

HEALTHNET NEWS

A newsletter for public librarians and others interested in consumer health information services

Volume XVIII Number 1

Spring 2003

UPDATE

HEALTHY WEB SITES PROGRAM STILL BEING OFFERED



We are still offering the “Healthy Websites” program to public libraries. If you are interested in hosting a program for the public on how to find quality health information on the Internet, contact us at 860/679-4055. We can offer a one to two hour program during the day or evening. We will even design a flyer and write a press release for you to use for publicity.

The program demonstrates the most important web sites consumers can use to find current, high quality health information and discusses how to evaluate sites to make certain they are authoritative. Attendees are given handouts with a list of the web sites discussed.

PROFESSIONAL READING

BEST CONSUMER HEALTH BOOKS – 2002

Even with the proliferation of online health resources for consumers, there are still good reasons for libraries to have up-to-date collections. Books are more portable and personal and some people still do not feel comfortable using a computer. The May 1, 2003 issue of **Library Journal** has a list of twenty-three consumer health books selected as “the best” for 2002 by Barbara Bibel, a frequent reviewer of health titles for LJ. Bibel is a Reference Librarian in the Science/Social/Government Documents Department, Oakland (CA) Public Library. Titles include those dealing with Alzheimer’s disease, cancer, children’s health, drugs, gastrointestinal disorders, hearing disorders, heart disease, men’s health, women’s health, and weight loss. Two reference titles are also included.



Each title entry contains complete bibliographic information, price, a brief description, and the date the original review appeared in LJ.

Another article in the same issue of LJ discusses recent trends in consumer health book publishing. Wilda Williams, Senior LJ Book Reviewer examines the reasons for the continued popularity of health titles. She describes what publishers are doing to expand their visibility in health book marketing. Many publishers have found that titles with a specific focus on a single disease sell better than general health titles. “Alternative” and “natural” are no longer “dirty words” in the publishing industry evidenced by the phenomenal success of titles on herbs, acupuncture, and other alternative health titles.

Williams points out that publishers are not driven to publish a title because the subject is the latest fad, but that interest in the right medical credentials and expertise and whether a topic has something new to offer are often the deciding factors determining what to publish.

Bibel B. Best Consumer Health Books 2002. **Library Journal** 2003 May 1; 128(8):61-2, 64-5.

Williams W. Consumer health goes proactive. **Library Journal** 2003 May 1; 128(8):66,68.



Healthnet: Connecticut Consumer Health Information Network
Lyman Maynard Stowe Library ♦ University of Connecticut Health Center
PO Box 4003 ♦ Farmington CT 06034-4003
Telephone: 860/679-4055 ♦ email : richetelle@nso.uhc.edu
<http://library.uhc.edu/departm/hnet>

NETNEWS

SARS – IMPORTANT, UP-TO-DATE INFORMATION



Several Internet sites have up-to-date information on Severe Acute Respiratory Syndrome (SARS), the atypical type of pneumonia that has been discussed daily in virtually every news media for the last few months.

MedlinePlus from the **National Library of Medicine** – <http://medlineplus.gov/>– has current news stories about SARS, general overviews of the disease from the Centers for Disease Control and Prevention and the World Health organization, information about diagnosis, treatment, prevention, and screening as well as statistics and basic information in other languages including French, Chinese, and Vietnamese.

The **World Health Organization** - <http://www.who.int/csr/sars/en/> - also has information about SARS including the latest case statistics, a map showing the reported probable cases worldwide, travel recommendations and advisories, and technical information about laboratory tests used to diagnose the disease.

The **Centers for Disease Control and Prevention (CDC)** - <http://www.cdc.gov/ncidod/sars/>- has similar information about SARS as the above mentioned sites. The CDC site also includes fact sheets for the management of school students exposed to SARS, guidelines for persons in the workplace environment, and information for airline, airport, and travel workers.

General news stories and informative essays on the SARS epidemic can be found in a special science section of the **New York Times** at <http://www.nytimes.com/pages/science/sciencspecial/index.html>. An interactive graphic on what kind of face masks work best and how they work and a slide show of scenes from around the world depicting the impact of SARS in our daily lives are featured on this site.

UNDERSTANDING THE NEW HEALTH PRIVACY LAW

If you had a medical appointment since April 14 of this year, you may have been given a brief questionnaire to complete about the disclosure of your medical information along with a booklet describing your right to the privacy of your medical information. This practice is required by a new law, the Health Insurance Portability and Accountability Act (HIPAA) of 1996, which became effective on April 14. An important provision of the law specifically applies to the privacy of personally identifiable medical information. The new privacy regulations ensure a national floor of privacy protections for patients by limiting the ways in which health plans, pharmacies, hospitals and other covered entities can use patients' personal medical information. The law has many different parts and covers more than privacy of medical information. Like most laws, it is very complex. There is, however, information available for the consumer who is interested in learning more about the privacy provisions of HIPAA.



The **United States Department of Health and Human Services, Office for Civil Rights**, has information about HIPAA at <http://www.hhs.gov/ocr/hipaa>. A fact sheet called "Protecting the Privacy of Patients' Health Information" describes the key provisions of the law related to access to medical records, how patients are to be notified of the healthcare providers privacy practices, and the limits that are placed on the use of personal medical information. The fact sheet also describes the new limits and restrictions on the use of personal health information for marketing purposes. Other provisions discussed are the patient's right to request confidential communications of their medical information and the patient's right to file a formal complaint regarding the privacy practices of a covered health plan or provider.

The fact sheet also describes other specific obligations of healthcare entities related to HIPAA which include having written privacy procedures and providing training for employees about the regulations and how they are to be implemented. The law also provides for civil and criminal penalties ranging from fines of \$50,000 up to \$250,000 and up to ten years in prison for entities that misuse personal medical information.

TIPS ON EVALUATING HEALTH INFORMATION ON THE INTERNET

How can you be sure you're getting the most current and accurate health information on the Internet? **The American Association for Retired Persons (AARP)** has developed an online primer for older adults for evaluating health information and other kinds of online information - <http://www.aarp.org/confacts/health/wwwhealth.html> .

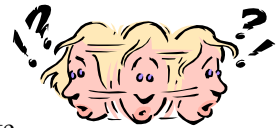
The primer cautions that there are no rules governing what kind of information appears on the Web, nor are there restrictions about who can publish the information. When evaluating a site, web surfers should determine who is responsible for the information and whether the individual or group has expertise in the subject matter. The user should also check to see if the information is current. AARP recommends checking the facts by consulting with a healthcare professional.

The user should also determine if the site is selling a product since this could mean the information is biased. AARP suggests that users apply the "Too good to be true" test to information - if it sounds too good to be true, it probably is.

Along with guidance on evaluating web sites, AARP offers a list of 100 credible medical web sites. For additional information about evaluating Internet health resources, see Healthnet's "Evaluating Web Sites for Consumer Health Information" at <http://library.uchc.edu/departm/hnet/rbevalwebsite.html> .

CONFUSED ABOUT MEDICAL NEWS STORIES?

Health InSight - <http://www.health-insight.com/ns/index.html> - is a project developed by the Harvard School of Public Health's Center for Risk Analysis. Its aim is to help consumers evaluate health and scientific information and to consider how the information can be used to improve their lives. The site has a "Consumer's Guide to Taking Charge of Medical Information" which helps consumers evaluate the information they are reading in newspapers and online or hearing via television or radio.



A list of ten questions is presented with an explanation of the reasons for asking the question. The questions include: What is the message? ; Is the source reliable?; How strong is the evidence overall?; Does this information matter?; What do the numbers mean?; How does this risk compare to others?; What actions can be taken to reduce the risk?; What are the trade-offs?; What else do I need to know?; and Where can I get more information?.

AN INSIDE STORY ABOUT ALZHEIMER'S DISEASE

Alzheimer's disease, probably the most frequent type of dementia among the elderly, occurs in nearly 4 million Americans. It is more common among older adults. Almost half of all adults eighty-five and older suffer from Alzheimer's disease.

A revised edition of a National Institutes of Health publication for health consumers on the progression and causes of Alzheimer's disease has been recently published. "Alzheimer's Disease: Unraveling the Mystery" is available in print form, at no charge, from the Alzheimer's Disease Education and Referral Center of the U.S. National Institutes of Health. You may request a copy by phoning their toll free number (1-800-438-4380) or by sending an email request to adear@alzheimers.org . The publication is also available online, in both PDF and HTML versions, at <http://www.alzheimers.org/unraveling/index.htm>.

This 64-page book is accompanied by a CD-ROM that includes an animation of the disease's progression in the brain as well as text files and illustrations from the book. The book, in PDF format, is also part of the CD-ROM.

Intended for the general public, the publication is written in brief, readable language. The text is enhanced by medical illustrations and PET scan photos showing the human brain as Alzheimer's disease progresses. There are pictures of beta amyloid plaques and the diminished brain as the disease reaches later stages. The section "A Walking Tour of the Human Brain" describes and illustrates the brain's normal functioning and changes that occur when Alzheimer's disease develops. Other topics discussed include the genetics of the disease, possible causes, recent research, and clinical trials and how to participate in them. A glossary, a bibliography, and a listing of helpful organizations for caregivers are also provided.

GENETICS AND GENETIC CONDITIONS

The National Library of Medicine has a new Web site, the **Genetics Home Reference**. The Genetics Home Reference is NLM's web site for consumer information about genetic conditions and the genes responsible for those conditions.



Each condition and gene summary provides a basic discussion of that particular topic and links to outside resources for more information. In addition, each genetic condition page links to summaries for genes that are related to that condition; each gene also links back to the associated conditions. At the bottom of each summary page, a list of glossary terms links to definitions of technical terms found in the summary.

For users who would like more general information about genetics, the online publication "Help Me Understand Genetics" provides a basic explanation of how genes work and how mutations cause genetic disorders. It also includes current information about genetic counseling, genetic testing, gene therapy, and the Human Genome Project.

The Genetics Home Reference can be accessed directly at <http://ghr.nlm.nih.gov/>. It may also be accessed from MEDLINEplus health topic pages – <http://medlineplus.gov/> - (type in "genetics" in the topics page search box then select "Genetics Home Reference").

For a different approach to offering basic information about genetics and medicine, go to the University of Michigan Health System's site at <http://www.med.umich.edu/genetics/home.htm>. Using the metaphor of a symphony orchestra to demonstrate basic concepts in genetics, this site allows visitors to learn about how genes, proteins, and cells work in tandem and to browse through sections on various genetic diseases to obtain a brief overview of each condition. There is also information about ongoing research for each of the conditions.

CANCER TREATMENT AND ALTERNATIVE MEDICINE

The **M.D. Anderson Cancer Center at the University of Texas, Houston** has a database on their web site called Complementary/Integrative Medicine Educational Resources (CIMER). The database, located at <http://www.mdanderson.org/departments/CIMER>, contains evidence-based reviews of complementary or alternative cancer therapies as well as links to their authoritative resources. These reviews evaluate the designs and the results of published research on herbal, mind-body, energy, nutrition, and other biological /organic/pharmacological (e.g., cartilage) substances. Detailed scientific reviews are provided to assist health care professionals in guiding patients who would like to integrate these therapies with conventional treatments. Since this site was designed for physicians, much of the information is technical although not out of reach for an educated consumer. Some reviews have a brief summary written for patients along with a more technical report written for physicians.

Each profile for the therapy has a list of related terms, basic background information, uses based on scientific evidence with an efficacy grade for each use, a listing of uses based on tradition or theory (unscientific evidence), dosing information, safety, interactions with drugs, herbal products, and supplements, and selected references to scientific research. A date is given for when the information on the therapy was peer-reviewed.

DATABASE OF HERBAL MEDICINES

HerbMed – <http://www.amfoundation.org/index.htm> - is an interactive, electronic herbal database. It provides hyperlinked access to scientific and medical research articles on the use of herbs for treating medical conditions. This evidence-based information resource is for professionals, researchers, and the general public. The database was developed and is maintained by the Alternative Medicine Foundation, a non-profit organization with the mission of providing responsible and reliable information on alternative medicine to the public and health professionals.



It

Each herbal description includes links to citations and abstracts in the Medline database of medical and scientific journal articles. These links are grouped in the following topic areas: evidence for efficacy (human data); methods of preparation; evidence of activity; warnings; and formulas and blends. Other information includes photographs of the herb, articles on cultivation, conservation, and ecology related to the herb, and a listing of related online resources. There is also a section of "live PubMed" (Medline) searches on different topics related to the herb. Selecting the topic automatically runs a search of the Medline database.

The HerbMed site also has resource guides on different alternative medicine treatment modalities, such as acupuncture, homeopathy, ayurveda, and naturopathy. Each resource guide describes the specific treatment method, its history, and how to find a qualified practitioner. When available, the guides also list treatment centers where the therapy is practiced. There is also a list of recommended books and Internet resources on the topic and links to organizations and professional associations.

Five resource guides are also available on autoimmune diseases, cancer, cardiovascular disease, healthy aging, and women's health. These guides follow the same format as treatment method guides.

FOR YOUR CONSIDERATION



The following books are recommended for public libraries and health sciences libraries with consumer health collections. They are not part of the UCHC library collection.

Health insurance resources manual: Options for people with a chronic disease or disability. Dorothy E. Northrop and Stephen Cooper. Demos Medical Publishing, 2003. 196 p. (ISBN 1-888799-69-2), \$24.95.

For anyone seeking health insurance coverage, not only those “with a chronic disease or disability,” this manual is an extremely helpful information source.

The book includes important details about eligibility, deductibles, waiting periods, premiums, income limits, and other important data needed to seek and select health insurance. The information is comprehensive and well organized, often laid out as bulleted lists of significant qualifications and guidelines.

There are chapters about managed care and indemnity plans, Medicare and Medicaid coverage, Social Security Disability Insurance, Supplemental Security Income, COBRA, and HIPAA. The book's appendix includes state-by-state information about health insurance coverage for high risk individuals, a directory of state insurance departments, state pharmaceutical assistance programs, a list of relevant government and organization websites, and a glossary of acronyms for government programs.

Integrative Medicine. David Rakel. Saunders, 2003. 891 p. (ISBN 0-7216-9288-5), \$69.95.

Integrative medicine is not the same as complementary and alternative medicine. It encompasses allopathic (conventional) medicine as well as alternative medicine. According to author Dr. David Rakel, director of the Integrative Medicine Program at the University of Wisconsin, and his mentor, Dr. Andrew Weil, integrative medicine's focus is the informed selection of effective therapies, appropriate to the patient, whether they are alternative or conventional. It involves the patient directly in the healing process, uses the least invasive therapy whenever possible, and focuses on prevention of disease and maintaining good health.

Written for the primary care physician, this book is a comprehensive, well-organized guide to treatment and prevention of nearly eighty medical conditions. References to journal articles and books cited within the text appear at the end of each brief chapter. In addition to Dr. Rakel, a number of physicians, many who specialize in integrative medicine, are the authors of individual chapters. The contributors' hospital or university affiliations are listed. The book concludes with chapters on how to implement a number of alternative and complementary techniques, e.g. meditation, guided imagery, self-hypnosis, acupuncture.

Each disease-related chapter includes sections on the disease's symptoms and background, types of therapy possibly effective including nutrition, mind-body techniques, medications, spirituality, and surgery. Also in the chapter are “Therapies to consider,” ones that may be effective but have not been proven scientifically, and a “Therapeutic review” briefly highlighting therapies recommended in the chapter.

This is a comprehensive resource, unique for its inclusion of both alternative and conventional therapies.

Talking to Alzheimer's. Simple ways to connect when you visit with a family member or friend.

Claudia J. Strauss. New Harbinger Publications, Inc. 161 p. (1-57224-27-1), \$12.95 pap.

Communication consultant Claudia Strauss' experiences as a frequent visitor to a hospitalized Alzheimer's patient taught her a great deal about how to communicate effectively and compassionately with an individual who is often frightened and confused but still in great need of human connection. This brief, compassionate guide to conversing with an Alzheimer's patient provides specific suggestions for conversations, even supplying the exact words in many cases. It is designed to help conduct a conversation without embarrassing the patient who may have forgotten not only specifics of her life but also the specifics of a conversation held moments before.

This practical book includes a resource guide to books, organizations, and websites and a Topic Finder which cites the page on which a specific question such as "What if I say the wrong thing?" "What if my intuition tells me to lie?" is answered.

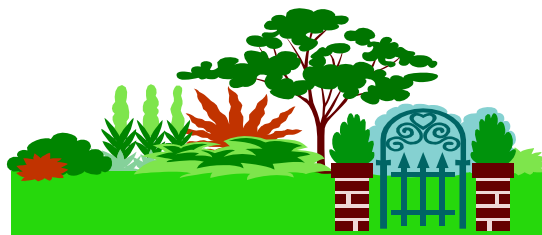
UCHC RECENT ACQUISITIONS

The following book was recently added to the Health Center Library collection. Public libraries and health sciences libraries may want to consider it for purchase.

The 5-Minute Herb and Dietary Supplement Consult. Adriane Fugh-Berman, editor. Lippincott, Williams & Wilkins, 2003. 475 p. (ISBN 0-683-30273-6), \$59.95. UCHC call # QV 766 F958 2003.

Although this guide to herbs and dietary supplement is concise, the research-based information provided in each herb's two page description is comprehensive and detailed. Compiled by a physician who is a professor at George Washington University School of Medicine, the 5-Minute Consult describes more than one hundred sixty herbs, vitamins, minerals, and dietary supplements. Written mainly in technical terms for a medical audience, the information is clearly laid out and categorized by topics such as active ingredients, mechanism, adverse reactions, evidence of effectiveness, and dosage. The author has summarized selected clinical trials in her discussions of each herb's effectiveness in demonstrating its claimed benefits. At the beginning of each herb's brief article, the most important facts are reduced to a "10 Second Take" that summarizes information about the herb's uses and safety, (e.g. Foxglove is a toxic herb that should not be used medicinally.")

Footnotes in the text refer to books and medical journal articles that form the basis of descriptions of the herbs' effects, uses, and risks. An appendix of reference tables includes translations of the English name of one hundred three herbs into the technical pharmacopoeia name as well as Latin, Spanish, French, and German. There are tables of recommended dietary intakes by age group for vitamins and dietary supplements and tables specifying caffeine, choline, and oxalate content of specific foods.



*Healthnet News is written by Alberta L. Richetelle and Judith Kronick.
If you have questions about anything in the newsletter or about Healthnet services for Connecticut public libraries,
please call 860/679-4055; e-mail address :richetelle@nso.uchc.edu*

© 2003 University of Connecticut Health Center. All rights reserved.

ISSN: 1526-8624