

HEALTHNET NEWS

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

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UPDATE

SAVE THE DATE - MEDICAL REFERENCE WORKSHOP ON OCTOBER 23, 2002

A Medical Reference Tools and Techniques workshop will be held on Wednesday, October 23, 2002 at the Wallingford Public Library. This workshop is for public library staff who work the reference desk. The program's emphasis is on consumer health information and will cover services offered by Healthnet, guidelines for providing medical information to consumers, and important print and Internet resources for answering common questions.

For more details see the enclosed flyer. To register, complete the tear-off registration form and mail it to Healthnet. The registration deadline is October 11th.

For more information, contact Healthnet at 860/679-4055.

NETNEWS

WOMEN'S HEALTH INITIATIVE – IMPORTANT CLINICAL TRIALS AFFECTING WOMEN

The National Institutes of Health (NIH) established the Women's Health Initiative (WHI) in 1991 to address the most common causes of death, disability and impaired quality of life in postmenopausal women - cardiovascular disease, cancer, and osteoporosis. The WHI is a 15 year multi-million dollar endeavor and one of the largest U.S. prevention studies of its kind. Its three major components are:



- a randomized controlled clinical trial of promising but unproven approaches to prevention;
- an observational study to identify predictors of disease;
- a study of community approaches to developing healthful behaviors.

The web site of WHI - <http://www.nhlbi.nih.gov/whi/index.html> – describes the goal of WHI which is to focus on the major causes of death, disability and frailty in postmenopausal women. The plan is to reduce coronary heart disease, breast and colorectal cancer, and osteoporotic fractures among postmenopausal women via prevention strategies and risk factor identification.

The site also has information about current clinical trials and a listing of the 40 Clinical Centers where the trials are conducted. Recruitment for all of the trials has been completed.

Fact sheets are available on the current five major clinical trials being conducted, one of which is the hormone replacement therapy trial recently in the news. One arm of the trial in which women were taking estrogen and progestin was stopped because it was determined the risks outweighed the benefits of this intervention. The other part of this



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trial, in which women were taking estrogen alone, is continuing. There are a number of informational resources related to this study on this site with an explanation of the reasons for its discontinuation. There is information for women who participated in the study, for consumers and health professionals, and press releases about the study.

In addition to the hormone replacement study, another clinical trial is looking at the effect of a low-fat, high fruit, vegetable and grain diet on breast cancer, colorectal cancer and heart disease in postmenopausal women. Another study is testing whether a calcium/vitamin D supplement can reduce the risk of colorectal cancer and the frequency of hip and other bone fractures in postmenopausal women.

An observational study is also being conducted to attempt to estimate risk factors which will predict heart disease, cancers, and fractures and to identify "new" risk factors. A community prevention study is focusing on community-based prevention strategies to enhance adoption of healthful behaviors, with a particular focus on women of diverse races, ethnic groups, and socioeconomic strata.

All of this is important information for women who want to keep up-to-date on research related to risk factors affecting their health and well-being in later life.

INFORMATION ABOUT STROKE

The **Internet Stroke Center (ISC)** - <http://www.strokecenter.org/> - is a non-profit, educational service of the Stroke Center at Barnes-Jewish Hospital, Washington University Medical Center and the Cerebrovascular Diseases Section of the Department of Neurology at Washington University School of Medicine in St. Louis. The Internet Stroke Center exists to advance understanding of stroke research and clinical care and to provide current, professional, un-biased information about stroke. Although much of the information is aimed at physicians who treat patients who have had a stroke, the site has a special section for stroke patients and their families. The sections for professionals also have much to offer patients and their families in the way of important research and clinical information.



The main feature of the patient section is an illustrated guide to understanding stroke. Accompanied by colorful and comprehensive images, the guide describes in detail the basics of stroke including the different types of stroke, how stroke is diagnosed, and the various treatment options available. Information is given on laboratory tests and procedures such as carotid and transcranial Doppler, cerebral arteriogram, lumbar puncture, and blood chemistry and coagulation tests, to name just a few. Treatment information includes specific medications, carotid endarterectomy, and clinical trials currently being developed.

A special feature offers a patient and family guide to recovery after a stroke to help in adjusting to life's changes. The guide has information on how to find a stroke support group, accounts of stroke survivors, and techniques for adapting a home to help the person who has had a stroke maintain as much independence as possible. Several streaming videos about stroke treatment and rehabilitation are included in this section. There is a special caregivers guide which includes links to important Internet resources and a web cast on-demand broadcast which discusses the caregivers role in post-stroke rehabilitation.

Other features of this well designed and informative site include a Spanish language version of the illustrated guide to understanding stroke, recent news stories related to stroke prevention, treatment, and rehabilitation, a directory of stroke centers in the United States, organizations concerned with stroke, and other Internet resources.

Other important Internet resources on stroke include:

American Stroke Association - <http://www.strokeassociation.org/>

A division of the American Heart Association., this site has information about stroke warning signs, diagnosis, and treatment, and includes a heart and stroke encyclopedia, a stroke assessment quiz, and how to get a free subscription to their magazine *Stroke Connection*.

National Stroke Association - <http://www.stroke.org/about.cfm>

This site features information about the causes, diagnosis, and treatment of stroke, stroke prevention, current research, regional stroke centers, and survivor and caregiver resources.

National Institute of Neurological Disorders and Stroke -

http://www.ninds.nih.gov/health_and_medical/disorders/stroke.htm

From the National Institute of Health, this site offers information about stroke diagnosis and treatment and current research.

DIABETES BOOKLET AVAILABLE ONLINE

The **National Diabetes Information Clearinghouse** has recently made available an online edition of its publication *Your Guide to Diabetes – type 1 and type 2*. The booklet is an update of their booklet *Do Your Level Best* and is available at <http://www.niddk.nih.gov/health/diabetes/pubs/type1-2/index.htm>

The booklet describes what diabetes is and how to take care of it. Written at an eighth-grade reading level, it summarizes steps for daily care, procedures to follow when blood glucose levels are high or low, how to prevent or delay long-term complications, and management of diabetes during special times such as an illness, travel, or pregnancy. The booklet also describes target levels for the A1C hemoglobin test and daily blood glucose self-monitoring and has a “daily diabetes record page” for recording blood glucose readings and medication dosages and times.

Print copies of the publication may also be obtained by contacting the National Diabetes Information Clearinghouse at their web site at <http://www.niddk.nih.gov/health/diabetes/pubs/dmpubs/dmform.htm>. You can print the order form and mail it to the Clearinghouse. They also have many other free publications available on diabetes.

SPANISH LANGUAGE HEALTH SITES

According to statistics from the 2000 U.S. Census, there are over 13 million Hispanics in the United States who do not speak English well. Although Internet usage by Hispanics continues to increase, there are still only a few sites that offer quality health information in Spanish. Also, according to the Agency for Healthcare Research and Quality (AHRQ), the rate of diseases such as diabetes, hypertension, and heart disease is much higher for racial and ethnic minorities than for whites. There is a need by Hispanics for greater access to high quality, authoritative Spanish language health information that is also culturally sensitive.

The following sites offer information in English with Spanish translations. Several sites are specifically designed for a Spanish speaking population, some are primarily English language sites with much of their information available in Spanish. Some sites offer information in other languages as well.

Agency for Healthcare Quality and Research - <http://www.ahrq.gov/consumer/espanoix.htm>

Spanish language information about wellness, managing common conditions, and effectively using our healthcare system.

American Association of Child & Adolescent Psychiatry - Facts for Families -

<http://www.aacap.org/publications/factsfam/index.htm>

Online publications on child development, mental health, behavior problems, and medical conditions. Available in English, Spanish, German, French.

Centers for Disease Control - <http://www.cdc.gov/spanish/>

Information on alcohol and drugs, allergies, immunizations, mental health, disease prevention and special topics on the health of men, women, children, and elderly persons.

Healthfinder.gov - <http://www.healthfinder.gov/espanol/> Offers information on asthma, diabetes, cholesterol, depression, nutrition, sexually transmitted diseases, immunizations, and more.

MEDLINEplus - National Library of Medicine - <http://www.nlm.nih.gov/medlineplus/>

Many of the over 400 disease and conditions topics include Spanish language publications

National Cancer Institute - <http://www.healthfinder.gov/espanol/>

The premier web site for comprehensive information on cancer diagnosis, treatment, support, financial issues.

National Heart, Lung and Blood Institute - Latino Cardiovascular Health -

http://www.nhlbi.nih.gov/health/prof/heart/latino/lat_pat.htm

Bi-lingual publications on cardiovascular health, including cholesterol and heart disease, exercise, low-fat eating, weight management, and smoking cessation.

National Information Center for Children and Youth With Disabilities –

<http://www.nichcy.org/spanish.htm>

Spanish language fact sheets, news guides, parenting guides, and lists of local resources on disability related issues.

National Women's Health Information Center - <http://www.4women.gov/spanish/index.htm>

Information on cholesterol, diet, cancer, pregnancy, sexually transmitted diseases, diabetes, gynecological health, and more.

Noah - New York Online Access to Health - <http://www.noah-health.org/>

Spanish language information and resources from organizations and governmental agencies.

Patient Education materials from the University of Utah Health Sciences Center -

<http://www.med.utah.edu/pated/handouts/indexspan.cfm>

Over 200 patient education publications translated in Spanish on topics such as women's health, diabetes, nutrition, heart disease.



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.

◆ **American Medical Association guide to home caregiving.** Angela Perry, medical editor. John Wiley & Sons, 2001. 242 p. (ISBN 0-471-41409-3), \$14.95 pap.

For someone suddenly responsible for the home care of an ill or elderly family member, the challenges often seem overwhelming. One of a series of books written under the auspices of the American Medical Association especially for patients and families, this down-to-earth handbook provides easy-to-understand, helpful advice about caring for a sick or elderly relative at home, whether the reader is going to provide hands-on care or direct others who will provide day-to-day care.

Its focus is on caring for patients with Alzheimer's disease and other terminal illnesses. The chapter on Alzheimer's disease discusses the characteristics of the disease--how each differs from normal forgetfulness-- and explains the Alzheimer's Association Safe Return program for patients who wander away from home.

An excellent basic overview of patients' needs, the Guide describes types of rehabilitation services such as occupational and physical therapy, discusses hiring and supervising a home healthcare provider, selection of a nursing home and monitoring a family member's care in a nursing home, insurance options, advance directives, and hospice services.

Also included are clearly written, illustrated, practical instructions on how to provide day-to-day care, such as bathing a person confined to bed, changing a wound dressing, bed making, and moving an immobile patient in bed.

The book concludes with a chapter on "Care for the Caregiver," that emphasizes the importance of maintaining one's own health and continuing to have "a life of your own." There is an index and an annotated list of organizational resources, including contact information and web addresses. (JK)

◆ **The encyclopedia of mental health.** Ada P. Kahn and Jan Fawcett. Facts on File, 2001. 468 p. (ISBN 0-8160-4062-1), \$71.50.

There have been changes in popular mental health topics since this one volume encyclopedia was published in 1993. The updated 2001 edition includes a variety of new topics of current interest. Alphabetically arranged, entries range from one paragraph to three pages. Written for the layman. Some entries include one or more references to articles or books on the topic discussed. Often include SEE ALSO references at the End of the article to related topics in the Encyclopedia. (JK)

◆ **Informed decisions.** Second edition. Harmon J. Eyre, Dianne Partie Lange, Lois B. Morris. American Cancer Society, 2002. 768 p. (ISBN 0-944235-27-1), \$29.95 pap.

The American Cancer Society has published an updated, paperback edition of its comprehensive, consumer-oriented guide to cancer types, treatment, and coping skills, published originally in 1997. This book is among the highly recommended books on Healthnet's "core list" of important health reference books, designated on the list by a double asterisk, indicating Healthnet considers it "essential for a basic collection in any size library." (The list appears on the Healthnet website at <http://library.uchc.edu/departm/hnet/corelist.html>).

Although the vast amount of the text discussing prevention and screening, causes and risks, principles of treatment, investigational therapies, alternative and complementary therapies is the same as that of the first edition, some additions and changes have been made. Newer forms of treatment and methods of diagnosis have been included. There are new chapters on cancer-related medical emergencies, coping with fatigue, and financial aspects of cancer treatment including insurance, financial planning, loans, and home equity conversion. (JK)

◆ **Living well with macular degeneration. Practical tips and essential information.** Bruce Rosenthal and Kate Kelley. New American Library, 2001. 266 p. (ISBN 0-451-20264-3), \$12.95 pap.



Because of the increased life span of U.S. citizens, there has been a rise in the number of cases of macular degeneration, a painless eye disorder that causes loss of central vision. Although there is no specific cure for dry macular degeneration, the more common form of the disease, there are resources to help in day-to-day coping with reduced vision.

Optometrist Bruce Rosenthal, chief of Low Vision Programs at Lighthouse International, an organization that provides vision rehabilitation, and writer Kate Kelly have compiled a basic guidebook for newly diagnosed patients. They describe the symptoms of macular degeneration and discuss ways to halt its progression. They provide information about the low vision aids currently available such as closed circuit television reading machines, video headsets, and optical character recognition machines. Continuing with the text's encouraging tone, much of the book deals with organization skills and environmental modifications that enable an individual to continue "living well" despite reduced vision. One chapter focuses on the ability to drive and state laws that govern acceptable eyesight for maintaining a driver's license. This easily understood, helpful guide concludes with a glossary, index, and resource list of organizations and reading and listening materials. (JK)

◆ **NORD Resource Guide.** Fourth edition. National Organization for Rare Disorders, Inc. 2000. 1152 p. \$45. plus \$5.00 shipping.

Rare diseases affect more than twenty-five million Americans. Each of these approximately six thousand rare disorders are found in fewer than 200,000 people in the United States. The updated NORD Resource Guide, published by the Connecticut-based National Organization for Rare Disorders, is a valuable source of information, help, and support for patients and families of patients with rare diseases. The new edition is a comprehensive guide to over one thousand relevant support organizations, clearinghouses, and agencies.

Founded in 1983, the National Organization for Rare Disorders is an umbrella organization of voluntary health groups focused on specific, rare "orphan" diseases. In addition to its publications and databases, NORD provides a Family Networking Program, a Medical Assistance Program for patients in need of investigational drugs or financial support for medications, federal government patient advocacy, funding for clinical research, and a Patient Services Department to help patients in accessing benefits.

This extensive alphabetical directory includes a one-paragraph description of each organization's focus and services, contact information, home page address, and languages other than English spoken. Since many of these organizations work with more than one rare disease, each entry includes a listing of those rare disorders supported by the organization. The list is varied enough to include Dogs for the Deaf, Inc. and the medical genetics departments of universities and medical centers. International organizations are also part of the list. The second alphabetical organization listing focuses on health-oriented United States governmental service agencies.

The lengthy cross-referenced index allows users to find organizations by name of the disease, key word in the disease name, disease category, and by name of the organization.

The contents of the Guide is also posted on the website of the National Institutes of Health Combined Health Information Database at [http:// www.chid.nih.gov/](http://www.chid.nih.gov/) and in NORD's Organizational Database at <http://www.rarediseases.org/>. (JK)

◆ **When the brain can't hear. Unraveling the mystery of auditory processing disorder.** Teri James Bellis. Pocket Books, 2002. 342 p. (ISBN 0-7434-2863-3), \$25.00.

Teri James Bellis writes from first hand experience. After more than fifteen years' as a university lecturer on auditory neuroscience, specializing in auditory processing disorder, Dr. Bellis became a patient herself. She experienced auditory processing disorder as a result of head trauma suffered in an automobile accident. Her experience helped her to communicate even more compassionately with her patients.

Often misdiagnosed, auditory processing disorder is a condition in which words heard by a person with excellent hearing become distorted on the path to brain. It may be exhibited differently in different people. This disability interferes with affected children's ability to understand spoken language, learn to read, and write. Adults and children with APD often experience extreme difficulty reading, spelling, understanding conversations, and participating in social situations. They may compensate for their difficulties by withdrawing from conversations and interactions with others.

The book is addressed to parents of children with APD and to adults who have this disorder. Illustrated with case histories of both adults and children whom Dr. Bellis has treated, this comprehensive, informative guide analyzes the types of difficulties a person with APD experiences, presenting technicalities in layman's terms. Dr. Bellis clearly describes her treatment approaches: modifying the environment, training to enhance listening skills, and techniques to compensate for this disability.

There is extensive information on the diagnostic process, treatment, and how to manage to live as successfully as possible despite this disorder. The book is written with a great deal of compassion and understanding. It discusses the grieving process that accompanies acceptance of any disability, adapting to college, as well as offering guidance on parenting siblings of a child with APD. Includes an index and glossary of terms. (JK)



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If you have questions about anything in the newsletter or about Healthnet services for Connecticut public libraries,
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