



CHRC News

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Introduction

This issue of the *CHRC News* features web sites in the news, as well as those of special interest to medical interpreters. CHRC Project Manager Julie Whelan reports on the annual meetings of both the Massachusetts Library Association and the Medical Library Association.

In the News

New CHRC Rolodex cards are now available. Please feel free to request some for your files. Contact information is on the last page.

Treadwell Staff News

Remarks from Julia Whelan

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Massachusetts Library Association: The CHRC was one of the exhibitors at the annual meeting of the Massachusetts Library Association (MLA) in Falmouth in early May. The Statewide Legal Reference Service (SLRS) librarians were kind enough to share their exhibit space as well as offer warm hospitality and enthusiastic support. For some of the many conference attendees who stopped by the shared table, the CHRC's display was an introduction to a

service they either did not know about, or had heard of but never used. For others, it was a chance to discuss the service and offer suggestions. As the new CHRC manager, I am particularly interested in feedback both positive and negative, so that we can work to improve our service. I learned from several visitors that they find the e-mail messages I have sent out listing new web resources particularly helpful. However, when I offered to send out more of these messages, the suggestion was greeted with chuckles and the comment that the current frequency was just about right. I am currently arranging our fall workshops so I look forward to seeing many of our users during these upcoming sessions.

Medical Library Association: The second MLA involved a trip to Dallas for the annual meeting of the Medical Library Association (MLA). This is a forum where the National Library of Medicine (NLM) gives its annual report and outlines priorities and plans for the coming year. NLM continues to emphasize consumer health information as a top priority. Future programs will particularly focus on reaching special populations including ethnic groups, geographic groups (a project on Arctic Health is an example) and developing materials in non-English languages. Outreach to rural and inner city populations continues to be a major goal.

Consumer Health Topics at MLA:

Consumer health presentations at MLA focused on four main categories: providing AIDS/HIV information, providing information on genetic testing to consumers, outreach to rural populations and partnerships between medical and public libraries.

Senior Citizens: Recent studies indicate that senior citizens are the demographic group most frequently looking for health information on the web. In response to these findings, NLM joined with the National Institute on Aging (NIA) and the National Institutes on Health (NIH) to produce a special resource called **NIH Senior Health**, <http://nihseniorhealth.gov/>. Research from the NIA informed the design of this easy-to-navigate site and selection of its content, including large print and short, easy-to-read segments of information. Material on the site is presented in a way that increases the likelihood it will be retained in memory. To that end, the first topics offered are Alzheimer's disease, caring for someone with Alzheimer's Disease, and exercise for older adults. For related information, see ***Making Your Web Site Senior Friendly*** elsewhere in this issue.

Genetics Information: Dr. Angela Scheuerle, Medical Director of the Texas Birth Defects Research Center, described her evaluative study of the wide variety of information on genetics available to consumers. On the web, some professional organizations provide in-depth information of excellent quality. However, other web sites, primarily hosted by individual doctors, are often outdated and in some instances

give incorrect information. There are several excellent print texts, many of them produced by advocacy and parent groups. While web bulletin boards and chat rooms are often positive sources of patient support, they should present a balance of positive and negative experiences that reflects actual treatment outcomes. This study indicated that anecdotal information is dominated by negative accounts. It appears that patients who feel cheated, uninformed or mistreated use these forums to vent their frustrations, while people who are coping well do not seem to be using the media as heavily.

Both MLA meetings succeeded in providing stimulating topics for investigation, contact with colleagues, and rejuvenated enthusiasm for library work.

Web sites in the News

Healthnet: Connecticut Consumer Health Information Network
<http://library.uhc.edu/departm/hnet/rbcurrentresearch.html>

This excellent site from the Lyman Maynard Stowe Library at the University of Connecticut Health Center - Farmington has recently added tips to help consumers carry out their own research on the Internet. Some of the unique features of this site include: how to research information on a disease or medical condition using selected resources, how to locate information on health care providers, and how to evaluate web sites.

Introduction to Herbal Supplements

<http://www.mcp.edu/rc/citpc/herbs/>

As part of CHRC Project Manager Julie Whelan's 1999 National Networks of Libraries of Medicine (NN/LM) outreach grant, she worked with colleagues for two years to create web-based education programs on complementary medicine. Recently made available on the web, this site covers a wide range of information about herbs in general and detailed information about ten major herbal supplements. The site includes a history of herbal supplements from a variety of healing traditions, instructions on reading a supplement label, a partial list of drug interactions, herbs to avoid in pregnancy, and annotated links.

Knowledge Path: Children with Special Health Care Needs (NCEMCH)

<http://www.ncemch.org/CSHCN/TOC.htm>

The National Center for Education in Maternal and Child Health (**NCEMCH**), based at Georgetown University, is funded by the U.S. Department of Health and Human Service. It provides national leadership to the maternal and child health community in program development, education, and state-of-the-art knowledge, to improve the health and well being of children and families. Section One of the **Knowledge Path** contains links to general resources including organizations, web resources, medical reference books, directories, bibliographies, and other print publications, as well as tools for identifying additional resources. Section Two focuses on practical resources to assist families and other caregivers in providing the best care

for children with special health care needs. **NCEMCH** also includes **MCHLine**, a database containing pamphlets, fact sheets, books and journal articles, available at <http://www.ncemch.org/databases/MCHLineSearch.lasso>. Each record includes an abstract, subject heading, and full ordering information. **Knowledge Paths** on related topics are available at http://www.ncemch.org/RefDes/knowledge_path.html.

Making Your Web Site Senior Friendly

<http://www.nlm.nih.gov/pubs/checklist.pdf>

Produced by NIA and NLM, this 15 page PDF document focuses on goals to keep in mind when developing a site that can easily be used by senior citizens. There is also an extensive bibliography. According to "Wired Seniors" a recent report by the Pew Internet & American Life Project, http://www.pewinternet.org/reports/pdfs/PIP_Wired_Seniors_Report.pdf, "Neither income level nor educational attainment makes much difference in whether or not seniors seek out health information. However, experience with the Internet does make a difference." Of those who have had three or more years' experience online, 65% have searched for medical advice online.

Patient Education Resource Center (PERC)

<http://www.cancer.med.umich.edu/learn/lear.es.htm>

The CHRC is often called upon to answer questions about cancer diagnosis and treatment in non-technical language. This is easy enough for general information on

commonly found tumors, but much more difficult for less frequently encountered cancer types. The Spring, 2002 issue of the *Cancer Librarians Section News* <http://www.selu.com/cancerlib/spring%202002%20newsletter.pdf> contains an article, “Beyond ‘Cancer 101’: The Librarian’s Challenge” that discusses this problem, and describes readable, reliable, but unindexed publications. Some of these publications are available full-text on the web. Librarians at the Patient Education Resource Center (PERC) located at the Comprehensive Cancer Center, University of Michigan have selectively indexed seventeen newsletters, listed in an appendix to “Beyond ‘Cancer 101’ ” and three cancer magazines: *Mamm*, *InTouch*, and *Coping with Cancer*. Search the PERC catalog by keyword (truncate for variant endings with an asterisk), author, and subject at <http://perc.cancer.med.umich.edu/winnebago/index.asp> The PERC catalog does not provide links to full-text articles.

TalkingQuality.gov

<http://www.talkingquality.gov/default.html>

The purpose of **TalkingQuality** is to offer expert advice and suggest approaches to dealing with the task of developing and distributing health care information that consumers can understand and use. It is designed to be a comprehensive guide for organizations that are developing reports for consumers about health care quality. Its goal is to serve as an educational resource for those relatively new to this task, as well as a reference for anyone looking for information on specific topics related to quality reports or examples of different

approaches to reporting data. The site also offers a planning tool to help report designers work through all of the steps involved in generating an effective report. This excellent site is sponsored by several government agencies including the Agency for Healthcare Research and Quality (AHRQ).

MEDICAL INTERPRETERS

Hospital-Based Interpreter Services

<http://www.state.ma.us/dph/omh/interp/interpreter.htm>

This site, from the Massachusetts Department of Public Health, includes information in PDF format on new legislation. Links include community language banks and commercial local interpreter services, telephonic interpreter services, and links to non-English language sites.

Massachusetts Medical Interpreters Association (MMIA)

<http://www.diversityrx.org/HTML/MOASSA.htm>

The purpose of this 350+ member organization includes defining educational requirements and qualifications for medical interpreters, establishing professional standards of practice and norms of medical interpretation, and promoting the establishment of professional interpretation services and the use of professional translation by medical institutions and related agencies. The site also includes links to other organizations.

What a Difference an Interpreter Can Make: Health Care Experiences of Uninsured with Limited English Proficiency

http://www.accessproject.org/downloads/c_LEPreportENG.pdf

The findings in this 16 page PDF document, published by **The Access Project**, a program of the Center for Community Health Research and Action of the Heller School for Social Policy and Management at Brandeis, indicate that uninsured respondents with limited English proficiency who have access to an interpreter have strikingly better experiences in a wide range of areas, including ability to understand medication instructions, ability to get financial assistance to pay for care, and overall satisfaction with their health care encounter, compared to those who did not have an interpreter.

CHRC Reviews: In Print

The first year -- IBS (irritable bowel syndrome) : an essential guide for the newly diagnosed / Heather Van Vorous ; foreword by David B. Posner / New York / Marlowe / Distributed by Publishers Group West / 2001. The author, a food writer who has suffered from IBS for over two decades, offers straightforward advice, personal stories, coping strategies, and the always sought-after recipes. There are chapters on both prescription drugs and alternative medicine, and how to eat safely when not at home.

The Gale encyclopedia of genetic disorders / Stacey L. Blachford, editor / Detroit / Gale Group / 2002. This is an impressive two-volume reference source covering 400 diseases and conditions of genetic origin. Every entry includes definition, description, genetic profile, demographics, signs and symptoms, diagnosis, treatment, prognosis, and resources (references to one or more medical books or journal articles, web sites and organizations). There is judicious use of color illustrations and pedigree charts. There is an index and *see* references. It should be remembered that less frequently encountered genetic diseases are not covered in this otherwise excellent source. Please don't hesitate to contact the CHRC for assistance in locating information about these rare diseases.

The OASIS guide to Asperger syndrome : advice, support, insights, and inspiration / Patricia Romanowski Bashe and Barbara L. Kirby ; foreword by Tony Attwood / New York / Crown Publishers / 2001. Co-author Kirby is founder of the Online Asperger Syndrome Information and Support Web Site (**OASIS**). This is a very readable, comprehensive book for anyone, whether parent, educator, or general reader, covering every aspect of Asperger Syndrome (AS). There are chapters ranging from medication to legal issues, coping strategies for parents, friendship skills for children, bullying, and developmental issues. There is a sample "letter of introduction" for AS children entering a school system, also available on the extensive **OASIS** web site,

<http://www.aspergersyndrome.org/> (click on “Education”).

Parkinson's disease : a complete guide for patients and families / William J. Weiner, Lisa M. Shulman, Anthony E. Lang / Baltimore / Johns Hopkins University Press / 2001. The authors, all physicians and experts in the field, state that they have “delineated the common problems associated with the early, middle and advanced stages of Parkinson’s disease” and each problem is discussed in detail. The authors offer suggestions on how to better live with these problems, and have reviewed many of the common non-motor symptoms that can occur with Parkinson’s. There are chapters covering drug and surgical interventions. There is also a list of frequently asked questions and answers as well as an annotated resource list.

What would you like to see covered in the *CHRC News*? Please don’t hesitate to tell us!

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<http://www.mgh.harvard.edu/library/chrcindex.html>

