

HOW TO FIND **MEDICAL** INFORMATION

Department of Health and Human Services

National Institutes of Health

National Institute of Arthritis and Musculoskeletal and Skin Diseases

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You May Want More Information

After contacting the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) or the NIAMS Information Clearinghouse, you may want to find additional information on a disease or disorder. Searching for medical information can be confusing, especially for first-timers. However, if you are patient and stick to it, you can find a wealth of information. Today's computer technology is making it easier than ever for people to track down medical and health information. Other good sources of information include textbooks, journal articles, reference books, and health care organizations. This booklet explains how to locate these important sources of information.

Where to Find Medical Information

- Community library
- Federal Government clearinghouses
- Associations and voluntary organizations
- Medical, hospital, or university libraries
- Personal physician
- Nurse, pharmacist, dietitian, or other health professional
- Telephone or fax services
- Computer databases
- The Internet

Start With Your Community Library

Most people have a library in or near their community, and it's a good place to start to look for medical information. Before going to the library, you may find it helpful to make a list of topics you want information about and questions you have. Also, if you've received a NIAMS information package, you'll notice the list of additional references at the end of most articles. You may want to get a copy of some of these articles. Your topic list and the information package will make it easier for the librarian to direct you to the best resources.

The following are some types of resources you are likely to find at, or access through, your local library:

Basic Medical References

Many community libraries have a collection of basic medical references. These references may include medical dictionaries or encyclopedias, drug information handbooks, basic medical and nursing textbooks, and directories of physicians and medical specialists (listings of doctors). You may also wish to find magazine articles on a certain topic. Look in the *Reader's Guide to Periodical Literature* for articles on health and medicine that were published in consumer magazines.

Computer Databases

Infotrac, a CD-ROM computer database available at libraries or on the Web, indexes hundreds of popular magazines and newspapers, as well as some medical journals such as the *Journal of the American Medical Association* and *New England Journal of Medicine*.

Your library may also carry searchable computer databases of medical journal articles, including MEDLINE®/PubMed® (<http://pubmed.gov>) or the *Cumulative Index to Nursing and Allied Health Literature*. Many of the databases or indexes have abstracts

that provide a summary of each journal article. Although most community libraries don't have a large collection of medical and nursing journals, your librarian may be able to get copies of the articles you want. Interlibrary loans allow your librarian to request a copy of an article from a library that carries that particular medical journal. Your library may charge a fee for this service.

Articles published in medical journals can be technical, but they may be the most current source of information on medical topics.

Medical and Health Directories

You may find many useful medical and health information directories at your library. Ask your librarian about the following resources:*

- *Directory of Physicians in the United States*. Chicago, IL: American Medical Association (AMA). Updated yearly. Provides information such as address, medical school attended, year of license, specialty, and certifications for physicians who are members of the AMA.
- *Health Hotlines*. A booklet of toll-free numbers of health information hotlines available from the National Library of Medicine (NLM) or on the Internet at <http://healthhotlines.nlm.nih.gov>.
- *Medical and Health Information Directory*. Detroit, MI: Gale Research. Updated yearly. Includes publications, organizations, libraries, and health services (three volumes).

* Names of resources and organizations included in this booklet are provided as examples only, and their inclusion does not mean that they are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular resource or organization is not mentioned, this does not mean or imply that it is unsatisfactory.

- *The Official ABMS Directory of Board Certified Medical Specialists*. New Providence, NJ: Marquis Who's Who. Updated yearly. Provides information on physicians certified in various specialties by the American Board of Medical Specialists.
- Rees, A., editor. *The Consumer Health Information Sourcebook*. 7th edition. Phoenix, AZ: Oryx Press, 2003. Lists information clearinghouses, books, and other resources.
- White, B.J., & Madone, E., editors. *The Self-Help Sourcebook: The Comprehensive Reference of Self-Help Group Resources*. 7th edition. American Self-Help Group Clearinghouse, 2003. Lists over 1,000 organizations that offer support groups.

MedlinePlus.gov also has a number of directories available freely to search for health facilities, health providers, and services at: <http://www.nlm.nih.gov/medlineplus/directories.html>.

If you find a particularly useful book at the library, you can buy a copy at your local bookstore. If the book isn't in stock, your bookstore can probably order a copy for you.

Some medical references have been converted from book form to a CD-ROM or disk for use on a personal computer. If you have a computer with a CD-ROM drive, color monitor, and sound card, you can use compact disks to locate medical information. Check with your local bookstore or computer store for software programs that contain health information. Many other medical references or databases are available online through the Internet.

Some Popular References for the Home Library

- *American Medical Association Family Medical Guide*. 4th edition. 2004. John Wiley & Sons (available in book and CD-ROM format) and *American Medical Association Complete Medical Encyclopedia*. Random House, 2003.
- *Johns Hopkins Symptoms and Remedies: The Complete Home Medical Reference*. New York: Rebus Publishing, 2003.
- *Mayo Clinic Family Health Book*, Third Edition. HarperResource, 2003.
- *The Merck Manual of Medical Information (Home Edition)*. 2nd Edition. Rahway, NJ: The Merck Publishing Group, 2004.
- *Professional Guide to Diseases*. 7th edition. Lippincott Williams & Wilkins, 2001.

Take Advantage of Services Provided by the Federal Government and Other Organizations

The Federal Government as well as many medical societies and nonprofit health organizations are also good sources of information.

The Federal Government operates a number of clearinghouses and information centers, including the NIAMS Information Clearinghouse. Services vary but may include publications, referrals, and answers to consumer inquiries. To obtain a free list of Federal information clearinghouses, visit the National Health Information Center's home page (<http://www.health.gov/nhic>), write to P.O. Box 1133, Washington, DC 20013-1133, or call (800) 336-4797.

Many voluntary health organizations are devoted to specific diseases or conditions (i.e., the Scleroderma Foundation, National Alopecia Areata Foundation, National Psoriasis Foundation, Arthritis Foundation, Lupus Foundation of America, etc.). Other organizations, such as the American Association of Retired Persons, serve a particular population group and provide information on a variety of topics, including health-related ones.

Your librarian or a NIAMS Information Clearinghouse information specialist can help you locate appropriate organizations and support networks. Many of these organizations offer referrals, publications, newsletters, educational programs, and local support groups. Your doctor may be able to tell you about support groups in your community as well.

Examples of Health-Related Associations and Organizations That Provide Information on Arthritis and Musculoskeletal and Skin Diseases

- American Academy of Dermatology
- American Academy of Orthopaedic Surgeons
- American College of Rheumatology
- American Physical Therapy Association
- American Skin Association
- Arthritis Foundation
- National Osteoporosis Foundation

There are many more organizations; call the NIAMS Information Clearinghouse for additional information.

Look for a Medical Library

Medical libraries can usually be found at medical, nursing, and dental schools; large medical centers; and community hospitals. Not all hospital or academic libraries are open to the public, but a librarian at your community library may be able to give you information about the closest medical library open to the public. Medical libraries may also be listed in your telephone book under “hospitals,” “schools,” or “universities.” In addition, you can call the National Network of Libraries of Medicine (<http://nmlm.gov>) of the National Library of Medicine (NLM), National Institutes of Health (NIH), at (800) 338-7657 to find the location of the nearest medical library open to the public.

A medical library has a large collection of resources, including many medical and nursing textbooks and a comprehensive collection of medical and health-related journals. Although you may not be allowed to check out materials, most libraries have photocopiers you can use to copy material you want to take home.

Library Resources

- Computer databases
- Directories of board-certified medical specialists
- Drug reference books
- Medical and diagnostic laboratory testing manuals
- Medical and health information directories
- Medical dictionaries
- Medical encyclopedias
- Medical, nursing, and allied health textbooks

Investigate Other Options for Finding Information

People who are unable to get to a community or medical library have several options for finding additional medical information. Some community libraries provide access to online databases that can be searched from a home computer via a modem. In addition, your doctor, nurse, pharmacist, dietitian, or the patient education department at your local hospital may be able to provide you with pamphlets, brochures, and journal articles or direct you to classes, seminars, and health screenings.

Use Telephone and Fax Services

Some communities have a telephone medical service that allows callers to listen to audiotapes on certain disease topics. Also, your health insurance company or health maintenance organization may have a nurse available to answer health-related questions over the telephone.

If you have access to a fax machine, you can get health information from some organizations in just a few minutes. If a faxback system is available, use the telephone on your fax machine to call the faxback number of the organization and listen to the instructions. In most cases, you can request a list or menu of information to be sent to you first.

The Centers for Disease Control and Prevention at (888) 232-3299 (toll-free) is an example of an organization that has information available by fax. Your librarian can help you locate other fax services.

Explore Computer Databases

The computer has become an important tool for helping people locate medical and health information quickly and easily. Most software and information services are user friendly and allow

people with no formal training in computer searching to use databases to obtain information. Using a computer at home or in the library, you can find health information by searching CD-ROM databases, searching online on the Internet, or using a health-related software program.

As mentioned earlier, many public libraries have *Infotrac*, a database that includes consumer health information. It indexes popular magazines and newspapers and 2 to 4 years' worth of medical publications. Medical libraries have more extensive medical databases. Just ask your librarian to help you find the most appropriate CD-ROM or online (Internet) databases for your needs. Many medical databases can also be accessed from your own home or work computer or wherever you have Internet access.

Here are some major databases worth searching:

- **MEDLINE®/PubMed®.** This database contains citations and often abstracts for over 15 million articles in over 4,800 biomedical journals on all aspects of biomedicine and allied health fields. MEDLINE®/PubMed® (<http://pubmed.gov>) now covers the literature from 1951 to the present and is available free of charge through the NLM Web site at <http://www.nlm.nih.gov>. Some free full-text articles are available through publishers and PubMed Central™ (<http://pubmedcentral.nih.gov>).
- **DIRLINE®.** This database contains location and description information about a wide variety of resources, including organizations, research resources, projects, databases, and electronic bulletin boards concerned with health and biomedicine. The database is available online through the NLM at no fee at <http://dirline.nlm.nih.gov>.

Search the Internet

The Internet is a worldwide network of computers that can exchange information almost instantaneously. The World Wide Web (abbreviated *www* in computer addresses), or more simply, the Web, is a system of electronic documents linked together and available on the Internet for anyone with a computer, a modem, and an Internet provider account. While the terms “Internet” and “World Wide Web” are often used interchangeably, the Web is actually the part of the Internet that supports the use of graphics, pictures, sound, and even video.

In addition to the aforementioned databases, you can find a wealth of information on the Web—everything from the latest medical research to facts about particular conditions. The Internet also offers other resources such as bulletin boards, online publications, forums for discussion of current medical issues, and online support groups. For example, the American Self-Help Clearinghouse offers an online version of its *Self-Help Sourcebook* at <http://www.mentalhelp.net/selfhelp> that provides information on support groups and networks available in your community and throughout the world. The site also provides a link to the Self-Help Resource Room that contains information about online support groups and other health resources.

Help With Searching on the Internet

Searching for health information on the Internet can be confusing and difficult. The sheer volume of information can be overwhelming, and people often find it difficult to narrow down search topics or find specific Web sites. Although an Internet

Some Health Resources to Check Out on the WWW

**National Institute of Arthritis and Musculoskeletal
and Skin Diseases**

<http://www.niams.nih.gov>

National Institutes of Health

<http://www.nih.gov>

Combined Health Information Database

<http://chid.nih.gov>

MedlinePlus®

<http://medlineplus.gov>

healthfinder®

<http://www.healthfinder.gov>

National Library of Medicine

<http://www.nlm.nih.gov>

Agency for Healthcare Research and Quality

<http://www.ahrq.gov>

Arthritis Foundation

<http://www.arthritis.org>

American Academy of Dermatology

<http://www.aad.org>

search engine such as GOOGLE®, YAHOO!® or Netscape® is meant to help you find information, search results on specific topics often reveal thousands of Web sites, many of which may be unrelated to the information you want. You may want to get a copy of a reference book that provides tips on how to find health information on the Internet.

National Library of Medicine

Following are some services offered by the National Library of Medicine:

MEDLINE® and MedlinePlus®. You can search the NLM's MEDLINE® database, free of charge, on the Web. The link to this database can be found on the NLM home page at <http://www.nlm.nih.gov>. You can conduct a search in the Web-based product, PubMed®. It provides you with free access to MEDLINE® and, for a fee, allows you to use Loansome Doc Delivery Service to order copies of articles. PubMed® links you to publishers' sites for over 4,400 full-text journals; some are by subscription only. You can also access NLM databases (<http://pubmedcentral.nih.gov>) through the NLM Gateway®, <http://gateway.nlm.nih.gov/>, which searches many NLM databases simultaneously.

MedlinePlus® is designed to assist consumers in locating authoritative health information on the Internet. This service provides access to extensive information about specific diseases and conditions and has links to consumer health information from the National Institutes of Health, dictionaries, lists of hospitals and physicians, clinical trials, health information in English and Spanish, and some selected materials in other languages. Links to preformulated searches of the MEDLINE® database allow you to find references to the latest health

professional articles on each topic. The adam.com medical encyclopedia included in MedlinePlus® brings health consumers an extensive library of medical images, as well as over 4,000 articles about diseases, tests, symptoms, injuries, and surgeries. Drug information from the United States Pharmacopoeia and the American Society of Health-System Pharmacists is also available on the site. In addition, MedlinePlus® has an online medical dictionary licensed from Merriam-Webster and interactive patient tutorials licensed from the Patient Education Institute on a variety of health topics in English and Spanish.

NIH SeniorHealth.gov®. This Web site (<http://nihseniorhealth.gov/>) for older adults was developed by the National Institute on Aging and NLM to access health information, including the choice of speech-activated text and resources for low-vision seniors.

ClinicalTrials.gov. ClinicalTrials.gov is an information service of the National Institutes of Health developed by the NLM that provides patients, family members, health care professionals, and the public with easy access to information on clinical trials for a wide range of diseases and conditions. This database provides opportunities to participate in the evaluation of new treatments. The NLM is developing the database in collaboration with all NIH institutes, other Federal agencies, the pharmaceutical industry, and academic and other nonprofit organizations. You can access this database on the Web at <http://clinicaltrials.gov>.

Genetics Home Reference®. This is NLM's Web site for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions. Also included are discussions of genes, gene therapy, genetic testing, and consultation. You can access the database on the Web at: <http://ghr.nlm.nih.gov/>.

TOXNET® This is NLM's comprehensive toxicology and environmental health database. It can be accessed at: <http://toxnet.nlm.nih.gov/> and includes access to databases such as **DIRLINE®** and:

- **HSDB®** (Hazardous Substances Data Bank), a comprehensive, scientifically reviewed, factual database containing records for over 4,500 toxic or potentially toxic chemicals
- **TOXLINE®**, which contains references to literature on biochemical, pharmacological, physiological, and toxicological effects of drugs and other chemicals
- **Haz-Map®**, which has references to occupational exposure to hazardous materials
- **Tox Town®**, containing references to toxic chemicals and environmental health risks you might encounter in everyday life, in everyday places
- **Household Products Database®**, which addresses potential health effects, safety and handling of products found in your home and garage.

Department of Health and Human Services

healthfinder®. To help people find health information on the Internet, the Federal Government's Department of Health and Human Services has developed a Web site called **healthfinder®** (<http://www.healthfinder.gov>). This site serves as a gateway or point of entry to the broad range of consumer health information resources produced by the government and many of its partners. **healthfinder®** includes a searchable index and locator aids for news, publications, online journals, support and self-help groups, online discussions, and toll-free numbers.

Don't Believe Everything You Read

As you make purchases for your home library or search the Internet, keep in mind that not all information is written by qualified medical experts. Your doctor or a health organization may be able to recommend some good books or helpful Internet sites. When looking for health information on the Internet, don't believe everything you see. Articles published in peer-reviewed medical journals are checked for accuracy, but anyone can put information on the Internet, so there's no guarantee that the information you find is accurate or up-to-date. In addition, many companies set up Web sites primarily to sell their products. It may be helpful to ask a health professional about the information you find on the Internet, particularly before you buy any products. If you search and shop with care, you can add some medically sound reference materials to your home library and find accurate information on the Internet.

Use Information Wisely

It can be hard to judge the accuracy and credibility of medical information you read in books or magazines, see on television, or find on the Internet. Even people with medical backgrounds sometimes find this task challenging. The following are some important tips to help you decide what information is believable and accurate:

Books, Articles, and Television Reports

- Compare several different resources on the same topic. Check two or three other articles or books to see whether the information or advice is similar.
- Check the author's credentials by looking up his or her affiliations, such as university and medical school attended, associations, and lists of other publications.

For doctors, this information can be found in one of the physician directories at your library or on the American Medical Association's (AMA) Web site at <http://www.ama-assn.org> (click on AMA Physician Select). You can also call the American Board of Medical Specialists at (866) ASK-ABMS (275-2267) to see whether a physician is board certified in his or her specialty. Your librarian can help you find other resources to check the credentials of nonphysicians.

- Ask yourself if the information or advice “rings true.” That is, is it feasible, plausible, and common sense, or is it wishful thinking or sensationalism?
- Look for a list of references at the end of the article or book. Information that is backed up by other medical professionals and researchers is more likely to be accurate.
- Check out your information source. Was the article published in a peer-reviewed journal? Look for a list of editorial or review board members at the beginning of a journal. In a peer-reviewed journal, articles are reviewed by other qualified members of the profession for accuracy and reliability.
- Look very carefully at information published in newspapers and magazines or reported on television. Most reporters are journalists rather than medical experts. In addition, newspapers and television reporters may use sensationalism to attract more readers or viewers. Medical facts and statistics can be misrepresented or incomplete. Check to see whether the newspaper or magazine cites a source for its information and includes the credentials of the persons cited.

- Examine a magazine's list of editors. Do medical experts serve as editors and review articles? Be especially wary of personal testimonials of miracle cures. There's often no way of judging whether the story is true. Furthermore, don't trust medical product advertisements claiming miracle cures or spectacular results.

The Internet

- Compare the information you find on the Internet with other resources. Check two or three articles in the medical literature or medical textbooks to see whether the information or advice is similar.
- Check the author's or organization's credentials. They should be clearly displayed on the Web site. If the credentials are missing, consider this a red flag. Unfortunately, there are many so-called doctors and other health professionals making false claims on the Internet.
- Find out if the Web site is maintained by a reputable health organization. Remember that no one regulates information on the Internet. Anyone can set up a home page and claim anything. Some reliable Web sites providing health information include those of government agencies, health foundations and associations, and medical colleges. In general, sites ending in .gov (government), .edu (education) and .org (organization) are more likely to provide more reputable medical information than those ending in .com (commercial; that is, a site designed to sell a product or products).
- Be wary of Web sites advertising and selling products that claim to improve your health. More important, be very careful about giving out credit-card information on the Internet. Further, even if nothing is being sold on a

Web site, ask yourself if the site host has an interest in promoting a particular product or service.

- Ask yourself whether the information or advice seems to contradict what you've learned from your doctor. If so, talk to your doctor to clarify the differences in the information.
- Be cautious when using information found on bulletin boards or during “chat” sessions with others. Testimonials and personal stories are based on one person's experience rather than on objective facts or proven medical research.

To Make Informed Decisions About Your Health Care, You Need to Understand Your Health Problem

Medical information, especially material written for health care providers, can be hard to understand, confusing, and sometimes frightening. As you read through your materials, write down any words or information you don't understand or find confusing. Make a list of your questions and concerns. During your next office visit, ask your doctor, nurse, or other health professional to review the information with you so that you understand clearly how it might be helpful to you.

If the medical information you gathered is for a personal health problem, you may want to share what you found with your spouse, other family members, or a close friend. Family members and friends who understand your health problem are better able to provide needed support and care. Finally, you might want to consider joining a support group in your community. You may find it helpful to be able to talk with others who have the same health problem and share your feelings or concerns.

You may wish to look at several MEDLINEplus® health topic pages that deal with patient issues and communicating with your health care provider:

- Talking with Your Doctor (<http://www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html>)
- Patient Issues (<http://www.nlm.nih.gov/medlineplus/patientissues.html>)
- Choosing a Doctor or Health Care Service (<http://www.nlm.nih.gov/medlineplus/choosingadoctororhealthcareservice.html>)
- Personal Medical Records (<http://www.nlm.nih.gov/medlineplus/personalmedicalrecords.html>)

Ultimately, the information you gather from print and electronic resources can help you approach issues about your health care: how to prevent illness, maintain optimal health, and address your specific health problems. Armed with this knowledge, you can more actively work in partnership with your doctor and other health care professionals to explore treatment options and make health care decisions. Health care experts predict that today's computer and telecommunication systems will result in a new era—the health care system information age—built around health-savvy, health-responsible consumers who are the primary managers of their own health and medical care.

For More Information

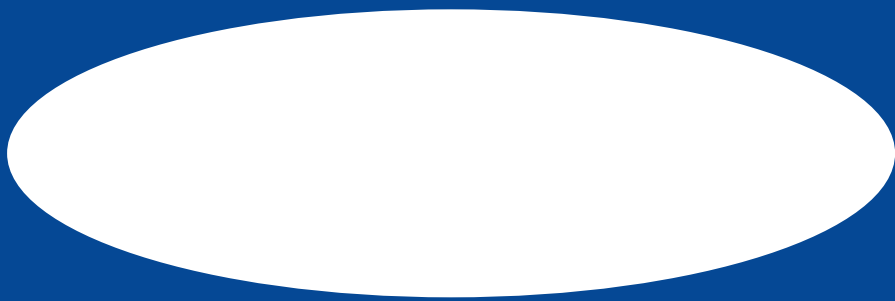
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The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. The National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. Additional information can be found on the NIAMS Web site at www.niams.nih.gov.



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and Human Services**

Public Health Service

National Institutes of Health

**National Institute of Arthritis and
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