Consumer Health Reference Center * Treadwell Library
Massachusetts General Hospital

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CHRC News

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CHRC Annual Report

Kate Kelly, CHRC Project Manager, submitted the CHRC's Annual Report for FY00 to the Massachusetts Board of Library Commissioners. In it, she reported the following statistics:

Treadwell Library received a grand total of 532 queries from 245 libraries. Public libraries accounted for 77% of queries and special libraries for 12% of queries. The remainder came from academic, school and law libraries, and regional library offices.

The Southeast and Metrowest Regions together accounted for close to half the queries, while the rest of the regions accounted for the remainder.

The most frequently asked queries involved delivery of health care (representing a wide range of medical questions about diagnoses and drugs); neurologic disorders; requests for recommendations (books, journals, internet sites), and medical or surgical procedures.

We are delighted to assist you and look forward to answering more questions. Please don't hesitate to be in touch with us.

In the News

Health Reference Interviews

Three excellent web sites discussing reference interview strategies for public librarians recently came to light.

Introduction to Health Reference and Research

http://www.nnlm.nlm.nih.gov/mar/training/healthreference.html

Prepared by the National Network of Libraries of Medicine (NNLM) serving the Mid-Atlantic Region, this up-to-date and fact-filled site reminds librarians of important points:

- The reference interview is absolutely necessary to determine the level of information needed.
- Consider whether the information is likely to be available over the Internet. If unlikely, consider more traditional channels of research first.
- Before you pursue the information you find, evaluate it.

This site also offers sample questions and a list of general characteristics of consumers seeking health information.

Reference Interview

http://www.sjvls.lib.ca.us/sjvls/corr/med/CCMED.HTM

A correspondence course prepared by California Opportunities for Reference Excellence (CORE) at San Joaquin Valley [California] Information Service, this site gives guidelines for handling medical questions in public libraries. Even though the course was prepared before the advent of the web, the general tenets hold true. Information is given under general headings:

- Find out what the patron wants.
- Find information the patron can understand.
- Distinguish between giving information and giving advice.

The authors of this course remind librarians to:

- Explain why it's important that the patron be as specific as possible.
- Be tactful, and use your best judgement to obtain as much information as possible without embarrassing yourself or the patron.
- Always remind the patron to consult with his or her health care provider.
- Find out if the patron is interested in consumer-level literature, or material written for the health care provider or scientist.
- Remember to differentiate between what you **can** do - provide information, and what you **can't** do - diagnose or provide medical advice.

- Use extreme caution with diagnoses and drugs that sound alike but which have entirely different meanings.
- Take care when responding to medical questions over the telephone because it is so easy to mis-hear, misinterpret, or misunderstand.

Information that will be helpful for you to obtain could include, but not necessarily be limited, to the following:

1. Ask the patron for an exact spelling of the disease or drug, if possible, including the part of the body affected, if relevant.
2. What is the age of the person who has the condition?
3. Is the information for the patron? Is the patron a health professional?
4. What level is needed? Can the patron handle technical material?

Special Kinds of Questions - Medical and Legal

http://www.nlc.state.ne.us/ref/star/chapter9.html

From the Nebraska Library Commission's Statewide Training For Accurate Reference Reference Manual (*STAR Manual)*, and bearing some resemblance to the ***Reference Interview*** above, this site provides sample caution statements for particular situations (telephone; providing drug information; what to do when the patron provides symptoms and wants a diagnosis to match.) A checklist for evaluation of medical web sites is

included, as well as a sample reference intake form and a bibliography.

Rare Diseases and Syndromes

This issue of the *CHRC News* focuses on a few selected sources of information for syndromes and rare diseases. Such written information (and often, accompanying illustrations) can be upsetting to the librarian who retrieves the pages from the fax machine and to the patron for whom it is intended, but as all the experts above agree, such material cannot be "censored." We try to provide information from more than one source, if possible, so that if your patron hasn't indicated a need for consumer level (or technical level) literature, a variety will be available.

It can sometimes seem difficult and even intimidating to try and find information about rare diseases and syndromes. Once investigation begins, it's often startling to find how much information is available. Even though it may be written more for the health care provider or scientist than the consumer, there are often non-profit organizations and support groups to help individuals and their families. A rare or "orphan" disease affects fewer than 200,000 people in the United States. There are more than 6,000 rare disorders that, taken together, affect approximately 25 million Americans. One in every 10 individuals in this country has received a diagnosis of a rare disease.

NORD

http://www.rarediseases.org/

One of the most important sources of information about rare diseases is the National Organization for Rare Disorders, Inc. **NORD** is a federation of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. Thousands of affected individuals and their families, as well as support groups, health care and human service professionals, and advocates for people with rare disorders and disabilities, rely on **NORD**'s assistance and leadership. **NORD** is dedicated to helping people with rare diseases and assisting the organizations that serve them. Since its inception in 1983**,** **NORD** has served as the primary non-governmental clearinghouse for information on rare disorders. **NORD** also provides referrals to additional sources of assistance and ongoing support.

Treadwell librarians are more than happy to search **NORD** for you and print out the complete reports, which would otherwise cost $7.50 each. Abstracts are available free. **NORD** is easily searched by typing the name of the disease you're looking for into the search box on the home page.

For instance, try searching for **Landau Kleffner Syndrome**, a rare neurological disorder of childhood. There is no need to use hyphens or apostrophes, and it's a good idea to omit the word "syndrome" or "disease". **NORD** allows for truncation: enter the first few characters of the word you are looking for, followed by an asterisk. Synonyms as well as Related Disorders are listed, along with a brief abstract, and links to web sites of support organizations

Genetic & Rare Disorders

http://www.mgh.harvard.edu/library/chrcindex.html

An excellent beginning place is the link to **Genetic & Rare Disorders,** under **Diseases, Disorders, & General Health Information** on the Consumer Health Reference Center site. The **Massachusetts Department of Public Health's Genetics Program** at http://www.acadia.net/nergg/state_programs.html#MA is one of many programs with a variety of services available to the public, including consumer information and referral, health care provider education, congenital anomaly surveillance, technical assistance in genetics education materials and projects, grant preparation and implementation, liaison to newborn screening, genetics education and outreach to underserved populations, and family-centered consumer information and referral.

DIRLINE: Directory of Information Resources Online

http://dirline.nlm.nih.gov/

The **D**irectory of **I**nformation **R**esources On**line** (**DIRLINE**) is the National Library of Medicine's online database containing location and descriptive information about a wide variety of information resources including organizations, research resources, projects, and databases concerned with health and biomedicine. This information may not be readily available in bibliographic databases. There are 14,000 records including genetic and rare diseases. Each record contains information on publications, holdings, and services. **DIRLINE** is easy to search. For instance, type **aneurysm** and you'll find full contact information for the Brain Aneurysm Foundation, Inc., located in Boston.

OMIM - Online Mendelian Inheritance in Man Database

http://www.ncbi.nlm.nih.gov/Omim/

OMIM is a catalog of human genes and genetic disorders developed for the web by the **National Center for Biotechnology Information (NCBI)**. Much of **OMIM** is highly technical and meant for the scientist and researcher. It can be useful as a "last resort" for the lay person. Click on “Search the **OMIM** Database” and type the name of the disease. As with **NORD**, you can allow for truncation with an asterisk. For instance, type **scoliosis**. Fifty diseases are listed, ranked in relevancy order. The text includes scientific and historic information. The links to Medline citations may be the most useful part of **OMIM** for the general user.

Stanley Jablonski’s Online Multiple Congenital Anomaly / Mental Retardation (MCA/MR) Syndromes©

http://www.nlm.nih.gov/mesh/jablonski/syndrome_title.html

This 700-entry database describes congenital abnormalities associated with mental retardation. Special attention is given to the type of information which, because of space limitations of the printed form, is often completely omitted in the existing reference sources. Searching can be carried out in a variety of ways: in all fields of the document; by **OMIM** number; by a major characteristic of the syndrome, or by “Personalia” (the scientist or physician who made the original

discovery). For instance, choose Personalia and type **Angelman**. His first name and nationality are listed, along with a summary of the syndrome which bears his name, a genetic disorder with many neurologic components. Click on the name of the syndrome to find complete information, including links to Medline subject headings; links to the entry in the **OMIM** database; major features of the syndrome, historical references, and a Medline bibliography.

Office of Rare Diseases (ORD)

http://rarediseases.info.nih.gov/ord/

The **ORD**'s web site covers 6000 rare diseases, including current research, publications from scientific and medical journals, completed research, ongoing studies, and patient support groups. **ORD**, which is a branch of the **National Institutes of Health** (**NIH**), also provides links to many clinical trial databases to find information on current or planned rare disease studies. The Patient Travel and Lodging section includes direct links to organizations supplying special airfare flights to research and treatment sites, as well as links to hotels, motels and other lodging near medical centers.

Print Resources

We often use print sources to supplement web-based information. Sometimes, books are our primary source of information.

Birth defects encyclopedia : the comprehensive, systematic, illustrated reference source for the diagnosis, delineation, etiology, biodynamics, occurrence, prevention, and treatment of human anomalies of clinical relevance / Mary Louise Buyse, editor-in-chief. Cambridge, Mass.: Blackwell Scientific Publications, 1990. This extraordinarily comprehensive book runs to almost 2000 pages with 2000 articles and 1700 black-and-white photographs, and is arranged in alphabetic order, with numerous *see* references as well as complete information about the disease, treatment and prevention, if applicable, bibliographic references, and **OMIM** number, if available. In addition to familiar diseases, such as sickle cell anemia and fetal alcohol syndrome, it also includes benign diseases, such as **ACHOO Syndrome** (Autosomal Dominant Compelling Helioophthalmic Outburst Syndrome.) It should be noted there is no indication of the availability of a newer edition.

Another frequently-used reference book, **The encyclopedia of genetic disorders and birth defects / James Wynbrandt and Mark D. Ludman**. New York: Facts on File, 2000, contains over 1000 entries. Definitions range in length from a paragraph to three pages, with numerous *see* references. Terms associated with the field of genetics, such as recombinant DNA, are also defined. Appendices include congenital malformation statistics, birth defect statistics, selected web resources, and an extensive bibliography.

Dictionary of medical syndromes / edited by Sergio I. Magalini and Sabina C. Magalini / Philadelphia: Lippincott-Raven, 1997, is another source to which we frequently refer for brief information. The thorough index includes *see* references. An important feature of this book is the

inclusion of "classic citations," references to the original articles that described the syndrome.

Often, information about a specific syndrome will be included in a textbook on a broader topic. For instance, **Shadow syndromes /** John J. Ratey and Catherine Johnson. New York: Pantheon Books, 1997 includes chapters on masked depression, hypomanic personality, intermittent rage disorder, attention deficit disorder, and autism. Syndromes related to neuro-muscular disease, such as acid maltase deficiency or carnitine deficiency syndrome, can be found in such textbooks as **Myology : basic and clinical** / editors, Andrew G. Engel, Clara Franzini-Armstrong. New York: McGraw-Hill, 1994.

Trying to find information about genetic and rare diseases can be both frustrating and rewarding. Please don't hesitate to contact us for assistance.

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http://www.mgh.harvard.edu/library/chrcindex.html