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## Healthnet News v.17:no.1 Spring 2002

Judith S. Kronick

*University of Connecticut School of Medicine and Dentistry*

Alberta Richetelle

*University of Connecticut School of Medicine and Dentistry*

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# HEALTHNET NEWS

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

Volume XVII Number 1

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## UPDATE

### *CONSUMER HEALTH CONFERENCE A RESOUNDING SUCCESS*

Our April 30 conference on Consumer Health Information: Networking and Technology, which was held at the Publick House in Sturbridge MA, was a huge success. Eighty-seven people attended the conference representing medical libraries, public libraries, public health agencies, academic libraries, clinics, and schools.

All of the speakers were well received as they offered information on the importance of networking to provide consumers with quality health information. Bob and Fran Nadeau, members of the Hepatitis C support group at the University of Connecticut Health Center, were the hit of the program. They told about how important it was for them to have accurate and current information on Hepatitis C when Fran was first diagnosed. Bob had glowing words to offer about his local public library in South Windsor and the invaluable assistance he received from the librarians with searching the Internet to find the information he and Fran needed in order to make decisions about her health care.

Among the exhibitors were the Arthritis Foundation, the National Library of Medicine Regional Medical Library Program at University of Massachusetts Medical Center, the Silent Spring Institute in Massachusetts, Connecticut Poison Control Center, the Learning Center at Beth Israel Deaconess Hospital in Boston, and the Consumer Health Information Reference Center at the Treadwell Library, Massachusetts General Hospital.

Thanks to the UCHC Library staff for their contributions in helping to make this a successful conference.

## PROFESSIONAL READING

### *HELP IN UPDATING YOUR CONSUMER HEALTH COLLECTION*

**Library Journal** has had several excellent articles on consumer health resources useful for keeping your collection up to date.



The January 2002 issue has a resource list of books and other information sources on arthritis. Although there are over 100 forms of arthritis, the list concentrates on general arthritis, osteoarthritis, and rheumatoid arthritis. Close to 18 million people in the United States suffer from at least one form of this disease. The Centers for Disease Control estimates by the year 2020, this number will increase to over 59 million.

There are eighteen books listed, one magazine, one video, and five web sites. The first section covers general titles dealing with arthritic and rheumatic conditions including osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, juvenile rheumatoid arthritis, and fibromyalgia. Following this are separate listings of books on osteoarthritis, rheumatoid arthritis, rheumatoid arthritis in children, diet, and exercise. All of the titles, including the video, magazine, and web sites are annotated. Core purchases are indicated by a ★.



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.uchc.edu  
<http://library.uchc.edu/departm/hnet>

The April 2002 issue has a resource list of books, videos, and web sites on care giving. Three out of four adults now live to age 65 and well beyond. Although the majority in this group are independent and lead productive lives, 8.5 million of the over age 65 group will develop chronic health problems by the age of 70 and will need help with simple daily tasks such as dressing, bathing, and cooking. Many families are now responsible for the care of an elderly relative, with adult daughters being the primary caregiver.

Information for these caregivers is vitally important. Basic information on health, finances, legal issues, hiring homecare workers, and nursing homes and other housing choices can make the caregivers job easier and ensure the elderly person gets the services and assistance he or she needs.

The caregiving resource list includes an annotated list of 23 books on topics such as basic care giving methods and guidelines, caregiving for those with Alzheimer's disease, legal and financial guides, nursing homes and housing, and books to provide support and encouragement for the caregiver. Descriptions of three videos and ten important web sites are included.

In the May 2002 issue, LJ offers a resource list on fitness. Included are thirty-four books, seven periodicals, twenty-four videos, four web sites, and eight associations. It's easy to understand what the big money makers are for publishers as they attempt to meet an insatiable demand by the public for information on new and better ways to achieve a high level of fitness.

The book titles are arranged in categories including general fitness, and fitness for men, women, children, and teens. Titles on fitness during pregnancy, sports medicine, and fitness for healing are also included. As in the other resource lists, each entry is annotated and core purchases are indicated by a ★ .

Also in the May 2002 issue is a list of 22 of the most outstanding consumer health titles of 2001. Categories of titles include allergies and asthma, alternative medicine, Alzheimer's disease, cancer, children's health, drugs, general medical guides, nutrition, pain, sports medicine, surgery, and women's health.

Hendler GY, Gallagher PE. Rx for aching joints: arthritis collections. **Library Journal** 2002 January: 59-62.

Bensing KM. Helping hands: caregiving resources. **Library Journal** 2002 April 1:65-68.

Hagloch SB. Shape up your fitness collection. **Library Journal** 2002 May 1: S3-S8.

Bibel B. Best consumer health books 2001. **Library Journal** 2002 May 1:S10-12.

## NETNEWS

### *HELP FOR WOMEN WHO NEED INFORMATION ON MENOPAUSE*

The **North American Menopause Society (NAMS)** at <http://www.menopause.org/index.html> is the leading nonprofit organization dedicated to promoting women's health from midlife and beyond through an understanding of menopause. It has a multidisciplinary membership of over 2,000 leaders in clinical and basic sciences and experts in nursing, sociology, psychology, nutrition, anthropology, epidemiology, and psychology. The site contains information on perimenopause, early menopause, menopause symptoms and long-term health effects of estrogen loss, and a wide variety of therapies to enhance health.



There are separate sections for professionals, consumers, and the media. Among the features of the consumer section is the **Menopause Guidebook: Helping Women Make Informed Healthcare Decisions through Perimenopause and Beyond**. The complete 60 plus page guidebook is available online or a print copy may be ordered for \$10.00. There's also an online edition available in Spanish, which may also be purchased for \$10.00. A Braille edition is also available for purchase.

The Guidebook's topics include menopause basics and a discussion of how menopause status is confirmed, perimenopausal changes, such as insomnia, reduced fertility, hot flashes, psychological changes, and changes in sexual functioning, treatment options for menopause, and achieving optimal health. Adobe reader is required to view the guidebook.

The consumer section also includes a referral list of NAMS members, organized by state, for women in the United States and Canada who are searching for physicians and other healthcare providers to help them manage their health through menopause and beyond. Adobe Reader is required to view the referral list.

Also included is a suggested annotated reading list of books, booklets, and newsletters for those who want to read more than what's available in the guidebook. A listing of additional Internet resources is provided for further research. Listed are sixty web sites from government sources, non-profit organizations, educational institutions, and commercial companies. Sites were evaluated and selected for their specific relevancy to menopause and no site that sells a product, other than information, is included.

#### *AUTHORITATIVE INFORMATION ON PANCREATIC CANCER*

**Pancreatica.org** at <http://www.pancreatica.org/> aims to serve as a worldwide focal and gathering point on the Internet for the latest news and information in regard to clinical trials and other responsible medical care in the treatment of pancreatic cancer. The advisory board for the site includes cancer specialists from Johns Hopkins University in Baltimore, Maryland, the M.D. Anderson Cancer Center in Houston, Texas, Memorial Sloan-Kettering Cancer Center in New York City, the University of California, San Francisco, and the University of Heidelberg, Germany. The development of the site was spearheaded by the sister of a pancreatic cancer patient who died in March 2000.

Pancreatic cancer is one of the more lethal forms of cancer. Each year, more than 20,000 people in the United States are diagnosed with this rare disease. The incidence of pancreatic cancer increases with age; most people are between the ages of 60 to 80 when they receive the diagnosis and men tend to be over-represented. The median survival for untreated pancreatic cancer is three months; with treatment survival is six months.

Features of the site include a searchable database of clinical research trials, pancreatic cancer news from journals, clinical trials, press releases, and news sources, current newspaper articles from newswire services, and frequently asked questions about pancreatic cancer.



### **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.

◆ **Childhood brain and spinal cord tumors. A guide for families, friends, and caregivers.** Tania Shiminski-Maher, Patsy Cullen, and Maria Sansalone. O'Reilly, 2002. 546 p. (ISBN 0-596-50009-2), \$29.95 pap.

The authors of this extremely informative and compassionate new book in the O'Reilly Publishers' Patient Centered Guides series have direct experience with children who have received this potentially devastating diagnosis. Two are nurse practitioners who specialize in treating childhood cancer patients. The third is a mother who heard the "shocking and shattering" diagnosis of a brain tumor in her then two-year-old son.

This comprehensive guide for parents very effectively balances basic information about the anatomy and physiology of the brain, and details about types of brain tumors, with guidance about coping with the myriad details of diagnostic tests, treatment, and communicating with the variety of health professionals who care for a young cancer patient. In addition to explaining the processes of chemotherapy, bone and stem cell transplantation, and clinical trials, the book is especially helpful in discussing the circumstances that accompany a child's serious illness—involvement of school and friends, financial issues, behavioral changes, effect on siblings and relatives, even mundane matters such as obtaining parking at the hospital.

Especially valuable and touching are the brief, honestly told anecdotes from parents of patients. They provide practical guidance and understanding. The appendix includes information on blood counts and their meanings, helpful organizations and websites, and a list of U.S. pediatric neurosurgeons. (JK)

◆**The depressed child: A parent's guide for rescuing kids.** Douglas A. Riley. Taylor Trade, 2000. 195 p. (ISBN 0-87833-187-5), \$12.95, pap.

Clinical child and adolescent psychologist Dr. Douglas A. Riley, author of **The Defiant Child**, provides a practical, supportive guide to a taking proactive role in parenting a depressed child. He suggests a specific way that parents can intervene to improve their child's situation. Modeled after his therapy method, his approach focuses on structured discussions with a child suffering from depression that disprove the unrealistically pessimistic views of life she has adopted. The method is, first of all, intended to reassure the child or adolescent that a parent is in charge of her chaotic, sad life. The book is interspersed with illustrative dialogues between Dr. Riley and a young patient. ("Those other kids at school hate us. Every single one of them." "That's not true. All of them don't even know us.") Often Dr. Riley switches roles in his therapy dialogues so that his young patients will contradict the incongruity of his negative statements.

Though he discusses a basically psychological approach focused on "cognitive depression" rather than depression initiated by "biochemical imbalances" or "environmental stresses," Dr. Riley acknowledges that some depressed children need the help of medications, professional therapy, and sometimes hospitalization. This is an important emphasis since not all depressed children may be receptive to this admittedly intrusive approach nor all parents skilled in implementing it.

Interspersed with many illustrative case histories, and written in a straightforward, informal style, this is a helpful guide to understanding childhood depression as well as helping to encourage change in a depressed child's life.

◆**The Oasis Guide to Asperger Syndrome: Advice, Support, Insight, and Inspiration.** Patricia Romanowski Bashe and Barbara L. Kirby. Crown Publishers, 2001. 468 p. (ISBN 0-609-60811-8), \$27.50.

Barbara Kirby found so few sources of information for parents when her young son was diagnosed with Asperger Syndrome in 1994 that she, and fellow parent Patricia Romanowski Bashe, initiated a website with the hopeful name OASIS (Online Asperger Syndrome Information and Support). After an extremely frustrating search for information when her son was initially diagnosed with Asperger syndrome, Ms. Kirby was delighted to find one other mother, via the Internet, whose child shared her son's characteristics of normal intelligence, obsessive behavior, and limited social skills. These symptoms are typical of Asperger syndrome, a pervasive developmental disorder that is part of the autism spectrum.

Their website -<http://www.aspergersyndrome.org/>- continues to be an up-to-date source of background information on Asperger syndrome, as well as current research, technical papers, news of conferences, schools and summer camps, and strategies for reinforcing social skills.

The **Oasis Guide** encourages parents to be assertive advocates for their children. It continues the positive approach illustrated by the website's content. The sections of the guidebook, entitled "Taking Control," and "The Whole Child" include chapters on medication, "education basics," "building the foundation for success," school experience, and social life. There are appendices on psychotropic medications and abbreviations, acronyms, and websites relevant to Asperger syndrome. The **Guide** includes descriptions and examples of common Asperger syndrome behaviors, such as lack of eye contact, repetitive motor movements, and repetition of phrases just heard.

The **Oasis Guide's** practical, comprehensive information has been gleaned from healthcare providers and experienced parents. There are also helpful quotes from parents of children with Asperger syndrome and adults with Asperger syndrome, gathered from a survey conducted on the OASIS website. A potentially great source of help for parents and teachers of children with Asperger syndrome

◆**Parent's guide to children's congenital heart defects. What they are, how to treat them, how to cope with them.** Gerri Freid Kramer and Shari Maurer. Three Rivers Press, 2001. 265 p. (ISBN 0-609-80775-7), \$14.00



Written by two mothers of children with surgically repaired congenital heart defects, this is a practical and very helpful guide. The authors compassionately convey the experience of parenting a child with CHD. The book's medical explanations are enriched by the authors' commentaries and by carefully placed, relevant remarks about family experiences contributed by other parents. An excellent complement to the Johns Hopkins Press guide **The heart of a child. What families need to know about heart disorders in children.**(2001), this book addresses a wide range of congenital heart defects, including tetralogy of Fallot, atrial septal defect, and coarctation of the aorta.

Most of the book is comprised of extensive medical information about surgical procedures, recovery, post-operative complications, nutrition, and related technical topics. This information is detailed in paragraph-long explanations written in accessible terms by physicians (many pediatric cardiologists), nurses, and social workers who are the “contributing experts” to the book. Their names, titles, and institutional affiliations are at the front of the book. There are also chapters that focus on coping with the child’s condition, and day-to-day living, e.g. explaining the heart condition to an older sibling, treating colds and childhood illnesses, how to communicate parental needs to family and friends.

In the text are important “Tips on Using the Internet” and an explanation of basic research techniques using libraries and the Internet, written by a graduate student in library science who was born with a heart defect.

Includes a glossary of medical terms, resource guide to organizations, support groups, and websites, and a recommended bibliography of books for children and parents about congenital heart defects and hospitalization. (JK)

◆**The Yale Child Study Center Guide to Understanding Your Child: Healthy Development from Birth to Adolescence.** Linda C. Mayes and Donald J. Cohen. Little Brown & Company, 2002. 624 p. ( ISBN 0-316-95432-2), \$40.

Since its founding by Dr. Arnold Gesell in 1911, the Yale Child Study Center has provided guidance to parents as well as conducted scientific research on the development of children. In that tradition, this attractive, easy-to-understand, encyclopedic guide provides helpful, basic, childrearing advice to parents, based on principles of child development. Written by physicians and other professional staff of the Yale Child Study Center, it focuses on emotional needs and stages. There is information on motor, cognitive and social development as well. Among the practical suggestions for new parents as the beginning of the book, there is a discussion of mentally adjusting to the new role of parent before the child’s birth. There are sections on moral development, choosing quality child care, and passing on family traditions.

An entire chapter discusses “Sharing Books With Your Child.” Among its unique features are sections on parenting a dying child, “help in the aftermath of violence,” and understanding cultural differences.

**The Yale Child Study Center Guide** complements other valuable childrearing books such as **Touchpoints** by T. Berry Brazelton, the American Academy of Pediatrics’ series beginning with **Caring for your baby and young child**, and the American Academy of Child and Adolescent Psychiatry’s **Your child: What every parent needs to know**. It would be especially helpful as a reference source for a new parent. (JK)

◆**Parent’s guide to childhood eating disorders.** Marcia Herrin and Nancy Matsumoto. Henry Holt, 2002. 324 p. (ISBN 0-8050-6649-7), \$16.00 pap.

Marcia Herrin speaks from experience in her informative, helpful book about childhood eating disorders. A registered dietitian, she is the founder and current co-director of the Dartmouth College Eating Disorders, Prevention, Education, and Treatment Program. Her book reflects understanding and compassion for children and adolescents with bulimia and anorexia, and for their parents. As a teenager, she became anorexic at a time of extreme stress within her family.

Written in understandable language, her book provides emotional and nutritional guidance to parents, who “play a crucial role in shaping the attitudes of their children toward food and eating.” It begins with a section on identifying eating disorders, their medical consequences, and guidance about how to try to prevent them by enhancing a child’s self-esteem and strengthening a child’s social and emotional health.

Illustrative examples drawn from Ms. Herrin’s experiences with patients and specific suggestions directed to parents and friends for “taking action” enrich the book. The book’s concluding section describes the author’s food plan for healthy eating and recovery. Though specific in the type of foods and quantities to eat, the eating guide would be more helpful if it included sample menus.

The guide is enhanced by diagnostic criteria for eating disorders, body mass index charts and explanations, a list of related organizations and websites, and an unendorsed list of residential and hospital programs. (JK)

◆**Power to the patient: The treatments to insist on when you're sick.** Isadore Rosenfeld. Warner Books, 2002. 480 p. ( ISBN 0-446-52694-0), \$25.95.

Physician and popular medical writer (Parade magazine, **Doctor, What Should I Eat?, Live Now, Age Later**, etc.), Dr. Isadore Rosenfeld has selected nearly forty, frequently encountered medical ailments to write about in informal, brief chapters, arranged alphabetically from acne to urinary incontinence. In easy-to-understand language, he discusses the disorder's description and history, symptoms, treatment, and management in everyday life. The questionable humor of each chapter's subtitle may discourage some readers from having confidence in the book's content. (Asthma: When you aim to wheeze, AIDS: Serious monkey business, Alzheimer's Disease: Forget about it).

This book is most valuable for the section concluding each chapter, entitled, "What to insist on." It explains which current diagnostic tests and treatments are important ones that the patient's doctor should recommend. Dr. Rosenfeld says the patient should "*insist*" on these procedures and therapies.

A good source for easy-to-read explanations of common disorders and their treatment. (JK)

◆**The teen health book. A parents' guide to adolescent health and well-being** Ralph I. Lopez. W.W. Norton, 2002. 448 p. (ISBN 0-393-02046-0), \$26.95.

Hormonal changes, sleep deprivation, eating disorders, sexuality, and risk of substance abuse are among topics of concern to adolescents and their parents as they mature from children to young adults. In this helpful, clearly written basic guide for parents, Ralph Lopez, M.D., (Weill Medical College, Cornell University ) uses his more than thirty years experience as a physician to adolescents to discuss these topics and to orient parents to the unique medical needs of teenagers. The book's second part provides, literally, a head-to-toe explanation of medical disorders common to teenagers.

Comfortable with the nuances of teenage conversation (or lack of conversation..), Dr. Lopez emphasizes the importance of a physician showing respect for a teen's need for independence in communicating with a doctor and in the medical appointment process. (These logistics, especially when an adolescent turns eighteen, are sometimes governed by provisions of the law.) He diplomatically intersperses recommended ways parents can respond when faced with medical revelations of risky behavior by their youngsters.

Since there are fewer parenting books for adults in the midst of raising teenagers than parents of young children, this book will be especially useful to parents facing adolescence in a child for the first time. Includes a recommended list of websites for parents and teenagers. (JK)



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