</sup>

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

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<sup>11</sup> 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.

<sup>12</sup> This section has been adapted from the AHRQ:  
[www.ahrq.gov/consumer/qntascii/qntdr.htm](http://www.ahrq.gov/consumer/qntascii/qntdr.htm).

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 ocular histoplasmosis syndrome?
- 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 ocular histoplasmosis syndrome?
- 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<sup>13</sup>**

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

- You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.
- It is important to tell your doctor personal information, even if it makes you feel embarrassed or uncomfortable.
- Bring a “health history” list with you (and keep it up to date).
- Always bring any medications you are currently taking with you to the appointment, or you can bring a list of your medications including dosage and frequency information. Talk about any allergies or reactions you have had to your medications.

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<sup>13</sup> This section has been adapted from the AHRQ:  
[www.ahrq.gov/consumer/qntascii/qntdr.htm](http://www.ahrq.gov/consumer/qntascii/qntdr.htm).

- 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:<sup>14</sup>

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<sup>14</sup> You can access this information at:

<http://www.nlm.nih.gov/medlineplus/healthsystem.html>.

- 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>

## Vocabulary Builder

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

**Ophthalmologist:** A medical doctor specializing in the diagnosis and medical or surgical treatment of visual disorders and eye disease. [NIH]

**Ophthalmology:** A surgical specialty concerned with the structure and function of the eye and the medical and surgical treatment of its defects and diseases. [NIH]

**Optometrist:** A primary eye care provider who diagnoses, manages, and treats disorders of the visual system and eye diseases. [NIH]

**Optometry:** The professional practice of primary eye and vision care that includes the measurement of visual refractive power and the correction of visual defects with lenses or glasses. [NIH]

## **CHAPTER 3. CLINICAL TRIALS AND OCULAR HISTOPLASMOSIS SYNDROME**

### **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 ocular histoplasmosis syndrome.

### **What Is a Clinical Trial?<sup>15</sup>**

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 ocular histoplasmosis syndrome is to try it on patients in a clinical trial.

### **What Kinds of Clinical Trials Are There?**

Clinical trials are carried out in three phases:

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<sup>15</sup> The discussion in this chapter has been adapted from the NIH and the NEI: [www.nei.nih.gov/netrials/ctivr.htm](http://www.nei.nih.gov/netrials/ctivr.htm).

- **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 ocular histoplasmosis syndrome.
- **Phase III.** Finally, researchers conduct Phase III trials to find out how new treatments for ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome. 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 Ocular Histoplasmosis Syndrome

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 ocular histoplasmosis syndrome.<sup>16</sup> 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.

- **Submacular Surgery Trials (SST)**

Condition(s): Macular Degeneration; Histoplasmosis

Study Status: This study is currently recruiting patients.

Sponsor(s): National Eye Institute (NEI)

Purpose - Excerpt: To determine whether surgical removal of subfoveal choroidal neovascularization (CNV) and associated hemorrhage in patients with age-related macular degeneration (AMD), the ocular histoplasmosis syndrome (OHS), or idiopathic CNV stabilizes or improves vision more often than observation. To determine how surgical removal compared to observation of subfoveal CNV due to AMD, OHS, or idiopathic causes changes the patient's perception of health- and vision-related "quality of life," as measured by telephone interview using the Medical Outcomes Survey Short Form-36 (MOS SF-36) instrument, the Hospital Anxiety and Depression Scale, and the National Eye Institute Visual Function Questionnaire (NEI VFQ-25). To determine whether randomized trials of surgery are warranted for patients with subfoveal CNV associated with age-related macular degeneration not suitable for laser treatment.

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<sup>16</sup> These are listed at [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov).



Phase(s): Phase III

Study Type: Interventional

Contact(s): see Web site below

Web Site: <http://clinicaltrials.gov/ct/gui/c/w2r/show/NCT00000150>

- **Macular Photocoagulation Study (MPS)**

Condition(s): Choroidal Neovascularization; Macular Degeneration

Study Status: This study is no longer recruiting patients.

Sponsor(s): National Eye Institute (NEI)

Purpose - Excerpt: To evaluate laser treatment of choroidal neovascularization (CNV) through randomized, controlled clinical trials. The Macular Photocoagulation Study (MPS) consisted of three sets of randomized, controlled clinical trials. Change in best-corrected visual acuity from baseline was the primary outcome for all MPS trials. Other measures of vision are evaluated in each set of trials. The purpose of each is described below. Argon Study: To determine whether argon blue-green laser photocoagulation of leaking abnormal blood vessels in choroidal neovascular membranes outside the fovea (200 to 2,500 microns from the center of the foveal avascular zone [FAZ]) is of benefit in preventing or delaying loss of central vision in patients with age-related (senile) macular degeneration (AMD), presumed ocular histoplasmosis (POH), and idiopathic neovascular membranes (INVM). A separate trial was conducted for each of the three underlying conditions. Krypton Study: To determine whether krypton red laser photocoagulation of choroidal neovascular lesions with the posterior border 1 to 199 microns from the center of the FAZ is of benefit in preventing or delaying large losses of visual acuity in patients with AMD, POH, and INVM. A separate trial was conducted for each of the three underlying conditions. Foveal Study: To determine whether laser photocoagulation is of benefit in preventing or delaying further visual acuity loss in patients with new (never treated) or recurrent (previously treated with laser photocoagulation) choroidal neovascularization under the center of the FAZ. Two separate trials, one for each type of lesion, were carried out.

Phase(s): Phase III

Study Type: Interventional

Contact(s): see Web site below

Web Site: <http://clinicaltrials.gov/ct/gui/c/w2r/show/NCT00000158>

## **Benefits and Risks<sup>17</sup>**

### **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 ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome. In cases where certain diseases or disorders run in families, your participation may lead to better care or prevention for your family members.

### **The Informed Consent**

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

### **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.

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<sup>17</sup> 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](http://www.clinicaltrials.gov/ct/gui/c/a1r/info/whatis?JServSessionIdzone_ct=9jmun6f291).

## **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 ocular histoplasmosis syndrome? 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](http://www.clinicaltrials.gov)) and search by “ocular histoplasmosis syndrome” (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 eye-related trials, visit and search the Web page of the National Eye Institute: **<http://www.nei.nih.gov/neitrials/index.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:

**Acuity:** Clearness, or sharpness of vision. [NIH]

**Anxiety:** The unpleasant emotional state consisting of psychophysiological responses to anticipation of unreal or imagined danger, ostensibly resulting from unrecognized intrapsychic conflict. Physiological concomitants include increased heart rate, altered respiration rate, sweating, trembling, weakness, and fatigue; psychological concomitants include feelings of impending danger, powerlessness, apprehension, and tension. [EU]

**Hemorrhage:** Bleeding or escape of blood from a vessel. [NIH]

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

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

**Posterior:** Situated in back of, or in the back part of, or affecting the back or dorsal surface of the body. In lower animals, it refers to the caudal end of the body. [EU]





## **PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL**

### **ABOUT PART II**

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



## **CHAPTER 4. STUDIES ON OCULAR HISTOPLASMOSIS SYNDROME**

### **Overview**

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

### **Federally-Funded Research on Ocular Histoplasmosis Syndrome**

The U.S. Government supports a variety of research studies relating to ocular histoplasmosis syndrome and associated conditions. These studies are tracked by the Office of Extramural Research at the National Institutes of

Health.<sup>18</sup> CRISP (Computerized Retrieval of Information on Scientific Projects) is a searchable database of federally-funded biomedical research projects conducted at universities, hospitals, and other institutions. Visit the CRISP Web site: [http://commons.cit.nih.gov/crisp3/CRISP.Generate\\_Ticket](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 ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome 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.

### **E-Journals: PubMed Central<sup>19</sup>**

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).<sup>20</sup> Access to this growing archive of e-journals is free and unrestricted.<sup>21</sup> To search, go to <http://www.pubmedcentral.nih.gov/index.html#search>, and type “ocular histoplasmosis syndrome” (or synonyms) into the search box. This search gives you access to full-text articles. The following is a sample of items found for ocular histoplasmosis syndrome in the PubMed Central database:

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<sup>18</sup> Healthcare projects are funded by the National Institutes of Health (NIH), Substance Abuse and Mental Health Services (SAMHSA), Health Resources and Services Administration (HRSA), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDCP), Agency for Healthcare Research and Quality (AHRQ), and Office of Assistant Secretary of Health (OASH).

<sup>19</sup> Adapted from the National Library of Medicine:

<http://www.pubmedcentral.nih.gov/about/intro.html>.

<sup>20</sup> 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.

<sup>21</sup> 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.

- **Involvement of Integrins  $\alpha$  v $\beta$  3 and  $\alpha$  v $\beta$  5 in Ocular Neovascular Diseases** by M Friedlander, CL Theesfeld, M Sugita, M Fruttiger, MA Thomas, S Chang, and DA Cheresh; 1996 September 3  
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?rendertype=abstract&artid=38503>

## 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.<sup>22</sup> 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.

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

## Vocabulary Builder

**Adenocarcinoma:** A malignant epithelial tumor with a glandular organization. [NIH]

**Anisometropia:** A condition of an inequality of refractive power of the two eyes. [NIH]

**Antibody:** An immunoglobulin molecule that has a specific amino acid sequence by virtue of which it interacts only with the antigen that induced its synthesis in cells of the lymphoid series (especially plasma cells), or with

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<sup>22</sup> 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.

antigen closely related to it. Antibodies are classified according to their mode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

**Ascites:** Effusion and accumulation of serous fluid in the abdominal cavity; called also abdominal or peritoneal dropsy, hydroperitonitis, and hydrops abdominis. [EU]

**Bile:** An emulsifying agent produced in the liver and secreted into the duodenum. Its composition includes bile acids and salts, cholesterol, and electrolytes. It aids digestion of fats in the duodenum. [NIH]

**Bilirubin:** A bile pigment that is a degradation product of HEME. [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, (CH<sub>2</sub>O)<sub>n</sub>. 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]

**Cerebellum:** Part of the metencephalon that lies in the posterior cranial fossa behind the brain stem. It is concerned with the coordination of movement. [NIH]

**Chimera:** An individual that contains cell populations derived from different zygotes. [NIH]

**Cognition:** Intellectual or mental process whereby an organism becomes aware of or obtains knowledge. [NIH]

**Cortex:** The outer layer of an organ or other body structure, as distinguished from the internal substance. [EU]

**Detoxification:** Treatment designed to free an addict from his drug habit. [EU]

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

**Epithelium:** The outermost layer of cells of the cornea and the eye's first defense against infection. [NIH]

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

**Exons:** Coding regions of messenger RNA included in the genetic transcript

which survive the processing of RNA in cell nuclei to become part of a spliced messenger of structural RNA in the cytoplasm. They include joining and diversity exons of immunoglobulin genes. [NIH]

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

**Glucose:** D-glucose, a monosaccharide (hexose),  $C_6H_{12}O_6$ , 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]

**Glucuronides:** Glycosides of glucuronic acid formed by the reaction of uridine diphosphate glucuronic acid with certain endogenous and exogenous substances. Their formation is important for the detoxification of drugs, steroid excretion and bilirubin metabolism to a more water-soluble compound that can be eliminated in the urine and bile. [NIH]

**Glycoproteins:** Conjugated protein-carbohydrate compounds including mucins, mucoid, and amyloid glycoproteins. [NIH]

**Granule:** A small pill made from sucrose. [EU]

**Hepatic:** Pertaining to the liver. [EU]

**Herpes:** Any inflammatory skin disease caused by a herpesvirus and characterized by the formation of clusters of small vesicles. When used alone, the term may refer to herpes simplex or to herpes zoster. [EU]

**Hybridization:** The genetic process of crossbreeding to produce a hybrid. Hybrid nucleic acids can be formed by nucleic acid hybridization of DNA and RNA molecules. Protein Hybridization allows for hybrid proteins to be formed from polypeptide chains. [NIH]

**Hydrogel:** A network of cross-linked hydrophilic macromolecules used in biomedical applications. [NIH]

**Hyperbilirubinemia:** Pathologic process consisting of an abnormal increase in the amount of bilirubin in the circulating blood, which may result in jaundice. [NIH]

**Immunity:** The condition of being immune; the protection against infectious disease conferred either by the immune response generated by immunization or previous infection or by other nonimmunologic factors (innate i.). [EU]

**Induction:** The act or process of inducing or causing to occur, especially the production of a specific morphogenetic effect in the developing embryo

through the influence of evocators or organizers, or the production of anaesthesia or unconsciousness by use of appropriate agents. [EU]

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

**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]

**Keratitis:** Inflammation of the cornea. [NIH]

**Kinetic:** Pertaining to or producing motion. [EU]

**Lectins:** Protein or glycoprotein substances, usually of plant origin, that bind to sugar moieties in cell walls or membranes and thereby change the physiology of the membrane to cause agglutination, mitosis, or other biochemical changes in the cell. [NIH]

**Lipid:** Any of a heterogeneous group of fats 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]

**Lipodystrophy:** 1. any disturbance of fat metabolism. 2. a group of conditions due to defective metabolism of fat, resulting in the absence of subcutaneous fat, which may be congenital or acquired and partial or total. Called also lipoatrophy and lipodystrophia. [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]

**Malformation:** A morphologic defect resulting from an intrinsically abnormal developmental process. [EU]

**Manifest:** Being the part or aspect of a phenomenon that is directly observable : concretely expressed in behaviour. [EU]

**Microbiology:** The study of microorganisms such as fungi, bacteria, algae, archaea, and viruses. [NIH]

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

**Monosomy:** The condition in which one chromosome of a pair is missing. In



a normally diploid cell it is represented symbolically as  $2N-1$ . [NIH]

**Mucins:** A secretion containing mucopolysaccharides and protein that is the chief constituent of mucus. [NIH]

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

**Neurology:** A medical specialty concerned with the study of the structures, functions, and diseases of the nervous system. [NIH]

**Neuronal:** Pertaining to a neuron or neurons (= conducting cells of the nervous system). [EU]

**Neurons:** The basic cellular units of nervous tissue. Each neuron consists of a body, an axon, and dendrites. Their purpose is to receive, conduct, and transmit impulses in the nervous system. [NIH]

**Neurophysiology:** The scientific discipline concerned with the physiology of the nervous system. [NIH]

**Orbital:** Pertaining to the orbit (= the bony cavity that contains the eyeball). [EU]

**Parietal:** 1. of or pertaining to the walls of a cavity. 2. pertaining to or located near the parietal bone, as the parietal lobe. [EU]

**Peroxidase:** A hemeprotein from leukocytes. Deficiency of this enzyme leads to a hereditary disorder coupled with disseminated moniliasis. It catalyzes the conversion of a donor and peroxide to an oxidized donor and water. EC 1.11.1.7. [NIH]

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

**Preclinical:** Before a disease becomes clinically recognizable. [EU]

**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]

**Predisposition:** A latent susceptibility to disease which may be activated under certain conditions, as by stress. [EU]

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

**Proprioception:** The mechanism involved in the self-regulation of posture and movement through stimuli originating in the receptors imbedded in the joints, tendons, muscles, and labyrinth. [NIH]

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

**Pseudomonas:** A genus of gram-negative, aerobic, rod-shaped bacteria widely distributed in nature. Some species are pathogenic for humans, animals, and plants. [NIH]

**Psychology:** The science dealing with the study of mental processes and behavior in man and animals. [NIH]

**Receptor:** 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

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

**Reflex:** 1; reflected. 2. a reflected action or movement; the sum total of any particular involuntary activity. [EU]

**Saliva:** The clear, viscous fluid secreted by the salivary glands and mucous glands of the mouth. It contains mucins, water, organic salts, and ptylin. [NIH]

**Schizophrenia:** A severe emotional disorder of psychotic depth characteristically marked by a retreat from reality with delusion formation, hallucinations, emotional disharmony, and regressive behavior. [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]

**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]

**Somatic:** 1. pertaining to or characteristic of the soma or body. 2. pertaining to the body wall in contrast to the viscera. [EU]

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

**Steroid:** A group name for lipids that contain a hydrogenated cyclopentanoperhydrophenanthrene ring system. Some of the substances included in this group are progesterone, adrenocortical hormones, the

gonadal hormones, cardiac aglycones, bile acids, sterols (such as cholesterol), toad poisons, saponins, and some of the carcinogenic hydrocarbons. [EU]

**Strabismus:** Deviation of the eye which the patient cannot overcome. The visual axes assume a position relative to each other different from that required by the physiological conditions. The various forms of strabismus are spoken of as tropias, their direction being indicated by the appropriate prefix, as cyclo tropia, esotropia, exotropia, hypertropia, and hypotropia. Called also cast, heterotropia, manifest deviation, and squint. [EU]

**Substrate:** A substance upon which an enzyme acts. [EU]

**Synergistic:** Acting together; enhancing the effect of another force or agent. [EU]

**Topical:** Pertaining to a particular surface area, as a topical anti-infective applied to a certain area of the skin and affecting only the area to which it is applied. [EU]

**Toxic:** Pertaining to, due to, or of the nature of a poison or toxin; manifesting the symptoms of severe infection. [EU]

**Tyrosine:** A non-essential amino acid. In animals it is synthesized from phenylalanine. It is also the precursor of epinephrine, thyroid hormones, and melanin. [NIH]

**Ulceration:** 1. the formation or development of an ulcer. 2. an ulcer. [EU]

**Uterus:** The hollow muscular organ in female mammals in which the fertilized ovum normally becomes embedded and in which the developing embryo and fetus is nourished. In the nongravid human, it is a pear-shaped structure; about 3 inches in length, consisting of a body, fundus, isthmus, and cervix. Its cavity opens into the vagina below, and into the uterine tube on either side at the cornu. It is supported by direct attachment to the vagina and by indirect attachment to various other nearby pelvic structures. Called also metra. [EU]

**Vaccination:** The introduction of vaccine into the body for the purpose of inducing immunity. Coined originally to apply to the injection of smallpox vaccine, the term has come to mean any immunizing procedure in which vaccine is injected. [EU]

**Vaccine:** A suspension of attenuated or killed microorganisms (bacteria, viruses, or rickettsiae), administered for the prevention, amelioration or treatment of infectious diseases. [EU]

**Vestibular:** Pertaining to or toward a vestibule. In dental anatomy, used to refer to the tooth surface directed toward the vestibule of the mouth. [EU]

**Virulence:** The degree of pathogenicity within a group or species of microorganisms or viruses as indicated by case fatality rates and/or the ability of the organism to invade the tissues of the host. [NIH]

**Xenobiotics:** Chemical substances that are foreign to the biological system. They include naturally occurring compounds, drugs, environmental agents, carcinogens, insecticides, etc. [NIH]

## CHAPTER 5. BOOKS ON OCULAR HISTOPLASMOSIS SYNDROME

### Overview

This chapter provides bibliographic book references relating to ocular histoplasmosis syndrome. You have many options to locate books on ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome 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.

### 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 "ocular histoplasmosis syndrome" (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:<sup>23</sup>

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<sup>23</sup> 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

- **Accommodation and vergence mechanisms in the visual system.** Author: edited by Ove Franzén, Hans Richter, Lawrence Stark; Year: 2000; Basel; Boston: Birkhäuser Verlag, c2000; ISBN: 3764360739 (alk. paper)  
<http://www.amazon.com/exec/obidos/ASIN/3764360739/icongroupinterna>
- **Bibliography on histoplasmosis.** Author: United States. Army. Chemical Corps. Technical Library; Year: 1955; Frederick, Md., 1955
- **Binocular vision and orthoptics: investigation and management.** Author: edited by Bruce Evans, Sandip Doshi; Year: 2001; Oxford; Boston: Butterworth-Heinemann, 2001; ISBN: 0750647132  
<http://www.amazon.com/exec/obidos/ASIN/0750647132/icongroupinterna>
- **Disease vector management for public health and conservation.** Author: edited by Patricia C. Matteson; contributing authors, Reg Allsopp ... [et al]; Year: 1999; Washington, D.C.: World Wildlife Fund, [1999]
- **Emergent techniques for assessment of visual performance.** Author: Committee on Vision, Commission on Behavioral and Social Sciences and Education, National Research Council; Year: 1985; Washington, D.C.: National Academy Press, 1985
- **Epidemiological studies of pulmonary histoplasmosis in a farm family, by Clayton G. Loosli [and others].** Author: Loosli, Clayton Garr, 1900-; Year: 1951; Chicago, Section of Preventive Medicine, Dept. of Medicine, Univ. of Chicago [1951]
- **Eye muscle surgery: basic data, operative techniques, surgical strategy.** Author: André Roth, Claude Speeg-Schatz; Year: 2001; Lisse: Swets & Zeitlinger, c2001; ISBN: 9026518587 (Hardback)  
<http://www.amazon.com/exec/obidos/ASIN/9026518587/icongroupinterna>
- **Geometrical and visual optics.** Author: Steven H. Schwartz; Year: 2002; New York: McGraw-Hill, Medical Pub. Division, c2002; ISBN: 0071374159  
<http://www.amazon.com/exec/obidos/ASIN/0071374159/icongroupinterna>

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

- **Histoplasmosis of the oral cavity, pharynx and larynx.** Author: Zimmerman, A. Leonard; Year: 1962; [Minneapolis] 1962
- **Histoplasmosis, protecting workers at risk.** Author: Steven W. Lenhart ... [et al.]; Year: 1997; [Atlanta, Ga.?]: U.S. Dept. of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Institute for Occupational Safety and Health: National Center for Infectious Diseases, [1997]
- **Histoplasmosis.** Author: Jan Schwarz; Year: 1981; New York: Praeger, c1981; ISBN: 0030584485  
<http://www.amazon.com/exec/obidos/ASIN/0030584485/icongroupinterna>
- **Histoplasmosis.** Author: Sweany, Henry Claris, 1890-; Year: 1960; Springfield, Ill., Thomas [c1960]
- **Histoplasmosis: diagnosis and treatment.** Author: Negroni, Pablo, 1904-; Year: 1965; Springfield, Ill., Thomas [c1965]
- **Histoplasmosis; a clinical pathological study.** Author: Vivian, Donald Norman, 1922-; Year: 1953; [Minneapolis] 1953
- **Histoplasmosis; proceedings of the Second National Conference, held at the Center for Disease Control, Atlanta, Georgia. Editorial board: Libero Ajello, Ernet W. Chick [and] Michael L. Furcolow.** Author: National Conference on Histoplasmosis (2d: 1969: Center for Disease Control); Year: 1971; Springfield, Ill., Thomas [c1971]
- **Ocular histoplasmosis: proceedings of the Ocular Histoplasmosis Symposium.** Author: presented by the Indiana University School of Medicine, Indianapolis, January 1975; edited by T. F. Schlaegel, Jr; Year: 1975; Boston: Little, Brown, 1975
- **Ocular histoplasmosis.** Author: by T. F. Schlaegel, Jr; Year: 1977; New York: Grune & Stratton, c1977; ISBN: 0808909940  
<http://www.amazon.com/exec/obidos/ASIN/0808909940/icongroupinterna>
- **Proceedings.** Author: Seminar on Histoplasmosis (1948: Bethesda, Md.); Year: 1948; [Bethesda? Md., 1948?]
- **Proceedings.** Author: Conference on Histoplasmosis (1952: Excelsior Springs, Mo.); Year: 1956; [Washington, U. S. Govt. Print. Off., 1956]
- **Update on ocular histoplasmosis.** Author: edited by T.F. Schlaegel, Jr; Year: 1983; Boston: Little, Brown, c1983

## General Home References

In addition to references for ocular histoplasmosis syndrome, 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):

- **American College of Physicians Complete Home Medical Guide (with Interactive Human Anatomy CD-ROM)** by David R. Goldmann (Editor), American College of Physicians; Hardcover - 1104 pages, Book & CD-Rom edition (1999), DK Publishing; ISBN: 0789444127;  
<http://www.amazon.com/exec/obidos/ASIN/0789444127/icongroupinterna>
- **The American Medical Association Guide to Home Caregiving** by the American Medical Association (Editor); Paperback - 256 pages 1 edition (2001), John Wiley & Sons; ISBN: 0471414093;  
<http://www.amazon.com/exec/obidos/ASIN/0471414093/icongroupinterna>
- **Anatomica : The Complete Home Medical Reference** by Peter Forrestal (Editor); Hardcover (2000), Book Sales; ISBN: 1740480309;  
<http://www.amazon.com/exec/obidos/ASIN/1740480309/icongroupinterna>
- **The HarperCollins Illustrated Medical Dictionary : The Complete Home Medical Dictionary** by Ida G. Dox, et al; Paperback - 656 pages 4th edition (2001), Harper Resource; ISBN: 0062736469;  
<http://www.amazon.com/exec/obidos/ASIN/0062736469/icongroupinterna>
- **Mayo Clinic Guide to Self-Care: Answers for Everyday Health Problems** by Philip Hagen, M.D. (Editor), et al; Paperback - 279 pages, 2nd edition (December 15, 1999), Kensington Publishing Corp.; ISBN: 0962786578;  
<http://www.amazon.com/exec/obidos/ASIN/0962786578/icongroupinterna>
- **The Merck Manual of Medical Information : Home Edition (Merck Manual of Medical Information Home Edition (Trade Paper))** by Robert Berkow (Editor), Mark H. Beers, M.D. (Editor); Paperback - 1536 pages (2000), Pocket Books; ISBN: 0671027263;  
<http://www.amazon.com/exec/obidos/ASIN/0671027263/icongroupinterna>

## Vocabulary Builder

**Antigen:** Any substance which is capable, under appropriate conditions, of inducing a specific immune response and of reacting with the products of that response, that is, with specific antibody or specifically sensitized T-lymphocytes, or both. Antigens may be soluble substances, such as toxins



and foreign proteins, or particulate, such as bacteria and tissue cells; however, only the portion of the protein or polysaccharide molecule known as the antigenic determinant (q.v.) combines with antibody or a specific receptor on a lymphocyte. Abbreviated Ag. [EU]

**Larynx:** An irregularly shaped, musclocartilaginous tubular structure, lined with mucous membrane, located at the top of the trachea and below the root of the tongue and the hyoid bone. It is the essential sphincter guarding the entrance into the trachea and functioning secondarily as the organ of voice. [NIH]

**Ophthalmic:** Pertaining to the eye. [EU]

**Orthoptics:** The study and treatment of defects in binocular vision resulting from defects in the optic musculature or of faulty visual habits. It involves a technique of eye exercises designed to correct the visual axes of eyes not properly coordinated for binocular vision. [NIH]

**Pulmonary:** Pertaining to the lungs. [EU]

**Tuberculosis:** Any of the infectious diseases of man and other animals caused by species of mycobacterium. [NIH]



## **CHAPTER 6. MULTIMEDIA ON OCULAR HISTOPLASMOSIS SYNDROME**

### **Overview**

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

### **Bibliography: Multimedia on Ocular Histoplasmosis Syndrome**

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

- **Abnormalities of the pupils & visual fields.** Source: J. Lawton Smith. Organization of the ocular motor system / Louis Dell'Osso. ; Year: 1977; Format: Sound recording; Dallas, Tex.: Medisette, 1977
- **African histoplasmosis.** Source: W. Peter Cockshott, Ricky Schachter, James Nethercott; [produced by] Division of Instructional Media Services, Faculty of Medicine, University of Toronto; Year: 1973; Format: Videorecording; Toronto: The Division, 1973
- **Diseases of the macula.** Source: Retinal Vascular Center, Wilmer Institute; Year: 1976; Format: Slide; [Baltimore]: The Center, c1976
- **Disorders of the Eye.** Source: a presentation of Films for the Humanities and Sciences; [presented by] Westmead Hospital, Westmead Children's Hospital, Westmead Neurological Centre; Year: 2000; Format: Videorecording; Princeton, NJ: Films for the Humanities and Sciences, c2000
- **Epidemic of histoplasmosis associated with an urban starling roost.** Source: U.S. Communicable Disease Center; produced by Kansas University Medical Center, Dept. of Audiovisual Education; Year: 1961; Format: Motion picture; [Atlanta]: The Center: [for loan by National Medical Audiovisual Center; Washington: for sale by National Audiovisual Center, 1961]
- **Mississippi Valley disease : histoplasmosis.** Source: a University of Kansas Television production; Kansas Tuberculosis & Health Association [and] Communicable Disease Center, Public Health Service; Year: 1956; Format: Motion picture; [United States]: University of Kansas, [1956]
- **Mycoses with emphasis on histoplasmosis.** Source: SMA, Video Access; Year: 1988; Format: Videorecording; [Birmingham, Ala.]: Southern Medical Association, c1988
- **Presumed ocular histoplasmosis syndrome.** Source: American Academy of Ophthalmology and Otolaryngology; Year: 1976; Format: Videorecording; Rochester, Minn.: The Academy, c1976
- **Pulmonary histoplasmosis.** Source: Emory Univ. School of Medicine and the National Medical Audiovisual Center; Year: 1969; Format: Videorecording; Atlanta: The Center, 1969

## Vocabulary Builder

**Motility:** The ability to move spontaneously. [EU]

**Tonometry:** The standard to determine the fluid pressure inside the eye (intraocular pressure). [NIH]

## **PART III. APPENDICES**

### **ABOUT PART III**

Part III is a collection of appendices on general medical topics which may be of interest to patients with ocular histoplasmosis syndrome 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 ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome. Research can give you information on the side effects, interactions, and limitations of prescription drugs used in the treatment of ocular histoplasmosis syndrome. 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<sup>24</sup>

The Agency for Health Care Research and Quality has published extremely useful guidelines on how you can best participate in the medication aspects of ocular histoplasmosis syndrome. Taking medicines is not always as simple as swallowing a pill. It can involve many steps and decisions each day. The AHCQR recommends that patients with ocular histoplasmosis syndrome 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,

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<sup>24</sup> This section is adapted from AHCQR: <http://www.ahcpr.gov/consumer/ncpiebro.htm>.

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 ocular histoplasmosis syndrome. 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.
- 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 ocular histoplasmosis syndrome). 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 ocular histoplasmosis syndrome. 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](http://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.<sup>25</sup>

While the FDA database is rather large and difficult to navigate, the Pharmacopeia 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.

## 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>**.

### 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>**.

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<sup>25</sup> Though cumbersome, the FDA database can be freely browsed at the following site: **[www.fda.gov/cder/da/da.htm](http://www.fda.gov/cder/da/da.htm)**.

## 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](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 ocular histoplasmosis syndrome--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 ocular histoplasmosis syndrome or potentially create deleterious side effects in patients with ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome. 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 ocular histoplasmosis syndrome. The FDA warns patients to watch out for<sup>26</sup>:

- 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](http://www.fda.gov)**.

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<sup>26</sup> This section has been adapted from <http://www.fda.gov/opacom/lowlit/medfraud.html>.

## 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):

- **Handbook of Drugs In Primary Eyecare** by D. Reid Woodard, R. Blair Woodard; Paperback - 477 pages, 2nd edition (March 13, 1997), McGraw-Hill Professional Publishing; ISBN: 0838536034;  
<http://www.amazon.com/exec/obidos/ASIN/0838536034/icongroupinterna>
- **O'Connor Davies's Ophthalmic Drugs: Diagnostic and Therapeutic Uses** by P. H. O'Connor Davies, et al; Paperback, 4th edition (June 1998), Butterworth-Heinemann Medical; ISBN: 0750629665;  
<http://www.amazon.com/exec/obidos/ASIN/0750629665/icongroupinterna>
- **Ophthalmic Drug Facts, 2002** by Jimmie D. Bartlett (Editor), et al; Paperback - 427 pages, 1st edition (January 15, 2002); Facts & Comparisons; ISBN: 1574391135;  
<http://www.amazon.com/exec/obidos/ASIN/1574391135/icongroupinterna>
- **Ophthalmic Medications and Pharmacology** by Brian Duvall, O.D., Robert M. Kershner, MD; Paperback - 118 pages, 1st edition (January 15, 1998), Slack, Inc.; ISBN: 1556423284;  
<http://www.amazon.com/exec/obidos/ASIN/1556423284/icongroupinterna>
- **Pocket Companion Clinical Ocular Pharmacology** by Bartlett, et al; Paperback, 4th edition (March 15, 2002), Butterworth-Heinemann; ISBN: 0750673443;  
<http://www.amazon.com/exec/obidos/ASIN/0750673443/icongroupinterna>
- **Textbook of Ocular Pharmacology** by Thom J. Zimmerman, Ph.D. (Editor), et al; Hardcover (September 1997), Lippincott, Williams & Wilkins Publishers; ISBN: 0781703069;  
<http://www.amazon.com/exec/obidos/ASIN/0781703069/icongroupinterna>
- **The Wills Eye Drug Guide** by Douglas J. Rhee, Vincent A. Deramo; Paperback, 2nd edition (May 15, 2001), Lippincott, Williams & Wilkins Publishers; ISBN: 0781732778;  
<http://www.amazon.com/exec/obidos/ASIN/0781732778/icongroupinterna>



## APPENDIX B. 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.<sup>27</sup>

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<sup>27</sup> 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):<sup>28</sup>

- **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/>

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<sup>28</sup> 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](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](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](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.lsuhscc.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](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](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 Resource 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](http://www.lvccld.org/special_collections/medical/index.htm)
- **New Hampshire:** Dartmouth Biomedical Libraries (Dartmouth College Library), [http://www.dartmouth.edu/~biomed/resources.html#conshealth.html#](http://www.dartmouth.edu/~biomed/resources.html#conshealth.html#/)
- **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/commplib.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](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 C. YOUR RIGHTS AND INSURANCE

### Overview

Any patient with ocular histoplasmosis syndrome 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.<sup>29</sup>

#### 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

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<sup>29</sup>Adapted from Consumer Bill of Rights and Responsibilities:  
<http://www.hcqualitycommission.gov/press/cbor.html#head1>.

network composition, the procedures that govern access to specialists and emergency services, and care management information.

- ***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.<sup>30</sup>

## 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."<sup>31</sup> 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.

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<sup>30</sup> 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.

<sup>31</sup> Adapted from <http://www.hcqualitycommission.gov/press/cbor.html#head1>.

- Use your health insurance plan's internal complaint and appeal processes to address your concerns.
- Avoid knowingly spreading disease.
- 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.<sup>32</sup> The U.S. Department of Labor, in particular, recommends ten ways to make your health benefits choices work best for you.<sup>33</sup>

**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

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<sup>32</sup> More information about quality across programs is provided at the following AHRQ Web site:

<http://www.ahrq.gov/consumer/qntascii/qnthplan.htm>.

<sup>33</sup> Adapted from the Department of Labor:

<http://www.dol.gov/dol/pwba/public/pubs/health/top10-text.html>.

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.

**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](http://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](http://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.<sup>34</sup>

### 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.

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<sup>34</sup> This section has been adapted from the Official U.S. Site for Medicare Information: <http://www.medicare.gov/Basics/Overview.asp>.

### **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.

**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>.

## Financial Aid for Eye Care<sup>35</sup>

Many state and national resources regularly provide aid to people with vision problems. The National Eye Institute, which supports eye research, does not help individuals pay for eye care. However, if you are in need of financial aid to assess or treat an eye problem, you might contact one or more of the following programs.

You may also contact a social worker at a local hospital or other community agency. Social workers often are knowledgeable about community resources that can help people facing financial and medical problems.

- **EyeCare America - National Eye Care Project**, coordinated by the American Academy of Ophthalmology (AAO), provides free and low-cost eye exams for U.S. citizens 65 and older who have not had access to an ophthalmologist in the past three years. Telephone: 1-800-222-EYES. Web site: <http://www.eyenet.org/public/pi/service/necp.html>.
- **VISION USA**, coordinated by the American Optometric Association (AOA), provides free eye care to uninsured, low-income workers and their families. Screening for the program takes place only during January of each year, with exams provided later in the year. Telephone: 1-800-766-4466.
- **Lions Clubs International** provides financial assistance to individuals for eye care through local clubs. There are Lions Clubs in most localities, and services vary from club to club. Check your telephone book for the telephone number and address of your local club. The telephone number for the national office is (630) 571-5466.
- **Celebrate Sight: Do You Know Your Glaucoma Risk?** coordinated by the American Academy of Ophthalmology, is a program offering free examinations and treatment for glaucoma to people who do not have medical insurance. Telephone: 1-800-391-EYES. Web site: [http://www.eyenet.org/public/glaucoma/gl\\_2001.html](http://www.eyenet.org/public/glaucoma/gl_2001.html)
- **Mission Cataract USA**, coordinated by the Volunteer Eye Surgeons' Association, is a program providing free cataract surgery to people of all ages who have no other means to pay. Surgeries are scheduled annually on one day, usually in May. Telephone: 1-800-343-7265.
- **Knights Templar Eye Foundation** provides assistance for eye surgery for people who are unable to pay or receive adequate assistance from current government agencies or similar sources. Mailing address: 5097 North

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<sup>35</sup> Adapted from <http://www.nei.nih.gov/health/financialaid.htm>.

Elston Avenue, Suite 100, Chicago, IL 60630-2460. Telephone: (773) 205-3838.  
 E-mail: [ktef@knightstemplar.org](mailto:ktef@knightstemplar.org).  
 Web site: <http://www.knightstemplar.org/ktef/>.

- **Sight for Students, a Vision Service Plan (VSP)** program in partnership with the Entertainment Industry Foundation, provides eye exams and glasses to children 18 years and younger whose families cannot afford vision care. Telephone: 1-888-290-4964. Web site: <http://www.sightforstudents.org/>.
- **New Eyes for the Needy** provides vouchers for the purchase of new prescription eyeglasses. Mailing address: 549 Millburn Avenue, P.O. Box 332, Short Hills, N.J. 07078-0332. Telephone: (973) 376-4903.
- **The Medicine Program** assists people to enroll in one or more of the many patient assistance programs that provide prescription medicine free-of-charge to those in need. Patients must meet the sponsor's criteria. The program is conducted in cooperation with the patient's doctor. Mailing Address: P.O. Box 4182, Poplar Bluff, MO 63902-4182. Telephone: (573) 996-7300. E-mail: [help@themedicineprogram.com](mailto:help@themedicineprogram.com). Web site: <http://www.themedicineprogram.com>
- *Directory of Prescription Drug Patient Assistance Programs 1999-2000*, published by Pharmaceutical Research and Manufacturers of America, identifies company programs that provide prescription medications free of charge to physicians for their needy patients. A copy of the directory is available online at <http://www.phrma.org/patients>. Telephone: 1-800-PMA-INFO.

## 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.<sup>36</sup> NORD 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

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<sup>36</sup> Adapted from NORD: [http://www.rarediseases.org/cgi-bin/nord/progserv#patient?id=rPIzL9oD&mv\\_pc=30](http://www.rarediseases.org/cgi-bin/nord/progserv#patient?id=rPIzL9oD&mv_pc=30).

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](http://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:<sup>37</sup>

- Health Insurance:  
<http://www.nlm.nih.gov/medlineplus/healthinsurance.html>
- Health Statistics:  
<http://www.nlm.nih.gov/medlineplus/healthstatistics.html>
- HMO and Managed Care:  
<http://www.nlm.nih.gov/medlineplus/managedcare.html>
- Hospice Care: <http://www.nlm.nih.gov/medlineplus/hospicecare.html>
- Medicaid: <http://www.nlm.nih.gov/medlineplus/medicaid.html>
- Medicare: <http://www.nlm.nih.gov/medlineplus/medicare.html>
- Nursing Homes and Long-term Care:  
<http://www.nlm.nih.gov/medlineplus/nursinghomes.html>
- Patient's Rights, Confidentiality, Informed Consent, Ombudsman Programs, Privacy and Patient Issues:  
<http://www.nlm.nih.gov/medlineplus/patientissues.html>
- Veteran's Health, Persian Gulf War, Gulf War Syndrome, Agent Orange:  
<http://www.nlm.nih.gov/medlineplus/veteranshealth.html>

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<sup>37</sup> You can access this information at:

<http://www.nlm.nih.gov/medlineplus/healthsystem.html>.

## 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](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 drkoop.com (**<http://www.drkoop.com/>**) and Web MD (**[http://my.webmd.com/adam/asset/adam\\_disease\\_articles/a\\_to\\_z/a](http://my.webmd.com/adam/asset/adam_disease_articles/a_to_z/a)**). 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 ocular histoplasmosis syndrome and keep them on file.

## 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 & Glossaries (Jim Martindale):  
**<http://www-sci.lib.uci.edu/HSG/Medical.html#DICTION>**
- 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/](http://dmoz.org/Health/Education/Patient_Education/Glossaries/)**
- StudyWeb: Reference: Medical Dictionaries (American Computer Resources, Inc.): **<http://www.studyWeb.com/links/675.html>**
- Web of Online Dictionaries (Bucknell University):  
**<http://www.yourdictionary.com/diction5.html#medicine>**

# OCULAR HISTOPLASMOSIS SYNDROME

## 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.

**Acuity:** Clearness, or sharpness of vision. [NIH]

**Adenocarcinoma:** A malignant epithelial tumor with a glandular organization. [NIH]

**Angiography:** Radiography of blood vessels after injection of a contrast medium. [NIH]

**Anisometropia:** A condition of an inequality of refractive power of the two eyes. [NIH]

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

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

**Anxiety:** The unpleasant emotional state consisting of psychophysiological responses to anticipation of unreal or imagined danger, ostensibly resulting from unrecognized intrapsychic conflict. Physiological concomitants include increased heart rate, altered respiration rate, sweating, trembling, weakness, and fatigue; psychological concomitants include feelings of impending danger, powerlessness, apprehension, and tension. [EU]

**Ascites:** Effusion and accumulation of serous fluid in the abdominal cavity; called also abdominal or peritoneal dropsy, hydroperitonitis, and hydrops abdominis. [EU]

**Bile:** An emulsifying agent produced in the liver and secreted into the duodenum. Its composition includes bile acids and salts, cholesterol, and electrolytes. It aids digestion of fats in the duodenum. [NIH]

**Bilirubin:** A bile pigment that is a degradation product of HEME. [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, (CH<sub>2</sub>O)<sub>n</sub>. 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]

**Cerebellum:** Part of the metencephalon that lies in the posterior cranial fossa behind the brain stem. It is concerned with the coordination of movement. [NIH]

**Chimera:** An individual that contains cell populations derived from different zygotes. [NIH]

**Choroid:** The layer filled with blood vessels that nourishes the retina; part of the uvea. [NIH]

**Cognition:** Intellectual or mental process whereby an organism becomes aware of or obtains knowledge. [NIH]

**Cones:** One type of specialized light-sensitive cells (photoreceptors) in the retina that provide sharp central vision and color vision. [NIH]

**Cortex:** The outer layer of an organ or other body structure, as distinguished from the internal substance. [EU]

**Detoxification:** Treatment designed to free an addict from his drug habit. [EU]

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

**Epithelium:** The outermost layer of cells of the cornea and the eye's first defense against infection. [NIH]

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

**Exons:** Coding regions of messenger RNA included in the genetic transcript which survive the processing of RNA in cell nuclei to become part of a spliced messenger of structural RNA in the cytoplasm. They include joining



and diversity exons of immunoglobulin genes. [NIH]

**Fovea:** The central part of the macula that provides the sharpest vision. [NIH]

**Fungus:** A general term used to denote a group of eukaryotic protists, including mushrooms, yeasts, rusts, moulds, smuts, etc., which are characterized by the absence of chlorophyll and by the presence of a rigid cell wall composed of chitin, mannans, and sometimes cellulose. They are usually of simple morphological form or show some reversible cellular specialization, such as the formation of pseudoparenchymatous tissue in the fruiting body of a mushroom. The dimorphic fungi grow, according to environmental conditions, as moulds or yeasts. [EU]

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

**Glucose:** D-glucose, a monosaccharide (hexose),  $C_6H_{12}O_6$ , 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]

**Glucuronides:** Glycosides of glucuronic acid formed by the reaction of uridine diphosphate glucuronic acid with certain endogenous and exogenous substances. Their formation is important for the detoxification of drugs, steroid excretion and bilirubin metabolism to a more water-soluble compound that can be eliminated in the urine and bile. [NIH]

**Glycoproteins:** Conjugated protein-carbohydrate compounds including mucins, mucoid, and amyloid glycoproteins. [NIH]

**Granule:** A small pill made from sucrose. [EU]

**Hemorrhage:** Bleeding or escape of blood from a vessel. [NIH]

**Hepatic:** Pertaining to the liver. [EU]

**Herpes:** Any inflammatory skin disease caused by a herpesvirus and characterized by the formation of clusters of small vesicles. When used alone, the term may refer to herpes simplex or to herpes zoster. [EU]

**Histoplasma:** A mitosporic Onygenales fungal species causing HISTOPLASMOSIS in humans and animals. *Histoplasma capsulatum* and its teleomorph *Ajellomyces capsulatus* are the offending species. [NIH]

**Hybridization:** The genetic process of crossbreeding to produce a hybrid. Hybrid nucleic acids can be formed by nucleic acid hybridization of DNA and RNA molecules. Protein Hybridization allows for hybrid proteins to be formed from polypeptide chains. [NIH]

**Hydrogel:** A network of cross-linked hydrophilic macromolecules used in biomedical applications. [NIH]

**Hyperbilirubinemia:** Pathologic process consisting of an abnormal increase in the amount of bilirubin in the circulating blood, which may result in jaundice. [NIH]

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

**Immunity:** The condition of being immune; the protection against infectious disease conferred either by the immune response generated by immunization or previous infection or by other nonimmunologic factors (innate i.). [EU]

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

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

**Inflammation:** The body's reaction to trauma, infection, or a foreign substance, often associated with pain, heat, redness, swelling, and/or loss of function. [NIH]

**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]

**Keratitis:** Inflammation of the cornea. [NIH]

**Kinetic:** Pertaining to or producing motion. [EU]

**Larynx:** An irregularly shaped, musclocartilaginous tubular structure, lined with mucous membrane, located at the top of the trachea and below the root of the tongue and the hyoid bone. It is the essential sphincter guarding the entrance into the trachea and functioning secondarily as the organ of voice. [NIH]

**Lectins:** Protein or glycoprotein substances, usually of plant origin, that bind to sugar moieties in cell walls or membranes and thereby change the physiology of the membrane to cause agglutination, mitosis, or other biochemical changes in the cell. [NIH]

**Lenses:** Pieces of glass or other transparent materials used for magnification or increased visual acuity. [NIH]

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

**Lipid:** Any of a heterogeneous group of fats 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]

**Lipodystrophy:** 1. any disturbance of fat metabolism. 2. a group of conditions due to defective metabolism of fat, resulting in the absence of subcutaneous fat, which may be congenital or acquired and partial or total. Called also lipoatrophy and lipodystrophia. [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]

**Macula:** The small, sensitive area of the central retina; provides vision for fine work and reading. [NIH]

**Malformation:** A morphologic defect resulting from an intrinsically abnormal developmental process. [EU]

**Mammary:** Pertaining to the mamma, or breast. [EU]

**Manifest:** Being the part or aspect of a phenomenon that is directly observable : concretely expressed in behaviour. [EU]

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

**Microbiology:** The study of microorganisms such as fungi, bacteria, algae, archaea, and viruses. [NIH]

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

**Monosomy:** The condition in which one chromosome of a pair is missing. In a normally diploid cell it is represented symbolically as  $2N-1$ . [NIH]

**Motility:** The ability to move spontaneously. [EU]

**Mucins:** A secretion containing mucopolysaccharides and protein that is the chief constituent of mucus. [NIH]

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

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

**Neurology:** A medical specialty concerned with the study of the structures,

functions, and diseases of the nervous system. [NIH]

**Neuronal:** Pertaining to a neuron or neurons (= conducting cells of the nervous system). [EU]

**Neurons:** The basic cellular units of nervous tissue. Each neuron consists of a body, an axon, and dendrites. Their purpose is to receive, conduct, and transmit impulses in the nervous system. [NIH]

**Neurophysiology:** The scientific discipline concerned with the physiology of the nervous system. [NIH]

**Ophthalmic:** Pertaining to the eye. [EU]

**Ophthalmologist:** A medical doctor specializing in the diagnosis and medical or surgical treatment of visual disorders and eye disease. [NIH]

**Ophthalmology:** A surgical specialty concerned with the structure and function of the eye and the medical and surgical treatment of its defects and diseases. [NIH]

**Optometrist:** A primary eye care provider who diagnoses, manages, and treats disorders of the visual system and eye diseases. [NIH]

**Optometry:** The professional practice of primary eye and vision care that includes the measurement of visual refractive power and the correction of visual defects with lenses or glasses. [NIH]

**Orbital:** Pertaining to the orbit (= the bony cavity that contains the eyeball). [EU]

**Orthoptics:** The study and treatment of defects in binocular vision resulting from defects in the optic musculature or of faulty visual habits. It involves a technique of eye exercises designed to correct the visual axes of eyes not properly coordinated for binocular vision. [NIH]

**Parietal:** 1. of or pertaining to the walls of a cavity. 2. pertaining to or located near the parietal bone, as the parietal lobe. [EU]

**Peroxidase:** A hemeprotein from leukocytes. Deficiency of this enzyme leads to a hereditary disorder coupled with disseminated moniliasis. It catalyzes the conversion of a donor and peroxide to an oxidized donor and water. EC 1.11.1.7. [NIH]

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

**Posterior:** Situated in back of, or in the back part of, or affecting the back or dorsal surface of the body. In lower animals, it refers to the caudal end of the body. [EU]

**Preclinical:** Before a disease becomes clinically recognizable. [EU]

**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]

**Predisposition:** A latent susceptibility to disease which may be activated under certain conditions, as by stress. [EU]

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

**Proprioception:** The mechanism involved in the self-regulation of posture and movement through stimuli originating in the receptors imbedded in the joints, tendons, muscles, and labyrinth. [NIH]

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

**Pseudomonas:** A genus of gram-negative, aerobic, rod-shaped bacteria widely distributed in nature. Some species are pathogenic for humans, animals, and plants. [NIH]

**Psychology:** The science dealing with the study of mental processes and behavior in man and animals. [NIH]

**Pulmonary:** Pertaining to the lungs. [EU]

**Pupil:** The adjustable opening at the center of the iris that allows varying amounts of light to enter the eye. [NIH]

**Receptor:** 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

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

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

**Reflex:** 1; reflected. 2. a reflected action or movement; the sum total of any particular involuntary activity. [EU]

**Retina:** The light-sensitive layer of tissue that lines the back of the eyeball; sends visual messages through the optic nerve to the brain. [NIH]

**Rpe:** The pigment cell layer that nourishes the retinal cells; located just outside the retina and attached to the choroid. [NIH]

**Saliva:** The clear, viscous fluid secreted by the salivary glands and mucous glands of the mouth. It contains mucins, water, organic salts, and ptylin. [NIH]

**Schizophrenia:** A severe emotional disorder of psychotic depth

characteristically marked by a retreat from reality with delusion formation, hallucinations, emotional disharmony, and regressive behavior. [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]

**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]

**Somatic:** 1. pertaining to or characteristic of the soma or body. 2. pertaining to the body wall in contrast to the viscera. [EU]

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

**Spores:** The reproductive elements of lower organisms, such as protozoa, fungi, and cryptogamic plants. [NIH]

**Steroid:** A group name for lipids that contain a hydrogenated cyclopentanoperhydrophenanthrene ring system. Some of the substances included in this group are progesterone, adrenocortical hormones, the gonadal hormones, cardiac aglycones, bile acids, sterols (such as cholesterol), toad poisons, saponins, and some of the carcinogenic hydrocarbons. [EU]

**Strabismus:** Deviation of the eye which the patient cannot overcome. The visual axes assume a position relative to each other different from that required by the physiological conditions. The various forms of strabismus are spoken of as tropias, their direction being indicated by the appropriate prefix, as cyclo tropia, esotropia, exotropia, hypertropia, and hypotropia. Called also cast, heterotropia, manifest deviation, and squint. [EU]

**Substrate:** A substance upon which an enzyme acts. [EU]

**Synergistic:** Acting together; enhancing the effect of another force or agent. [EU]

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

**Tonometry:** The standard to determine the fluid pressure inside the eye (intraocular pressure). [NIH]

**Topical:** Pertaining to a particular surface area, as a topical anti-infective applied to a certain area of the skin and affecting only the area to which it is applied. [EU]

**Toxic:** Pertaining to, due to, or of the nature of a poison or toxin; manifesting the symptoms of severe infection. [EU]

**Tuberculosis:** Any of the infectious diseases of man and other animals caused by species of mycobacterium. [NIH]

**Tyrosine:** A non-essential amino acid. In animals it is synthesized from phenylalanine. It is also the precursor of epinephrine, thyroid hormones, and melanin. [NIH]

**Ulceration:** 1. the formation or development of an ulcer. 2. an ulcer. [EU]

**Uterus:** The hollow muscular organ in female mammals in which the fertilized ovum normally becomes embedded and in which the developing embryo and fetus is nourished. In the nongravid human, it is a pear-shaped structure; about 3 inches in length, consisting of a body, fundus, isthmus, and cervix. Its cavity opens into the vagina below, and into the uterine tube on either side at the cornu. It is supported by direct attachment to the vagina and by indirect attachment to various other nearby pelvic structures. Called also metra. [EU]

**Vaccination:** The introduction of vaccine into the body for the purpose of inducing immunity. Coined originally to apply to the injection of smallpox vaccine, the term has come to mean any immunizing procedure in which vaccine is injected. [EU]

**Vaccine:** A suspension of attenuated or killed microorganisms (bacteria, viruses, or rickettsiae), administered for the prevention, amelioration or treatment of infectious diseases. [EU]

**Vestibular:** Pertaining to or toward a vestibule. In dental anatomy, used to refer to the tooth surface directed toward the vestibule of the mouth. [EU]

**Virulence:** The degree of pathogenicity within a group or species of microorganisms or viruses as indicated by case fatality rates and/or the ability of the organism to invade the tissues of the host. [NIH]

**Xenobiotics:** Chemical substances that are foreign to the biological system. They include naturally occurring compounds, drugs, environmental agents, carcinogens, insecticides, etc. [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 Acronyms & Abbreviations** by Stanley Jablonski (Editor), Paperback, 4th edition (2001), Lippincott Williams & Wilkins

Publishers, ISBN: 1560534605,

<http://www.amazon.com/exec/obidos/ASIN/1560534605/icongroupinterna>

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