

HEALTHNET NEWS

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

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NETNEWS

NEW ONLINE RESOURCE GUIDE FOR CAREGIVERS

Whether your days are filled with caregiving for an elderly parent or a child with special needs, reliable tips on their care and the support of trustworthy organization may be of great help. Healthnet has added to its website, at <http://library.uhc.edu/departm/hnet/>, a Resource Guide about Caregiving. The Caregiving Resource Guide gathers together information about recommended print resources, organizations, and websites that offer a wealth of caregiving information.

Topics include Caring for the Caregiver, Long Distance Caregiving, Alzheimer's Caregivers, Financial Assistance, Legal Resources, Organizations and Agencies That Offer Assistance, and Caring for Children.

Books range from **Caring for Your Parents: The Complete Family Guide**, written by the editor-in-chief of AARP Publications, that focuses on financial aspects of caregiving, to the classic practical guide **The 36-Hour Day** to specific advice on communicating with a person with Alzheimer's disease (**Talking to Alzheimer's**), written by a author who is a communication consultant and English professor. Among the agency links are the Connecticut Elder Law Center, the Connecticut Home Care Program for Elders, and the Grandparents as Parents Support Program. There are links to caregiving information on the websites of the Alzheimer's Association, the National Institute on Aging, and the Connecticut Parent Advocacy Center.

For caregivers and librarians in Connecticut needing more assistance in researching caregiving and health-related questions, the Healthnet program offers a free research service. Contact Healthnet at 860/679-4055 for help with personal health questions.

NEW CONNECTICUT PARENTING WEBSITE

A new parenting website has been launched by the Connecticut Department of Children and Families at <http://www.ctparenting.com>. Colorful, easy to navigate, and searchable, it includes sections directed to "Kids" and "Teens" as well as "Parents and Caregivers."



The "Teens" section connects to websites about sexually transmitted diseases, drug abuse, runaway teens, preventing date abuse, and gay and lesbian teens. The "Kids" section includes websites about safety games, bullying, and Internet safety. The "Parents and Caregivers" part is divided into subsections such as "dads," foster parents, adoptive parents, single parents, grandparents, and lesbian, gay, bisexual, and transgender parents.

Health and safety is one of five information areas on the website. Other areas focus on Child Development, Education, Basic Needs, and Family Fun. Each segment allows parents (and grandparents) to link to a variety of websites related to one of these broad topics.



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The Physical Health section of the “Health and Safety” area links to websites with information about asthma, hepatitis, HIV/AIDS, immunization, nutrition, and obesity/weight loss. The three website links about immunization are from the Connecticut Department of Public Health and U.S. Centers for Disease Control and Protection. Behavioral and emotional health, child safety, and abuse prevention are additional sections in the “Health and Safety” area.

Most websites are gleaned from reliable, recognizable sources such as the U.S. Department of Education, American Academy of Family Physicians, Connecticut Birth to Three System, and the New York University Child Study Center. However, the website does not include a statement about its mission or its criteria for selecting the links.

FINDING DIAGNOSES FOR MYSTERIOUS ILLNESSES

A number of patients and their concerned families face, not only the devastating symptoms of their sickness, but also the frustration and anxiety of encountering doctor after doctor who is unable to diagnose their illness.

The National Institutes of Health has launched a new clinical research pilot program to help “provide answers to patients with mysterious conditions that have long eluded diagnosis.” Each patient accepted into the Undiagnosed Diseases Program (<http://rarediseases.info.nih.gov/Undiagnosed>) will have the benefit of the experience and knowledge of more than twenty-five National Institutes of Health senior physicians from a variety of specialties. The program will also enlist the expertise of the NIH’s Office of Rare Diseases. In addition to trying to discover the previously undetermined source of a patient’s illness, the Program’s physicians are anxious to “advance medical knowledge about rare and common diseases.”

In order to be evaluated for possible inclusion in this Program, a patient must be referred by a physician or health-care provider. Additional information about the evaluation process is available by phoning **866/444-8806** and online at the Frequently Asked Questions area of the Program’s website (<http://rarediseases.info.nih.gov/UndiagnosedDiseases/FAQ.aspx>). There is no charge to patients who participate in the diagnostic process. Travel, meals, and housing may be paid for. After evaluation, patients will return to the care of their own physician, but they may be eligible for participation in an NIH research study.

PROBLEMS WITH A FOOD? DIETARY SUPPLEMENT? COSMETIC?

The U.S. Food and Drug Administration’s safety responsibilities extend to vaccines, medications, blood products, pet food, cosmetics, and specific types of food consumed by humans. To help health consumers learn about dangers posed by specific products, the FDA posts updates on its consumer health website at <http://www.fda.gov/consumer/>. (Additional details on page 2 of the Spring 2008 issue of Healthnet News at <http://library.uchc.edu/departm/hnet/Spring08.pdf>)

What if you have had a problem with a food, vaccine, or a FDA-regulated product sold online.....How do you communicate information about this situation to the FDA? “Your Guide to Reporting Problems to the FDA” at http://www.fda.gov/consumer/updates/reporting_guide061008.html advises consumers who are reporting problems. The Guide explains which specific information about the product is needed when reporting a problem and reminds consumers to save the product packaging and label for inspection.

A Quick Reference Chart describes the type of problem, type of product, and the office in the FDA bureaucracy to contact for a specific problem. There are also links to agencies that handle specific product contamination that is not under the FDA’s jurisdiction. (e.g. Call the Poison Control Center at the national referral number 1-800-222-1222 about accidental poisonings. Call the U.S. Drug Enforcement Agency for drug abuse and controlled substance concerns, etc.)

WHAT DO PATIENTS SAY ABOUT THEIR HOSPITAL STAYS?



Where do you find information about the experience of being a patient at a selected hospital? Friends and relatives may be eager to recount their complaints and compliments about their care after returning from a stay at a hospital. Is there another source of patient opinions?

Although hospitals may survey patients about their experiences at the end of a hospital stay, reports of patients' feedback about the care they received has not been publicly available. The Hospital Compare website, a publication of the Center for Medicare and Medicaid Services, part of the Department of Health and Human Services, at www.hospitalcompare.hhs.gov, has now added a "survey of patients' hospital experiences" to its website resources. Patients were asked about how "carefully" doctors and nurses listened to their concerns, how well health professionals explained their conditions and treatments to them, and if they treated them with "courtesy and respect." The patients were asked how quickly they received a response after summoning help, how well their pain was controlled, how clearly their medication's purpose and side effects was explained, how clean their room was kept, and how well they were briefed on their upcoming recovery period at home. The patient responses come from a random survey of patients in more than 2,500 U.S. hospitals from October 2006 to June 2007. Most "short-term, acute care, non-specialty hospitals" in the country participated in the survey.

The Hospital Compare website allows searchers to compare up to three hospitals on the basis of Process of Care Measures, Hospital Outcome of Care Measures, as well as Patients' Hospital Experiences. Among the Process of Care Measures are "Per Cent of Surgery Patients Who Received Preventive Antibiotics One Hour Before Incision," "Per Cent of Heart Attack Patients Given Aspirin at Discharge," and "Per Cent of Pneumonia Patients Given Initial Antibiotics Within 6 Hours After Arrival." The Outcome of Care Measures include "Adjusted Adult Heart Attack Mortality Rates" and "Adjusted Heart Failure Mortality Rates."

The website also reports on average Medicare payments to hospitals for specific procedures and medical conditions and the number of Medicare patients treated for a specific illness. The information is based on payments made between October 2005 and September 2006. Statistics are given for the average Medicare payment for a procedure within the state and within the country.

FIRST SIGNS OF AUTISM

How do parents with concerns about their young children determine if delayed social and communication behavior they observe in their child is a normal lag in development or if it is a warning sign of autism spectrum disorder? If an eighteenth-month-old does not respond to her name, doesn't point to objects or wave good-bye, doesn't smile in response to another person's smile, or prefers to play by herself.... are these signs of autism?

In order to help parents determine if specific behaviors are signs for concern, the National Institute of Child Health and Development publishes a list of "Possible Red Flags for Autism" on page 3 of a booklet for parents, entitled "Autism Overview: What We Know" at http://www.nichd.nih.gov/publications/pubs/upload/autism_overview_2005.pdf. Social, emotional, cognitive, and movement developmental milestones for ages 3 months to 5 years are described on the Centers for Disease Control and Prevention website at <http://www.cdc.gov/ncbddd/autism/actearly/>

A newly created web-based Autism Video Glossary at <http://www.autismspeaks.org/video/glossary.php> allows parents to view over one hundred video clips of usual childhood behaviors and corresponding behaviors that may be signs of autism. The video glossary was created by the FIRST WORDS project at Florida State University and two nonprofit autism advocacy organizations, Autism Speaks and First Signs.

A computer System Compatibility Check is provided at http://www.autismspeaks.org/video/system_check.php on the Video Glossary website. There are links to updates of Windows Media Player and Adobe Flash Player, in case they are needed to view the Video Glossary. Free online registration is required before viewing.



FOR YOUR CONSIDERATION

The following titles are recommended to public libraries and other libraries providing consumer health information services. They are not part of the UConn Health Center Library collection.

Germ Proof Your Kids. The Complete Guide to Protecting (without Overprotecting) Your Family from Infections. Harley A. Rotbart. ASM Press, American Society for Microbiology, 2008. 380 p. (ISBN 978-1-55581-427-4), \$29.95.

What should a parent believe: your mother's theories on the value of chicken soup and the dangers of wet hair and wet feet in preventing childhood illness or the theories of scientists who have studied the effects of germs and other microorganisms for more than 150 years? According to pediatric disease specialist Dr. Harley Rotbart, "the truth about infections rests somewhere between Mom and Pasteur." "...Healthy nutrition, sleep, exercise, and yes, maybe even those rubber boots in the rain" play a role in preventing the effects of children's infections, just as mother claimed.



Professor and Vice Chairman of Pediatrics at the University of Colorado School of Medicine and the Children's Hospital of Denver, Dr. Rotbart discusses specific germs apt to infect children and how they are transmitted, diseases and their level of contagion, prevention, and treatment, natural defenses against disease, controversies about the relation of vaccines to the development of autism, and the effect of consistent use of soaps containing antibiotics. In each chapter, he reviews which findings

have actually been scientifically proven.

The final brief chapter, "Wisdom of the Ages" is worth reading...and re-reading... by itself because of its thorough, understandable explanation of the role of research in advancing scientific knowledge and the news media's sometimes overenthusiastic embrace of each new research study.

The book's appendix includes a chart listing brand and generic names of medications used to "prevent or treat infections" and a reference to the chapter number in which they are discussed. Dr. Rotbart's GERMBlog, an enhancement of the book, at http://germproofyourkids.com/germblog/?page_id=2 discusses current news about infection outbreaks in perspective, with references to the chapter number in which a related topic is addressed.

Green Baby. Susannah Marriott. DK Publishing, 2008. 190 p. (ISBN 978-0-7566-3673-9), \$18.00.

The decision to make a determined effort to "go green," and thus have a minimal negative effect on our environment is new to many Americans, and to many new parents. To implement these good intentions, individuals need specifics about how to live a "greener" daily life.

Dr. Alan Greene's helpful guide to "pregnancy, childbirth, and baby care," Raising Baby Green (reviewed on page 6 of the Spring 2008 issue of Healthnet News at <http://library.uchc.edu/departm/hnet/Spring08.pdf>) includes a wealth of "earth-friendly" parenting suggestions.

An attractively designed, colorful guide published by British publishers Dorling Kindersley, Green Baby focuses on the day-to-day care of babies: bathing, feeding, sleep, providing playthings, dressing, and transportation. It is an additional resource for parents committed to a greener lifestyle for their babies. Candid, color photos of babies enhance the book's visual appeal.

Written by a freelance British writer who specializes in health books, Green Baby is a briefer book than Dr. Greene's comprehensive guide. It provides specifics on a four step recipe for making a cleansing lotion to replace baby wipes that utilizes organic chamomile tea bags and hemp oil, supports preparing homemade baby food from fresh fruits and vegetables, promotes the use of household objects, homemade and secondhand toys as playthings, specifies the "key [ingredient] features of green books" for children and encourages parents to "join your local library, one of the most enjoyable ways to reuse and recycle."

Herbs at a glance: A Quick Guide to Herbal Supplements. U.S. Department of Health and Human Services. National Institutes of Health. National Center for Complementary and Alternative Medicine, 2008. 106 p. (NIH Publication No. 08-6248)



Is aloe gel helpful in relieving pain from burns? Can cranberries effectively treat urinary tract infections? Will ginger relieve motion sickness on a boat ride? Many people want to know the definitive, scientific answers to these questions and others about the use of herbs for treating illness. An increasing number of Americans rely on herbal supplements to treat and prevent illness. So..”how can a consumer decide what’s safe or effective?”

The federal government has established the National Center for Complementary and Alternative Medicine at <http://nccam.nih.gov/> as its “medical research agency” for investigating the effectiveness of herbs used in dietary supplements. Research results are posted on the Center’s website at <http://nccam.nih.gov/research/results/>

Especially for health consumers, the National Center for Complementary and Alternative Medicine publishes Herbs at a Glance, (<http://nccam.nih.gov/health/herbsataglance.htm>) an online series of fact sheets about forty-two commonly used herbs and botanicals, such as aloe vera, grape seed extract, milk thistle, and noni. The fact sheets very briefly discuss uses of the herbs, scientific findings, and possible side effects.

The content of the Herbs at a Glance website is now available in an attractive, free publication distributed by the National Center for Complementary and Alternative Medicine. An online form for requesting the 106 page book is available at <https://www.nccaminfo.org/herbs/herbs.asp> In addition to the descriptions of herbs that appear on the website, the book includes introductory information about the history of herbs as medicine and their safety and an index by health conditions.

Our Bodies, Ourselves, Pregnancy and Birth. Boston Women’s Health Book Collective. Simon and Schuster, 2008. 370 p. (ISBN 0-7432-7486-9), \$15.00.

The nurses, physicians, midwives and mothers who authored the newest book by the Boston Women’s Health Book Collective consider the process of “bring[ing] a new life into this world” both “ordinary and extraordinary.” This practical, supportive, comprehensive guide encourages expectant and new mothers to be advocates for their own health care and helps them to make informed decisions about childbirth choices. The book discusses selecting a health care provider and appropriate setting for birth, preferably one with a minimum of “high tech” interventions and the comforting presence of a midwife or other “birth assistant.”

There are discussions of many practical decisions and situations faced by pregnant women: traveling during pregnancy, questions to ask when selecting a doula for support during childbirth, deciding whether to bottle-feed or breast-feed, accessing the federal WIC food program for nutritional support, details about prenatal testing and genetic counseling, premature labor, infections during pregnancy, sexuality and emotional support. There are chapters devoted to explanations of labor and delivery, pain relief techniques, possible complications, and cesarean births. In addition, the book describes a new mother’s recovery after childbirth and caring for a newborn.

The book’s many quotations from mothers about their pregnancy and childbirth experiences may mirror the experiences of readers and provide reassurance to them. These reminiscences are interspersed with information about related pregnancy and childbirth topics.

The text is enhanced by references to medical journal articles that substantiate the information in each chapter. A Resources section at the book’s conclusion includes lists of books, organizations, and websites, organized by the topics discussed in the book. The Boston Women’s Health Book Collective website at <http://www.ourbodiesourselves.org> offers additional information.

Stay Healthy, Live Longer, Spend Wisely. Making Intelligent Choices in America's Healthcare System. Davis Liu. Stetho Publishing, 2008. 263 p. (ISBN 0-9793512-0-0), \$24.95.

Author Davis Liu's background gives this patient-friendly guide a unique perspective.

Davis Liu is a board-certified family physician in Northern California with a university degree in business from the Wharton School and a medical degree from the University of Connecticut Health Center. His education in business as well as his medical studies give him a distinctive outlook on the health care system. He is well-informed about patients' health insurance needs as well as about ways they may effectively maintain their health and communicate with their physician.

In an informative, easy-to-read style, Dr. Liu guides patients, who currently have many choices to make independently. Physicians often lack time to inform patients about their options and help them reach decisions about treatments and surgeries. According to Dr. Liu, medical decision-making has become a "shared responsibility."

Dr. Liu describes insurance options, including Health Savings Accounts, in detail, and gives advice on disputes with insurance companies. He emphasizes the crucial importance of having health insurance in light of rising health care costs.

He urges patients to be both "proactive and informed" and recommends that patients prepare for a visit to their doctor by setting an agenda. He urges patients to tell the physician the most important problem at the start of the visit, and encourages patients to "be...effective storyteller[s]" when describing symptoms. His advice is interspersed with Real-Life Examples, some involving himself or his family, that illustrate how to handle a medical encounter.

The book concludes with a list of recommended websites by chapter and citations to sources of information in the text by chapter.



*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,
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