



# CHRC News

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## CHRC Annual Report

The first year of the Consumer Health Reference Center has been an exciting and busy one. During this time 247 libraries asked 555 questions. The Northeast, Southeastern and Metrowest regions accounted for 73% of those 555 questions and 73% of all queries came from public libraries. Aside from questions about CHRC services and policies, which were to be expected from such a new service, the top three topics of enquiry were cancer and cancer treatments, drugs and medications, and recommendations for health related books, journals and internet sites.

We at Treadwell have thoroughly enjoyed answering (or trying to answer in some cases!) the questions you have referred to us. We noticed the questions became more and more complex as the year progressed and we look forward to an even busier year ahead.

## CHRC Rolodex Cards

Accompanying this issue of the *CHRC News* is a Rolodex card with full details on how to contact the CHRC. We encourage you to put this card with all your other reference contacts. We know how easy it is to forget the number and the name unless

you use us all the time – we hope this helps a little.

## New Look for CHRC Web Page

The CHRC web page at:

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

has been completely redesigned. Please take a look and send us your comments. New features include a web form so you can send questions to us via the web, a search engine and many updated links. Some new links of interest include:

### *Needy Meds*

<http://www.needymeds.com/>

A listing of pharmaceutical companies drug offering assistance programs for people who can't afford the drugs they need.

### *School Nurse and Practitioner Links*

<http://www.hslls.pitt.edu/outreach/partners/nurse.html>

School librarians may find this annotated list of links for school nurses very useful.

### *New England Regional Genetics Group*

<http://acadia.net/nergg>

Educational materials and resources on genetics and genetic programs in New England.

Several language resources have also been added. Two worth checking out are:

***Multicultural Health Communications Services (New South Wales, Australia)***

<http://mhcs.health.nsw.gov.au/health-public-affairs/mhcs/index.html>

Extensive listing of publications in numerous languages. Publications may be viewed and printed without any language software although Adobe Acrobat is required for viewing.

***Translated Health Education Materials***

(British Columbia Ministry of Health, the Department of Canadian Heritage, the Vancouver Foundation)

<http://www.healthtrans.org>

Extensive list of publications in many different languages. Searchable by categories, agencies and languages.

***Massachusetts Models***

*In the fourth article in our series, **Massachusetts Models**, Susan Flannery, Director of the Cambridge Public Library describes the role of the public library in providing health information. This is the text of a presentation made to the Massachusetts Health Sciences Libraries Network (MaHSLIN) Annual Meeting in April 1999.*

In the past 20 years the role of the patient in health care has evolved from recipient to partner. The doctor is no longer God and the patient can no longer be passive.

The public library has a critical part to play in supporting individuals in their role as health care consumers. This function is not

incompatible with the traditional role of the public library as an information source but it does present some unique challenges.

There is a natural tension in many areas of reference service between advice vs. information, credible versus unvalidated sources, and intellectual freedom versus censorship. But nowhere is it more acute than in the field of medicine. Here we are frequently talking about life and death.

There are multiple reasons why an individual might seek out health information in a public library. These include, but are not limited to:

- Educational research
- Healthy lifestyle/prevention
- Informed decision making
- Crisis intervention

The data on clientele using health information at the Cambridge Public Library is not inconsistent with national findings. The majority of our users are students doing research and adults seeking personal health information. We do occasionally serve nursing students and practicing nurses. We do not, as a general rule, serve physicians and other medical professionals seeking health information.

Students' requests are straightforward and easily handled. The adults come in three different categories:

1. Those seeking a healthier life style. They are interested in prevention of major illness; weight loss, lowering

cholesterol, having a healthy pregnancy, how to stop smoking, etc.

2. Those who want to be forewarned and forearmed. They have been diagnosed with a particular disease, problem and/or are scheduled for tests, procedures, or surgery which they don't know anything about. For example, a young woman came into the Reference Room of the Cambridge Public Library and asked the reference librarian for information on Down's Syndrome. She had no idea what it was but had been told by her physician that the baby she was carrying would have it. When the librarian suggested that she might wish to discuss this further with her doctor, the woman made it clear that, for whatever reason, her doctor was not a potential source of information for her.
3. Patients in crisis/shock. They have received devastating news and are looking for a glimmer of hope that there is a cure. For example, a woman came to the reference desk looking for new "cures" for esophageal cancer. She made it clear that her doctor had told her that her case was terminal but she was determined to find out about a cure. She wanted something new and cutting edge... something that worked but was overlooked by "traditional" medicine.

Individuals frequently come to the public library when they or their loved ones are given a grim prognosis and they are desperate to find "good news" on the shelves or in the computer.

Imagine the challenges for a reference librarian in answering that question. The staff finds this work intensely personal and very draining. Surely, this is not the role that any of us envisioned when we signed on to be librarians.

In all instances, we expect our staff to treat our customers in a professional, respectful manner. But clearly these situations require much more. They necessitate sensitivity, tact, patience, empathy, and kindness. The librarian needs to answer the questions but how he or she does it is crucial. Imagine the sophistication level of someone who does not know what Down's Syndrome is.

This illustrates another of our challenges, namely the disparity in our constituency's levels of understanding of health information. There is no common denominator. Some of our users may have advanced degrees in the sciences and others may have less than a high school diploma and others, like myself, fall somewhere in between

This issue is most acute in accessing fast breaking medical information, which is most likely to be published for the "professional" and not for the lay person. Is information that one can't understand of any more use than no information at all? Does the reference librarian make this call when a patron does not have the luxury of waiting for the "pop" version?

A report published by the National Commission on Orphan Diseases (U.S. Dept. of Health & Human Services, 1989)

describes the difficulty patients diagnosed with orphan (rare) diseases have in obtaining information to assist them in making decisions. This problem was not limited to patients. Nearly half of the 247 physicians could not find printed material for their patients and more than one third could not find information summarizing ongoing research. (1)

If the “specialists” can’t find this information, what chance do we “generalists” have? Many times we do the best we can in an “alien” universe.

There is a natural tension in the medical field between what are accepted procedures and treatments, and emerging research and alternative therapies. While a medical practitioner or institution might choose to follow a particular school of thought, it has been the public library’s hallmark to leave the decision making up to the user. Therefore one might expect to find books, journals, etc. that an MD or RN would find medically unsound. Fad diet books are an obvious example of this. But so are publications that claim you can determine the gender of your child by your diet or that you can cure a life threatening illness by eating sunflower seeds.

Although it is essential that a public library provide access to mainstream medical information it is also our responsibility to provide information on alternative medical practices and ideas. Even if we hadn’t considered that our mission in the past, the explosion of medical information, both bogus and bona fide, on the Internet has

made it impossible for us to do anything else.

As professionals, we do not eschew our obligation to provide accurate information to our customers by leading them to the very best medical information available - if that is what they request. One way we assist our users in ferreting out the “good stuff” is by producing guides.

We have expanded our guides beyond the traditional book resources to include useful web sites with credible and up-to-date information on a variety of subjects.

That in no way suggests that we would actively lead a patron away from his or her desire to access non-traditional resources, un-moderated listservs, and chat rooms.

The revolutions in technology, the availability of shared access to electronic databases, the establishment of the Consumer Health Reference Center at Treadwell Library, MGH, and the Internet has greatly enhanced the health information resources of even the smallest library in the Commonwealth.

In 1999, the Cambridge Public Library has access to nearly 200 full-text medical or health journals on-line. Ten years ago I would have been surprised if we had more than five titles in our collection.

Public libraries are proud to be partners with medical professionals and patients in de-mystifying medicine and making it accessible to the lay person. In fulfilling

that mission we accept our unique role which we hope bridges the “medical gap”.

1. **The Status of health information delivery in the U.S.: the role of libraries in the complex health care environment.** Karen Hackleman Dahlen. *Library Trends*. Summer 1993).

Susan Flannery, Director Cambridge Public Library.

### **Gale Encyclopedia of Medicine Online via Health Reference Center**

Detroit: Gale Research, 1999. \$500

**The excellent *Gale Encyclopedia of Medicine* is now available in full text as part of the Searchbank Health Reference Center database.**

This five-volume set has proven itself a consistently reliable, useful, and quick way to answer a number of CHRC questions. Arranged in alphabetic order it is a “one-stop source for medical information on nearly 1,500 common medical disorders, conditions, tests and treatments [...]” which “uses language that laypersons can understand”. Each article follows a standardized format. For instance, the entry on **Ascites** (an abnormal accumulation of fluid in the abdomen) contains definition, description, causes and symptoms, diagnosis, treatments (both conventional and alternative), prognosis, and prevention. There is a box for key terms; a black-and-white radiographic image; and a brief bibliography of books, journal and popular articles, and contact information, including URL, for the American Liver Foundation.

### **Free Merck Manuals**

From the Merck website:  
<http://www.merck.com/pubs/>

“We are delighted to make the 17th edition of *The Merck Manual* available on our web site free of charge. This book--The Centennial Edition--was published in **April 1999**. Merck also provides the entire 2nd edition (1995) of *The Merck Manual of Geriatrics* and part of *The Merck Manual of Medical Information--Home Edition* (1997) available on our web site free as well. Please use them as often as you like”.

### **Catchy Drug Names and Reference Questions**

“I heard about a great new arthritis drug - something like Celeron, or Acela, or Celebrex, or maybe Celebra. Can you give me some more information?” Though ad execs on Madison Avenue may delight in finding catchy brand names for new products, the similarity in sounds can cause problems. **Celeron**™ is an Intel® processor which “expands Intel processing performance” ; **Acela** is an “ultramodern, high-speed train” which will go into service on the Northeast Corridor later this year; **Celebrex** is the FDA approved drug for treatment of rheumatoid arthritis and osteoarthritis.

Using the FDA web page search feature <http://www.fda.gov/search.html> and limiting your search to the “Press Release” section of the FDA website

instead of the default “Search All of FDA” is a quick and easy way to find out about new drugs. Doing this pulls up one brief, easy-to-read information sheet about Celebrex.

And what about Celebra? Is it that Disney-owned town in Florida? (No, that’s Celebration). **Celebra**™ is the name under which Celebrex is marketed in Brazil. The “Doctor’s Guide to New Drugs or Indications”, <http://www.pslgroup.com/NEWDRUGS.HTM> is another comprehensive source of information about drugs. Utilize the “find” function of your browser to locate the word you’re looking for. In this case, the title of the news release is “COX-2 Inhibitor, Celebra, Approved in Brazil for Arthritis Treatment”.

### ***Treadwell EJournals in the News***

The “New on the Net” column in the May, 1999 issue of *Medicine on the Net* includes recognition of Treadwell’s electronic publications. They say that we present an “invaluable list of sites offering full-text articles or abstracts and tables of contents.” Though most of these sites do require an MGH Internet address for access, some are freely available. One of those which may be useful to consumers, given that cancer and cancer treatments was the number one topic of questions referred to the CHRC, is the *M. D. Anderson OncoLog*. This publication of the University of Texas’ M. D. Anderson Cancer Center, “reports recent developments in cancer patient care,

significant diagnostic progress, and current clinical and basic science research activities at M. D. Anderson Cancer Center.” Articles date back to the beginning of 1996, and there are between three and eight articles per issue. Web addresses:

<http://www.mgh.harvard.edu/library/electron.htm>

<http://www.mdacc.tmc.edu/~oncolog>

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