



# CHRC News

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A Service Funded by the Massachusetts Board of Library Commissioners

## INTRODUCTION

Welcome to the first spring of the new millennium, and a new focus for the *CHRC News*. Each issue will highlight quality consumer health information on the web. This issue will be devoted to a broad overview of cancer, spotlighting just a few excellent web sites. Topics in upcoming issues will focus on exploring queries that the CHRC has received. Please let us know what topics you'd like to see covered.

## JOINT CHRC/SLRS WORKSHOPS

We hope the good weather will enable you to attend one of the upcoming CHRC/SLRS workshops listed below. In May, the Massachusetts Board of Library Commissioners (MBLC) will be sponsoring workshops covering services offered by the CHRC and the Statewide Legal Reference Services (SLRS). Based on some of the more unusual and thought-provoking queries received over the past year, the workshops will provide specialized information on print and electronic resources that may be best utilized to help answer your users' queries. These refresher workshops will allow an opportunity for input into future services that may be provided by these statewide reference programs. Library staff from any regional member library are welcome to attend on the date and location that is most

convenient, regardless of which region your library belongs to.

### **WMRLS:**

Mon., May 15, 1:00 p.m.–5:00 p.m.  
Western Region HQ  
58 Main Street  
Hatfield  
1-800-282-7755  
Please **do not pre-register** for this location.

### **NMRLS:**

Tues., May 16, 12:30 p.m.–4:30 p.m.  
Lucius Beebe Memorial Library  
Main Street  
Wakefield  
781-246-6334  
contact: Susan Grabski  
sgrabski@nmrls.org

### **CMRLS:**

Wed., May 17, 9:00 a.m.-1:00 p.m.  
Central Region HQ  
8 Flagg Road  
Shrewsbury  
508-757-4110  
contact: Margaret Cardello  
mcardell@cwmarshmail.cwmars.org

### **SEMLS:**

Thurs., May 18, 12:30 p.m.– 4:30 p.m.  
Middleborough Public Library

102 North Main Street  
Middleborough  
508-946-2470  
contact: Cheryl Bryan  
[cbryan@semls.org](mailto:cbryan@semls.org)

### **MMRLS:**

Fri., May 19, 9:00 a.m. – 1:00 p.m.  
Metrowest HQ  
135 Beaver Street  
Waltham  
781-398-1819  
contact: Barbara Andrews  
[andrews2@mmrls.org](mailto:andrews2@mmrls.org)

### **CHRC@MLA**

Kate Kelly, CHRC Project Manager, looks forward to meeting many of you on Friday, April 28, at her 2:45 p.m. presentation, “Consumer Health Reference” during the Massachusetts Library Association meeting at the Sheraton Hyannis. She will be focusing on electronic resources for consumer health services, with a brief introduction to collection development.

### **TREADWELL LIBRARY RECEIVES NLM GRANT**

We are pleased to announce that a joint proposal submitted by Treadwell Library and the Massachusetts General Hospital Community Health Associates was one of 49 electronic health information projects funded by the National Library of Medicine. This project will create a Health Resource Center, based in Revere that will serve Chelsea, Charlestown, Everett and Revere, and will

provide online access to health care information. MGH librarians and resource specialists from the Mass. Prevention Center in Boston will train outreach workers and other staff from the MGH Community Health Centers to assist local residents, community health care workers, and local organizations in accessing online health information via the Internet. Another partner in the project is Chelsea’s Department of Public Health. For more information, go to: [http://www.nlm.nih.gov/news/press\\_releases/ehip.html](http://www.nlm.nih.gov/news/press_releases/ehip.html) (NLM Press Release), and <http://www.nlm.nih.gov/nno/hipprojects.html> (Health Information for Public Projects)

### **CANCER ON THE WEB**

Many articles have been written about the problems inherent in finding quality medical literature on the web. As an article entitled “Cancer and the Internet” by Donald Earl Henson, M. D., in the August 1, 1999 issue of the journal *Cancer* stated, “On the Internet, there is no separation of peer-reviewed, scientifically proven conclusions from anecdotal information or personal reflections.” Another article in the same issue, “Evaluation of Cancer Information on the Internet” by J. Sybil Biermann, M. D., et al., highlighted the pitfalls of using search engines to look for information about cancer. The example chosen was Ewing sarcoma. Its variant spellings -- Ewing, Ewings, or Ewing’s -- resulted in a plethora of possible sites, some of which offered blatant misinformation, and others of which only mentioned the diagnosis in passing. The following web sites will help provide

consumers with quality information about cancer.

## **OncoLink**

<http://cancer.med.upenn.edu>

There are a number of contenders for “best cancer site.” Arguably the most all-encompassing, professionally written, yet accessible to the general public site is the University of Pennsylvania’s OncoLink. According to their home page, OncoLink was founded in 1994 to help cancer patients, families, health care professionals and the general public find accurate cancer-related information at no charge. It is updated every day, and is designed to make it easy for the general public to navigate through the pages. OncoLink provides comprehensive information about specific types of cancer, updates on cancer treatments and news about research advances.

There is a wealth of information, but don’t let yourself be intimidated. On the home page, you can connect to **Disease Oriented Menus** (written for the professional and the lay reader, in both English and Spanish); **Medical Specialty Oriented Menus** (for instance, radiation oncology or bone marrow transplantation); **Psychosocial Support and Personal Experience** (ways to cope; shared experiences); **Cancer Causes, Screening, and Prevention** (environmental, genetic, tobacco issues); **Clinical Trials** (with links to a variety of trials at governmental, organizational, and medical center sites); **Financial Issues for Patients** (billing, assistance programs); and more. Also on its home page, OncoLink provides a link to

book reviews on sixteen topics (to date), ranging from skin cancer to nutrition. Under each topic, there are a half dozen or more substantive book and media reviews written by physicians and health care professionals. OncoLink will also highlight those books containing irresponsible advice which they do not recommend.

Another way to find information in OncoLink is by taking advantage of their search engine, AltaVista. Using the advanced mode, you can search either the entire OncoLink database or restrict to various areas, which consist of **Frequently Asked Questions** or **FAQ** (answered by OncoLink staff, usually a physician or nurse); **Cancer News**, **Psychosocial Information**, **Citations from the National Library of Medicine’s CancerLit**, or **All Areas Except Citations**. The **Advanced Mode** is recommended because Boolean operators **AND**, **OR**, and **NEAR** can be used to good advantage. As an example, try looking for information about pain as it relates to non-Hodgkin’s lymphoma. (There are many different kinds of lymphoma, the type being determined by how the cells look microscopically.) Translate the search into a statement like this: **pain near non-Hodgkin’s lymphoma**. The advanced search mode in **All Areas Except Citations** yields (to date) five hits, some of which lead to more documents. It should be noted that there are no results when it is spelled without the apostrophe or without the hyphen. Most notably, there are two FAQs about pain in non-Hodgkin’s lymphoma, and there is a “Primary Document” on pain management, that links to a wide variety of carefully

chosen organizational and medical center resources.

## **ASCO**

<http://www.asco.org>

Worthy of brief mention is the site of the **American Society of Clinical Oncology (ASCO)**, whose mission, according to their home page, is to promote the “exchange of cancer-related information and news among the oncology community as well as the general public.” ASCO’s annual meeting is “the premier event in oncology, with leading specialists from around the world presenting the most recent advances in cancer prevention, treatment and research.” The ASCO site has just begun to make itself more accessible to the consumer, and by going to the **ASCO Shortcuts** drop-down menu, and searching by disease, you can see breast, lung, prostate and colon cancers listed. For each disease, links are available to **guidelines, resources, news, clinical research**, and other categories. This site will clearly be expanded and it appears as if it will eventually become a very useful site for consumers.

## **Lung Cancer**

<http://lungcanceronline.org>

There are a number of very high quality web sites devoted to cancer in specific parts of the body. **Lung Cancer Online** is one such site. It was founded by a librarian and lung cancer survivor, Karen Parles. Coincidentally, this site can be used to illustrate all the virtues that you hope to find in a quality web site, ranging from currency and reliability of

source information to statement of ownership. It loads very quickly, and there are no frames or graphics to clutter the screen. Lung Cancer Online provides links to such important and technical sites as the University of Iowa’s Virtual Hospital, <http://www.vh.org>, for instance, which describes in extensive clinical detail a wide variety of both common and rare tumors of the lung. Lung Cancer Online also links to easily understood sources such as the National Cancer Institute’s **What You Need to Know About Lung Cancer**, a booklet which includes line drawings and definitions, <http://cancernet.nci.nih.gov>.

## **Breast Cancer**

<http://www.cancernetwork.com/guidelines/Breast/Page1.htm>

There are a number of highly reputable sites for breast cancer information. One such site is a collaboration between the **National Comprehensive Cancer Network (NCCN)** and the **American Cancer Society (ACS)**. . According to the site’s home page, this partnership is meant to “provide patients and the general public with state-of-the-art cancer treatment information in understandable language. This information, based on the NCCN’s Clinical Practice Guidelines, is intended to assist you in the dialog with your physician.” The outstanding feature of this site is the **Decision Tree** section. Click on Stage 0 (LCIS, lobular carcinoma-in-situ), Stage 0 (DCIS, ductal carcinoma-in-situ), Stage I and II, Stage III, Follow-up/Recurrence, or Stage IV. You’ll be led, in logical progression, through a chain of “interactive flow charts,” as they’re

described, that represent different stages of breast cancer. Each decision tree shows how the patient and physician, working together, arrive at the choices needed to make a surgical, radiation, chemotherapeutic, or other, decision. Every term is clearly defined. It should be noted that male breast cancer is an entirely different disease from female breast cancer, and it is not covered in this web site.

### **Prostate Cancer**

<http://www.cancer.org/m2m/m2m.html>

Prostate cancer is the second leading cause of cancer death in men, but by comparison with breast cancer, there are fewer quality web sites on the subject. However, the **American Cancer Society's Man to Man: Prostate Cancer Patient Education and Support** is a great starting place. The Man to Man concept began ten years ago in Florida with a prostate cancer survivor, James Mullen, who began a support group. Patient education materials are available at this site, covering topics from the PSA blood test to postoperative incontinence management; risk factors; links to other prostate cancer sites, and eleven (to date) issues of the *Man to Man Newsletter*, a quarterly electronic newsletter covering scientific topics in a readable way. The current issue's headlines include "Finasteride may not prevent prostate cancer"; "Family history of breast cancer may increase risk of fatal prostate cancer"; "Focus on clinical trials" and "You may have heard about shark cartilage." One link from this site, **PSA Rising**, was particularly impressive in content, if not in layout. A pilot project in prostate cancer outreach sponsored by a Fort Lauderdale

cancer foundation, at <http://www.psa-rising.com>, this site is notable for a broad range of scientific news about new prostate cancer treatment. PSA Rising also links to news releases from pharmaceutical companies, as well as a wide range of treatment options. The goals of PSA Rising are clearly stated on their home page, and include, among others, alerting "the medically underserved, especially African-American men," helping those newly diagnosed gather information, and conveying news about clinical trials and medical research. The site has a search engine, and there is a prominent link to a Spanish language publication about prostate cancer from the American Cancer Society. It should be noted that other sites, like OncoLink, provide information in Spanish as well.

### **Brain Tumors**

<http://www.virtualtrials.com>

Though there are many extremely useful brain tumor sites sponsored by organizations and medical centers, offering news, support, glossaries, and treatment information, one of the most comprehensive and easily navigated is **The Musella Foundation for Brain Tumor Research and Information**. A 501(c)3 non-profit organization "dedicated to improving the quality of life and survival times for brain tumor patients," according to its home page, the site began in 1993. The site's Medical Advisory Board members (physicians from the New York-New Jersey area) are prominently listed, as are disclaimers. Although the ever-changing advertising banners (mostly from drug companies and medical institutions) can be

distracting, the quality of information is superb and is updated constantly. Some of the most useful topics covered include **How to Find Brain Tumor Treatment** (browse new listings or browse by brain tumor type) and **Learn about Treatments for Brain Tumors** (news stories, conference information, survivor stories, glossary). There are also listings of support groups, contact information for specialists and hospitals (though this section is not comprehensive) and links to other brain tumor sites. One feature which demonstrates the power of this site is the **Search for a Specific Brain Tumor Trial or Treatment** in the advanced search mode, which allows you to specify the following from drop-down menus: **tumor type; treatment type; clinical trial phase; age group; and geographic location**. If you chose to look for chemotherapy trials of glioblastoma multiforme in Massachusetts, you'll find six. The trials are listed by name, and clicking on "Details" for the "Phase I Dose Escalation Study of Gliadel in Adults with Recurrent Malignant Gliomas" informs you that this is a study for adults only who can care for most of their own needs. It mentions other types of tumors, other than glioblastoma multiforme, that this trial will consider, and gives complete contact information. In this case, the trial takes place at the Brain Tumor Center at MGH.

Though finding quality, current cancer information on the web can be challenging, it is also rewarding to both librarian and consumer. As always, please don't hesitate to contact us with any questions you may have.

### **CHRC Contact Information**

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or 617-726-8600**

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**Consumer Health Reference Center  
Treadwell Library  
Bartlett Hall Extension 1  
Massachusetts General Hospital  
Boston, MA 02114.**

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