

# HEALTHNET NEWS

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

Volume XIX Number 3-4

Fall/Winter 2004

## UPDATE

### *COMBINED FALL/WINTER ISSUE*

Note that this issue of **Healthnet News** combines the Fall and Winter issues. Since we were unable to meet our deadline for sending out the Fall issue of **Healthnet News**, we are combining the Fall issue with our Winter issue. We will return to our four issue format for 2005.

### *USING THE INTERNET TO ANSWER CONSUMER HEALTH QUESTIONS*

In November, Healthnet offered a three hour program "Using the Internet to Answer Consumer Health Questions". We were unable to accommodate everyone who wanted to attend this program so we are planning to offer it again in late March or early April 2005. Watch for announcements on Conntech and, if you receive email notification of Healthnet News, in your email. If you would like to be added to our email newsletter notification mailing list, contact Alberta Richetelle at mailto: [mailto:richetelle@nso.uhc.edu](mailto:mailto:richetelle@nso.uhc.edu) and ask to be placed on the email list.

## NETNEWS

### *BE INFORMED BEFORE YOUR SCHEDULED SURGERY*

The **Agency for Healthcare Research and Quality (AHRQ)** has published an online guide for patients facing surgery. AHRQ is part of the U.S. Public Health Service and sponsors and conducts research that provides evidence-based information on health care outcomes, quality, cost, use, and access. This information helps clinicians, patients, and health system leaders make more informed decisions about medical care and improve the quality of health care services.



AHRQ recently released the publication "Be Informed : Questions To Ask Your Doctor Before Surgery " to help patients and doctors communicate more effectively regarding the benefits and risks associated with surgery. This online guide is at <http://www.ahrq.gov/consumer/surgery.htm>. The guide lists twelve questions patients should ask their doctors before having surgery. Among these are: Why Do I Need the Operation?; Are There Alternatives to Surgery? What Are the Benefits of Having the Operation?; What Are the Risks of Having This Operation?; What has Been Your Experience in Doing the Operation?; and How Long Will it Take me To Recover?.

Along with the questions, there is a listing of additional publications related to surgery available from other government agencies and health organizations. These include a free series of publications on "When You Need an Operation" available from the American College of Surgeons, free booklets on anesthesia from the American Society of Anesthesiologists and the American Association of Nurse Anesthetists, and another free publication from the Agency for Healthcare Research and Quality on "Pain Control After Surgery : a patient's guide".



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## *CALCULATING YOUR RISK FOR HEART DISEASE*



There seems to be no end to the swirling controversy about the potential for arthritis medications increasing a person's risk for heart disease. In an article appearing in the December 28 2004 issue of The New York Times, Anahad O'Connor describes the anger and frustration many Americans are experiencing when deciding whether or not to continue taking the pain medication they've relied on for many years.

The problem, O'Connor points out, is that decisions are being based on incomplete and conflicting data. For example, in one study, Celebrex was shown to increase the risk of heart attack at high doses; two subsequent studies showed no such risks. Patients should meet with their doctors to discuss whether or not to take Celebrex (or any of the other similar drugs) and to have their heart disease risk determined.

A risk analysis tool is available at <http://hin.nhlbi.nih.gov/atp/iii/calculator.asp?usertype=pub> to help individuals determine their long term risk for heart disease. Developed by the National Heart, Lung and Blood Institute of the National Institutes of Health, this risk assessment tool asks for five pieces of information and then calculates your risk for having a heart attack in the next 10 years.

To find out what your risk score means and to read about how to lower your risk for a heart attack, go to the site of the National Cholesterol Education program at [http://www.nhlbi.nih.gov/health/public/heart/chol/hbc\\_what.htm](http://www.nhlbi.nih.gov/health/public/heart/chol/hbc_what.htm) and read "High Blood Cholesterol—What You Need to Know". There's also a link to the NCEP's Adult Treatment Panel guidelines on cholesterol "Live Healthier, Live Longer" at <http://www.nhlbi.nih.gov/chd/>. Both of these documents describe ways individuals can lower their heart attack risk by keeping their total cholesterol and other blood lipids at optimal levels.

## *YOUR FAMILY'S (MEDICAL) GENEALOGY*

When you and your relatives gather for holiday meals, does the conversation occasionally turn to Aunt Mathilda's diabetes and her tendency to request a second helping of pecan pie? Does an argument arise about the medical cause of Uncle Joe's early demise? Gathering details on your family's medical history at the dinner table can be a valuable and sometimes life-saving pursuit.

Since many diseases have a genetic pattern, the **U.S. Department of Health and Human Services** is encouraging families to gather the medical histories of family members in an organized way. Having background information about the physical and mental illnesses of her patients' ancestors may help a doctor to "create personalized disease prevention plans" for those patients.

"My Family Health Portrait," a free, downloadable computer program to help families record their health histories is now available online at the Department's website at <http://www.hhs.gov/familyhistory>. The program allows families to record family health history. The information is intended to be printed and shared with a family member's physician. The information remains on the hard drive of the computer to which it is downloaded. No information is transmitted to any government agency. It is not necessary to have medical background information on each family member to create a useful document. The software is available in Spanish as well as English. A print version may be requested by phoning the Federal Citizen Information Center at 1-888-878-3256.

The National Society of Genetic Counselors provides a brief overview about collecting a family history on its website at <http://www.nsgc.org/consumer/familytree/index.asp>.

## *HERBAL SAFETY – IMPORTANT INFORMATION YOU NEED TO KNOW*

More Americans are relying on herbal products to self-treat chronic conditions that have not responded to conventional treatments. Too often people think that because herbs are "natural" (not manufactured) they are safe to use. This unfortunately is not always true. Factual information about many herbs is often difficult to find. Companies that market herbal products may exaggerate the health claims of the product since they may be more interested in making a profit than providing accurate information. There is also a lack of quality control in some herbal product companies and different standards around the world often lead to mislabeling of comparable or very different products. Herbal products originating in other countries are not tested for purity, safety or efficacy before their introduction into the United States.

The **University of Texas at El Paso** and the **University of Texas Austin Cooperative Pharmacy Program** have developed a website on herbal safety to help educate individuals about the safe use of herbal products. The Herbal Safety website is located at <http://www.herbalsafety.utep.edu/>.

The main feature of the website is the herbal monographs. Currently sixteen out of a prospective 35 monographs have been completed. Each monograph includes the plant's common and scientific name, its botanical family, its name in Spanish, the history of its use, its medicinal properties and uses, safety precautions and herb interactions, a fact sheet written for consumers with a condensed profile of the herb, a synopsis of clinical trials conducted with the herb, and an extensive list of literature cited for the herb monograph. Each monograph, and other sections of the website, are available in Spanish.

Included under the link "Special Populations" is a list of herbal products to avoid during pregnancy and lactation. A separate list of herbs to avoid before surgery gives the uses for the herb and the possible complications or interactions that may occur during surgery.

Although this site currently has limited information because it is still in development, when completed it will serve as an excellent complement to other herbal websites such as **HerbMed** - <http://www.amfoundation.org/index.htm> . Well-worth waiting for.

#### *NEW SURGEON GENERAL'S REPORT ON BONE HEALTH*



The first U.S. Surgeon General's Report to address bone health states that, by the year 2020, half of all Americans will face a danger of bone fractures from osteoporosis if they fail to follow health recommendations that will reduce their risk. The Report makes the reassuring conclusion that osteoporosis is not an inevitable result of aging.

U.S. Surgeon General Richard H. Carmona warns that "Osteoporosis isn't just your grandmother's disease." He encourages Americans of all ages to take precautions by consuming recommended amounts of calcium and vitamin D, exercising, and maintaining a healthy weight.

The recently issued report, "Bone Health and Osteoporosis: A Report of the Surgeon General" is available online at the Surgeon General's website at <http://www.surgeongeneral.gov/library/bonehealth/>. Fact sheets for health consumers on bone disease, "myths and realities of bone disease," and "tips to improve your bone health" are also on the website. A colorful online booklet, "The 2004 Surgeon General's Report on Bone Health and Osteoporosis: What It Means To You", uses consumer-friendly language to summarize the Report and its recommendations for all age groups. It incorporates a "calcium calculator" to help readers determine their daily calcium consumption.

Printed copies of the Report and related publications may be requested online or by phone toll free at 1-866718-BONE (2663).

#### *MEDICAL HEADLINES - AN INTERNATIONAL PERSPECTIVE FOR CONSUMERS*

We've become accustomed to hearing about "medical breakthroughs" on the television evening news, on frequent radio news updates, and in daily newspapers. News outlets seem to compete to be first with these exciting announcements of new medications and discoveries of causes and genetic associations for diseases that affect many Americans. These increasingly frequent reports are usually based on scientific research studies published in medical journals.

But what about those studies that are later disproved by subsequent research? How many subjects should participate in a study for it to be considered a valid one anyway? And what about research studies that contradict each other?

How can a health consumer determine which of these many reports discuss reliable scientific evidence?

Since 1993, the **Cochrane Collaboration** - <http://www.cochrane.org/>-, an international nonprofit organization, has provided an impartial perspective on the proliferation of new medical research studies. Thousands of physicians, researchers, and other healthcare professionals as well as some health consumers, in more than ninety countries, organized by topical committees, volunteer to provide up-to-date reviews and evaluations of medical research studies on various treatments and medical interventions. The reviews are subject to specific quality standards. These frequently updated Systematic Reviews, on topics such as stroke, oral health, neuromuscular disease, multiple sclerosis, and schizophrenia, are published online.

According to the organization's website, the Cochrane Collaboration is "intended to help people to make informed decisions about health care, their own or someone else's. Cochrane Reviews are needed to help ensure that health care decisions throughout the world can be informed by high quality, timely research evidence."

Funds for these efforts come from royalties to the Cochrane Collaboration from the commercial publisher of the periodically released reviews of research studies. Paid subscriptions are required for full text access to the Systematic Reviews.

Fortunately for health consumers, for whom deciphering the technical medical language of research studies can be a definite challenge, the British National Health Service provides a free, consumer-oriented online database, the **National Electronic Library for Health** - <http://www.nelh.nhs.uk/> - that includes a helpful feature called "Hitting the Headlines." It is written to allow "the clinician and the patient to be able to quickly identify the reliability of news stories and the research evidence on which they are based." This brief feature analyzes and explains, in consumer-friendly language, a current medical topic discussed in news articles. One question in the "Hitting the Headlines" feature's question and answer format is "How reliable are the conclusions?" Any Cochrane Collaboration reviews written on the topic are cited.

There is an extensive, searchable archive. Writers provide "summaries of news stories within 48 hours of their publication." The December 12, 2004 feature discusses reports of possible increased breast cancer risk among women taking folic acid supplements.

**Behind the Medical Headlines** - <http://www.behindthemedicalheadlines.com/> - another excellent British consumer health news website, is published online by the Royal College of Physicians of Edinburgh and the Royal College of Surgeons of Edinburgh. The articles are written by individual member physicians. Each article displays a search form for the Online Medical Dictionary so readers need not be stumped by medical terms. Readers may browse the index or use the search engine to locate specific topics. This consumer friendly website even asks readers to suggest topics for review.

Help is available for confused health consumers who are avid medical news readers!

#### *RESEARCH RESULTS OF DRUG STUDIES*



The adverse effects of some prescription medications have made big news lately.

Drug companies have been under pressure to publicize the negative and positive results of pre-approval and post-approval clinical research trials involving human subjects. This is a result of the news about the adverse side effects of prescription medications revealed in research studies after the drugs have been approved by the U.S. Food and Drug Administration and have already been extensively prescribed to patients by physicians. Beginning in fall of 2004, the **Pharmaceutical Research and Manufacturers of America**, trade association of U.S. drug manufacturers, has posted a free, centralized, online clearinghouse of clinical research studies completed since October 2002 at <http://www.clinicalstudyresults.org/>. It is available to patients and the general public but its content is directed to physicians.

Participation by member drug companies is voluntary. About thirteen manufacturers have currently posted study results on approximately twenty medications.

The database includes clinically controlled trials, mainly those in Phase III and Phase IV, testing a specific hypothesis about the drug's use and post-marketing results. It omits smaller, early Phase I and Phase II tests that evaluate the safety and effectiveness of medications, study phases that the organization considers "exploratory." The database consists of summaries of both positive and negative results, not raw clinical data.

The database is searchable by company name, drug name (brand and generic), disease, and study name. There is a hyperlink to the full text of the approved drug information label. There are citations to medical journal articles discussing the research and some direct hyperlinks to Medline medical journal citations and article abstracts summarizing their content. Some drug entries include company reports summarizing study results. Many do not.

On the Pharmaceutical Research and Manufacturers of America clinical trials website, there is a brief glossary defining clinical trial phases and terms such as "Investigational Review Board" and "Hypothesis-testing studies" and a short list of drug approval-related websites with hyperlinks.

Eli Lilly Company, in addition to participating in the trade manufacturers' website, has posted its own clinical trials website at <http://www.lillytrials.com> that includes summaries of completed trials in Phase I through Phase IV since July 1, 2004. Currently, trial results for eight drugs for treating cancer, mental illness, and sepsis are included, searchable by therapeutic area and by drug name. There are also charts listing drug trials currently in process and charts for trials that are recruiting subjects. There are hyperlinks to documents with detailed participation requirements for trials still recruiting. There is also an "overview of the drug development process."

On the clinical trials register website of the British company GlaxoSmithKline at <http://www.gsk.com/index.htm> (Select "Clinical Trial Register"), there are currently two drugs posted.

For patients and physicians seeking ongoing clinical trials that are currently recruiting patients, the U.S. National Institutes of Health posts an extensive, searchable clinical trials registry at <http://www.clinicaltrials.gov>.



## FOR YOUR CONSIDERATION

**American Medical Association Family Medical Guide** 4<sup>th</sup> edition. Donna Kotulak, managing editor. John Wiley and Sons, Inc., 2004. 1184 p. (ISBN 0-471-26911-5), \$45.00

The American Medical Association, a prolific publisher for health consumers, has updated its extensive, comprehensive, reliable **Family Medical Guide**. The **Guide** is an essential purchase for public library reference collections and a very good choice, along with **Harvard Medical School family health guide** (1999) and **Merck manual of medical information : second home edition** (2003), for home collections.

Together with explanations of genetics, healthy lifestyle recommendations, heart disease, cancer, and terrorism (home supplies to have on hand in the event of a terrorist attack, types of biological agents), there are diagnostic charts for common symptoms and photographs to aid in diagnosis, making this book a valuable resource for those interested in self-diagnosis.

A color section incorporates an atlas of the body and its systems, diagnostic imaging techniques, and color photos of skin disorders to aid in diagnosis. Health problems within a span of age groups are discussed, concluding with the process of dying and the mourning process. There are explanations of diseases and disorders for a variety of body systems, including genetic disorders, mental health, and diseases of the teeth and gums.

The Guide has been updated to include information on alternative medical systems and herbal remedies, genetic counseling, abortion, and living with an implantable defibrillator.

The book concludes with a glossary of medical terms, a drug glossary, and an index.

**The Anatomy of Hope. How People Prevail in the Face of Illness.** Jerome Groopman, M.D. Random House, 2004. 248 p. (ISBN 0-375-50638-1), \$24.95.

Here is a book about experiencing illness from a different point of view---the viewpoint of a compassionate, practicing physician who has suffered from severe back problems. Jerome Groopman begins his saga during his fourth year of medical school when a young woman in his mentor's care suffers a fatal result after refusing to have treatment for her cancer.

At the beginning of the book, he distinguishes between "true hope and false hope." When relating incidences of "true hope," he explains that he is not referring to a mind-set of optimism in which individuals believe that everything "turns out for the best," but hope "rooted in reality." Only a patient with belief in her ability to influence her circumstances can experience genuine hope.

Early in his career, his attitude toward revealing details to patients is affected by a young woman in a poor community. A well-meaning physician had withheld information about the severity of her mother's cancer. During one of her mother's last doctor visits, she says "I guess... [your colleague] didn't think people like us are smart enough, or strong enough, to handle the truth."

It is "the middle ground where both truth and hope reside" that the book ultimately advocates.

The book concludes with information on scientific experiments in which the placebo effect was tested on patients and resulted in many positive responses.

A gifted writer, Dr. Groopman's compassion as a physician is clearly expressed through experiences he relates from his perspective of thirty years experience as a physician specializing in oncology. The book reads like a memoir rather than an informational book.

**The answer to cancer.** Caroline D. Runowicz,, Sheldon H. Cherry with Dianne Partie Lange. Rodale, Books, 2004. 290 p. ( ISBN 1-57954-730-3), \$24.95.

Addressing widespread public concern about the country's second most frequent cause of death, two physicians, experienced in gynecology and cancer treatment, present an encouraging, proactive plan for preventing cancer before it can be detected, for halting it in its earliest stages and preventing recurrences. Oriented to the health consumer, this book's understandable explanations discuss the cancer development process, statistics, the concept of cancer risk, as well as specific recommendations for reducing cancer risk.

Author Dr. Carolyn Runowicz, director of the Carole and Ray Neag Comprehensive Cancer Center at the University of Connecticut Health Center, is president-elect of the National Cancer Society, and a 12 year survivor of breast cancer. Her husband, co-author Dr. Sheldon H. Cherry, is a clinical professor of obstetrics and gynecology at Mount Sinai School of Medicine in New York City.

The authors provide advice on how to "outsmart 9 common cancers," skin, prostate, breast, lung, colorectal, ovarian, pancreatic, cervical, and oral cancers. Their recommendations for reducing risk include chemoprevention utilizing drug therapies, and lifestyle changes such as incorporating increased amounts of fruits and vegetables in the diet, exercising regularly, having recommended cancer screening tests, and faithfully using sun screen outdoors.

Although risk factors like diet and amount of exercise are modifiable, the authors caution that effectiveness of preventive measures vary with the individual and are influenced by genetics, environment, and lifestyle.

This book is especially valuable for its currency, candor, and research-focused consumer-friendly text, such as detailed explanations on research studies related to chemoprevention.



**The Merck Manual of Health and Aging.** Mark H. Beers, editor. Merck Research Laboratories, 2004. 961 p. (ISBN 0-911910-36-0), \$29.95.



An increasing proportion of the United States population includes aging, active, curious adults with a strong interest in maintaining their health. Merck Laboratories has published an important new consumer health book that addresses this trend.

Building on the success and popularity of their recently revised (2003) consumer health book **Merck Manual of Medical Information—Home Edition.**, and their publication **The Merck Manual of Geriatrics** (2000), that provides technical information on aging to health professionals, Merck Laboratories has published a comprehensive, consumer-friendly, reliable health guide focused on the aging process, preventive health care, and the medical disorders and health needs of the elderly. Names of the medical experts who authored individual chapters are listed along with their institutional affiliation.

In addition to information on preventive medical care, this clearly designed book includes guidance in navigating the health care system, recommendations for maintaining healthy nutrition, complementary and alternative medicine, as well as discussions of health-related ethical and social issues, such as financing health care, relationship intimacy, and living wills. It discusses how disorders and medication affect the elderly and incorporates a chart about specific medications and their side effects in the aging population. Most explanations of disorders are organized by subtopics: causes, symptoms, diagnosis, prevention, treatment and outlook. There is information about specific diagnostic tests and there are cross-references to a number of illustrations and tables within the text. A chapter on caregiving discusses its rewards and challenges. There are guidelines for long distance caregiving and preventing “caregiver burnout.”

The appendix includes two alphabetical medication charts: one that gives brand names for corresponding generic names of medications and a second that provides generic names for drugs listed by trade names.

A unique feature of this book is interspersed throughout the text. Twenty-five brief essays by distinguished and less well known older Americans that describe their lives, and their attitudes toward aging are included. Seventy-five year old author-illustrator Maurice Sendak contributed his essay in the form of a whimsical self-portrait with commentary.

Part of this valuable book is currently available online at [http://www.merck.com/pubs/mmanual\\_ha/contents.html](http://www.merck.com/pubs/mmanual_ha/contents.html). Additional text will be added to the online edition.

**Straight Talk About Psychological Testing for Kids.** Ellen Braaten and Gretchen Felopulos. Guilford Press ,2004. 260 p. (ISBN 1-57230-78706 pbk.), \$16.95,. (ISBN 1-57230-948-2 hardcover), \$35.00.

A concerned parent, anxious to obtain special academic or psychological services for her child, must prove this need to the child’s school. Often this means convincing the child’s teachers and the school administration that the child should be tested so that the need for services can be documented. Private testing at the parent’s expense might be a better alternative....but then, who is a reliable professional to administer the testing? Sometimes this first step in the search for help for the child may be as challenging as understanding the complexities of psychological testing.

In order to help parents facing these challenges, Drs. Ellen Braaten and Gretchen Felopulos, staff psychologists at the Psychology Assessment Center of Massachusetts General Hospital for Children, have written an understandable, comprehensive, parent-focused guide to the technicalities of psychological testing for children. The book describes specific common tests, their uses, test results and interpretations, preparing children for testing, and types of testing professionals.

There is an introductory chapter about how to determine if a child needs testing. The characteristics, diagnosis, and treatment of commonly occurring childhood disorders such as dyslexia, autism, Asperger syndrome, attention deficit/hyperactivity disorder, learning disabilities, depression and anxiety are discussed. The explanations are greatly enhanced by case histories and by lengthy questions from parents and answers from the authors related to concerns about specific disorders, their diagnosis, and treatment.

A guide to resources at the end of each chapter as well as a supplementary resource guide as the conclusion of the book recommends websites, books for parents and for children.

**Talking to Depression.** Claudia J. Strauss. New American Library, 2004. 200 p. (ISBN 0-451-20986-9 paperback), \$13.00.

According to the dedication page of this important publication, "This book is not for the therapist, it is for the rest of us--untrained--doing the best we can to live our lives and help those around us." "Everyday people in everyday situations can make a difference." The book is intended to help the reader understand the experience of clinical depression when it affects a friend or family member. Depression is a serious disorder, "an illness like any other" that influences the behavior, thought process, mood, and physical well being of the depressed individual.

This is a pragmatic guide written to help friends and family support, encourage, and communicate with an individual with depression during the great amount of time when she is not involved directly with a therapist. It is intended to help friends and family members "complement and supplement what [mental health] professionals offer."

Claudia J. Strauss, also author of the 2001 book **Talking to Alzheimer's**, is a communication consultant and adjunct professor of English at Albright College in Reading, Pennsylvania. In this brief, compassionate book she provides an overview of the symptoms of depression and gives insight into the feelings and circumstances of the depressed person. The book includes specifics on expressing support through body language, symptoms of childhood depression, identifying warning signs of suicide, and conveying inexpensive gifts from the heart that would have meaning to a depressed person.

One especially valuable chapter discusses what depression feels like and what types of support are considered most helpful by an individual suffering with it. There are detailed chapters entitled "Words That Wound:What Not to Say" and "Words That Work:What to Say." The book concludes with a section on helpful resources--organization, websites, books



*Healthnet News is written by Alberta L. Richetelle and Judith Kronick.  
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