CAPHIS Directory Available on the Web!

By Roz Dudden

The CAPHIS Directory project, started in 1994, now has a product! You can search this database of information from consumer health libraries on the Web at:

http://www.njc.org/caphis/find_intro.html

There are 62 libraries (four from outside the United States) who have submitted data in 1997, either through the update form or the form printed in the Winter Consumer Connections. The database has two audiences; consumers and librarians. Each audience gets different data returned to them.

Consumers can search by subject, state, textword, or obtain an entire list of libraries.

Librarians can do the same but also obtain management data. Librarians can also search for comparative lists of management data involving budget, staff, collection, space, and Web involvement.

I am using a Macintosh system, with a WebSTAR server. The database is in Filemaker Pro. The program Web*FM connects the two programs with a forms based search interface.

Kim O’Neill from the EPA library worked with me on this project setting up the database and with inputting the data. We started last summer. I couldn't have done it without her dedication to coming in whenever she had a chance.

I will be passing out a data form at MLA to get more participants. Also in the future, participants will be able to input or update their own data on the web. I will be sending information out over MEDLIB-L.

Take a look!

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Consumer Connections
Is indexed in the Cumulative Index to Nursing and Allied Health Literature™ and the CINAHL® database.

Editor ............... Kay Deeney
Assistant Editor ...... Claire Hamasu
Special thanks for editorial assistance from Alan Carr and Nancy Calabretta
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Consumer Connections is produced three times a year in the Summer, Winter and Spring.
Planning for the 1997 program in Seattle has been completed. Valerie Schultheiss, Chair-elect, has been hard at work planning, reviewing abstracts, and setting up the program. The program has been titled "Faster, Better, Smarter: Providing Consumer Health Information." Four abstracts have been accepted. The four abstract titles are:

2. Partnerships between a hospital library and public library for the distribution of consumer health information.
3. The bottom line on closed circuit educational television.

These papers, along with those accepted by the Cancer Librarians section (we are co-sponsoring this program) should make for some interesting programming. The Cancer Librarians section program is entitled "Diverse Cultures, Diverse Responses: Meeting the challenge of health information for all".

The MLA Books Panel has asked that CAPHIS consider compiling a BibKit on consumer health information resources. I have agreed that the section would like to produce such a publication. Last month I received the proposal guidelines and requirements. I would appreciate assistance from anyone interested in helping with this project.

MLA headquarters has also asked that CAPHIS address three questions about MLA's role in consumer health. MLA is supportive of the growing involvement of its membership in consumer health information and would appreciate CAPHIS' consideration of the following questions:

1. Should MLA play a producer or facilitator role in consumer health information (or both)?
2. How can MLA and its members play a leadership role in the quality filtering of consumer health information?
3. How can MLA assist its members and enhance their role in consumer health information?

I believe that CAPHIS must take an active role in addressing these significant issues. Because of the importance of these issues, I think this should be addressed at the annual meeting in Seattle. If there are any interested members who would like to be involved in a committee that would explore these issues and bring recommendations to the annual meeting, please contact me at my e-mail rox@unmc.edu or at 402/559-7228.

Welcome to the Spring issue of Consumer Connections. Your comments are welcome. Consumer Connections is published three (3) times a year in the Spring, Summer and Winter, and is the official publication of the Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association.

Deadlines for submitting articles:

Summer issue Jul. 15, 1997
Winter issue Oct. 15, 1997
Spring issue Feb 15, 1998

How to submit articles to the Newsletter:
Send your articles about patient and consumer health programs and successes, interesting experiences, news items, book reviews, exciting tidbits of information, etc., to me: Kay Deeney
Consumer Connections, Editor
See page 2 for address details.

I prefer receiving materials emailed to me or sent on IBM compatible floppy diskettes. With floppies—ASCII, WordPerfect or Word for Windows is acceptable. Otherwise, please contact me. Help make this an interesting, relevant and useful newsletter! Participate!

Kay Deeney
Editor
Released during the Partnerships '97 Conference in Washington, DC on April 15th, Healthfinder is a very exciting endeavor of the federal government. The Healthfinder is a "gateway" World Wide Web site, serving as an initial point of entry to the broad range of CHI resources produced by the federal government and its many partners. Healthfinder offers up-to-date health information and does not duplicate existing web sites. It is being developed by the Department of Health and Human Services, in collaboration with other federal agencies that have health communication responsibilities.

Healthfinder offers user-friendly searching so that consumers can more quickly locate the health information they need... 

Healthfinder includes hyperlinks to over 800 web sites, including federal, state, local, not-for-profit, university and other consumer health resources, links to nearly 500 selected online documents, FAQs on the top twenty health issues of concern to the American public, and links to online health discussion groups, listservs and self-help groups.

Goal
The Healthfinder's goal is to improve consumer access to the best federal consumer health information, without duplicating existing web sites. It will link information and services from multiple sites, organize resources by subject and audience, and offer user-friendly searching so that consumers can more quickly locate the health information they need.

The healthfinder site will be promoted to intermediaries to improve access to all audiences, including information "have nots." Libraries, schools, state and local agencies, health maintenance organizations, employers, and commercial online services can make it available to their service groups.

Benefits
For consumers, the Healthfinder will mean easier access to federal health information, less "information overload" and help in navigating to the sources they need.

For agencies, it will mean help in directing consumers to their resources, a chance to collaborate on developing, marketing, and evaluating health information, and improved customer service and referral methods.

Taken together, that means an expanded role for federal information in important consumer decisions about health.

Collaboration
Federal agencies can collaborate on the Healthfinder project in several ways:
- Joining the ad hoc oversight committee,
- Contributing a "frequently asked questions" document (FAQ) on a specific consumer health topic,
- Contributing financially—the project will seek to raise $150,000 in FY'97 and $250,000-$300,000 per year thereafter to supplement the resources HHS has committed, and
- Joint development of enhanced Internet-based health information resources.

Home Pages for Healthfinder
The Web site is located at http://www.healthfinder.gov. The final web design offers both graphical and text versions to accommodate all users.

(Continued on page 5)
Healthfinder...

(Continued from page 4)

To Join the Healthfinder Project

To join the project, or for more information, please contact
Dr. Mary Jo Deering at 202-260-2652 or e-mail: mdeering@osophs.dhhs.gov, or David Baker
at 202-401-0731 or e-mail:
dbaker@osophs.dhhs.gov, in the Office of Disease Prevention and
Health Promotion, Office of Public Health and Science, Office
of the Secretary, Department of Health and Human Services.

Nearly 40 percent of those on the Internet are using it to
access health information,* and
many are finding the search
process lengthy and difficult. The
need for a site to offer links to
credible, reliable, unbiased
health information resources has
never been greater. Healthfinder
provides a map to the maze, and
a menu to authentic, reliable and
timely health information.

*Consumer Health and Medical
Information on the Internet: Supply and
Demand, 1996
Information for this article has been
taken mostly from http://
www.odphp.osophs.dhhs.gov/
healthfinder/brochure.htm and a
press release.

CONSUMER HEALTH DATABASE

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Websites Offer Cancer Information to Patients and Their Families

By Beth A. Lewis

The development of the "World Wide Web", a protocol for the exchange of hypertext, video, color images and sound, popularized "surfing the web" for millions of people. One can not view a TV commercial or read a newspaper without noticing that just about everything has its own URL, or address on the World Wide Web. Millions of people are sitting in front of computers and surfing for all kinds of information every day. As cancer librarians, we can point cancer patients and their families to some easy-to-use and authoritative sites on the WWW. Here are a few sites to recommend:

OncoLink, http://cancer.med.upenn.edu/ was developed and is supported by the University of Pennsylvania Medical Center to educate health care personnel, patients, and families. OncoLink includes original material written by University of Pennsylvania authors, original material submitted by faculty from other institutions, and authoritative publicly available material from sources, such as the National Cancer Institute and the American Cancer Society. All content is reviewed by an Editorial Board consisting of health professionals at the University of Pennsylvania. Material is posted as soon as it is accepted by the Editorial Board, almost on a daily basis. It offers one-stop shopping to collections of valuable cancer information.

From OncoLink's homepage a user can link to a variety of menus that include information about specific cancers, information about medical specialists that deal with cancer, cancer causes and prevention, medical supportive care, as well as coping information and financial issues. Information screening and prevention, and information about investigational or newly approved drugs. It contains both Spanish and English versions of treatment and supportive care summaries.

The American Cancer Society http://www.cancer.org/acs.html has placed many (but not all) of its publications on its web site. Additionally, it contains sections devoted to breast and prostate cancer (Breast Cancer Network and Prostate Cancer Information). The popular statistical publication, Cancer Facts and Figures, is also available. The site also contains an electronic request form to have materials sent, but I have never been successful in receiving any materials requested. Hopefully, this "bug" will be worked out and they will continue to add more publications to this limited, but potentially useful site.

about clinical trials is also included. OncoLink also supports a WAIS (Wide Area Information Server) search engine that is easy and quick to use and delivers prioritized search results to the user.

I have used NCI's CancerNet to deliver readable, accurate, and authoritative information to patients as well as physicians for several years. It is now available on the Web and its URL is http://www.cic.nci.nih.gov.

It provides quick access to cancer information statements from PDQ and the NCI covering treatment, supportive care,
Cancer Websites...

(Continued from page 6)

The New York State Education and Research Network maintains a web site for breast cancer patients and their families. The New York State Breast Cancer Information Clearinghouse, http://nysernet.org/bcicf/ contains information from the National Cancer Institute, American Cancer Society, and New York State Department of Health. It offers a list of toll-free numbers and information hotlines, information about breast cancer legislation, and a newsletter for patients called Bone Marrow Transplants. It also contains an easy-to-use search engine.

A great source of current books for patients and consumers is Login Brothers Consumer Database Lookup, http://www.lb.com. From the homepage the user links to "bookstore" then "bookshelf database," "consumer health" and then clicks on the subject, i.e. "cancer". Presently, it lists over 70 titles for cancer, many of which are recently published or are awaiting publication. Each book entry includes basic bibliographic information. Some entries include commentary and some are rated as "best bet" and/or "sizzler".

These are just a few of many web sites to recommend to library patrons. Keep in mind that the sites change quickly; many will contain additional information and will look completely different in the near future.

Originally published in the Cancer Section newsletter, December, 1996. Reprinted with permission of the author. Beth is Assistant Librarian at Talbot Research Library, Fox Chase Cancer Center in Philadelphia.

Sharon Quist

Sharon Quist, who had been the medical circuit librarian for the Central New York Library Resources Council since 1988, died on January 18th, 1997. Her long-time interest in consumer health information led her to revise and teach the MLA Continuing Education course, Consumer Health Information Resources. She was a member of our section. She will be missed.

Official ISSN

Special thanks to Nancy Calabretta for her efforts in obtaining an ISSN (International Standard Serial Number) for Consumer Connections. Our number is proudly displayed on the front page!

by Kay Deeney, Editor

MLA Directory Information

Published annually by the Medical Library Association (MLA), the Directory provides quick and easy access to expert health sciences librarians in the health information profession, covering topics such as consumer health and patient information, medical informatics, and cancer research. On page S2 of the 1996/97 Directory the CAPHIS Section members are listed. Although limited by being a snapshot in time, the list of CAPHIS members is useful for checking to see if some of your colleagues are members of our Section.
CAPHIS Bylaws Committee Report

At the Annual Meeting of the Consumer and Patient Health Information Section during the Medical Library Association conference last year, the revised bylaws of the Section were passed by the membership with one change, the addition of the Newsletter Committee as a Standing Committee. A description of each Standing Committee was in the newly approved bylaws, except the Newsletter Committee.

This year the Bylaws Committee, with the help of Kay Deeney, Newsletter Editor, wrote up a description for the Newsletter Committee as a Standing Committee to add to the Section's bylaws. This addition was approved by the MLA Bylaws Committee in February and by the Executive Board of the Section in March. It is now being published so that next year the membership can approve this addition at the annual meeting of the Consumer and Patient Health Information Section during the MLA Conference.

ARTICLE VII. Committees
Section 1. Standing Committees
ADD:
F. The Newsletter Committee shall consist of sufficient members to support the activities of the Committee. The Chair is appointed by the Section Chair on the recommendation of the Chair-Elect. The members of the committee are appointed by the Chair of the Newsletter Committee. The Chair shall serve as the Editor of the Section's newsletter. The committee shall be responsible for creation and dissemination of the Section's newsletter.

We look forward to discussion on this addition to the bylaws during our Section's Annual Meeting.

By David Duggar,
CAPHIS Section Bylaws Committee Chair

Report of the Nominating Committee

The CAPHIS elections are completed and Terrie Wheeler has notified me of the results as shown below:

Chair-elect: Joanne Marshall
Secretary: Eric Delozier
Treasurer: Claire Hamasu
CAPHIS candidate to the MLA Nominating Committee: Nancy Clemmons

The Nominating Committee wishes to extend congratulations to the newly elected officers and our gratitude to all of the candidates for participating in the election process.

by Sandy Parker,
Chair, Nominating Committee

Treasurer Report

The roster of members from MLA from 1-8-96 to 1-31-97 listed 417 members. Our bank balance is $6338.85 as of March 27, 1997.

by Gail P. Gill

CAPHIS Section Webpage is at: http://www.njc.org/caphis/
Cataloging & Circulation at the ACS FYI Resource Center

by Judith A. Barnes

This is the second part of an article about the American Cancer Society FYI Resource Center in the Frandor Mall in Lansing, Michigan, focusing on cataloging issues. The first part was published in the Winter, 1997 issue of Consumer Connections.

All the cataloging for the Resource Center is done by the librarian. Books within the subject range of the National Library of Medicine are classified in an adapted and expanded form of that system (see page 10 for the Adaptation chart). Books which fall outside the National Library of Medicine scheme are cataloged using the Library of Congress classification, shortened to the first decimal of the class. All materials are assigned four-line call numbers consisting of the class and adapted number, cutter number, and date of publication. Audiovisual materials also include a format code in the fifth line of the call number (for example, VC, AC, SL, or Model).

A subject authority file is maintained in a database to track headings used in the catalog. A subject authority is necessary to control consistency, even though the catalog is maintained on a computer, and it enables free text searching of subject fields. Copy cataloging is employed frequently using Cataloging in Publication (CIP) data and many variations of subject headings are noted over the span of the collection. Because the collection is computerized, it is easy to locate materials on similar subjects for comparison of cataloging data when original cataloging is necessary.

All of the American Cancer Society's pamphlets and posters are freely available, as well as several from the National Cancer Institute. One copy of each pamphlet title is cataloged and maintained in the Center as a master. The computer assigns each title its own accession number, which is used to locate it in the files. This allows assignment of multiple subject headings to each title.

Audiovisual materials include videotapes, flip charts, and several models. The Center does not subscribe to any magazines and there is no vertical file for article and newspaper clippings. The Center also maintains a reference collection of major textbooks, directories, drug indexes and dictionaries. All of the Library's materials are maintained in the online catalog.

Books circulate for a period of fourteen days. Audiovisuals circulate for a period of three days. Most American Cancer Society video productions are less than 30 minutes in length and can be viewed in the Center. Circulation records are kept on computer. The file tracks the number of times each book circulates, and enables the librarian to print lists by classification or by individual book. Roughly one-fourth of the book collection is in circulation at one time.

(Continued on page 10)
Adaptation of the National Library of Medicine Classification Scheme, 4th Edition for the Neoplasms QZ 200+

200 Neoplasms (General) Cysts (General)
   --Textbooks, medical manuals, reference books

200.9 History, societies, etc.

201 Popular works on all aspects of neoplasms in general.

   202.1 Etiology
   202.13 Environmental
   202.16 Physical (stress)
   202.18 Habits (smoking)
   202.2 Metastasis
   202.3 Regression
   202.5 Prevention

204 Precancerous conditions

*206 Research (General)

241 Diagnosis

266 Therapy
   266.5 Diet therapy
   266.7 Alternative therapies

267 Drug therapy

268 Surgical technics

269 Radiotherapy

310 Embryonal and mixed tumors

340 Connective muscle, and vascular tissues

345 Sarcoma

350 Leukemia classify all aspects under WH 250+
   Lymphoma classify all aspects under WH 525+

365 Glandular epithelial tissues.
   Carcinoma (General or not indexed elsewhere)

380 Nervous tissue.

CHI Directory Information

Please remember to fill in the CHIS Directory project form included in the Winter 1997 issue of Consumer Connections. Please contact Rosalind F. Dudden for more information. See lead story on Page 1.

Judith A. Barnes is at the Michigan Capital Medical Center.
barnesj@nlc.lib.mi.us


Murphy-PW; Davis-TC; Mayeaux-Ed; Sentell-T; Arnold-C; Rebouche-C. Teaching nutrition education in adult learning centers: linking literacy, health care, and the community. *Journal of Community Health Nursing* 1996; 13(3): 149-58.


Calabretta N. The hospital library as provider of consumer health information. *Medical Reference Services Quarterly, 1996* Fall, 15(3):13-22. Abstract: The health care environment of the 1990s demands that hospital libraries develop creative strategies for providing consumer health information (CHI). Librarians at the Reuben L. Sharp Health Sciences Library at Cooper Hospital/University Medical Center have developed a multifaceted approach to the problem. Using a combination of institutional resources, private funding, and cooperative arrangements with public libraries, the Sharp Library helps to serve the consumer health information needs of the southern New Jersey community.


Entwistle VA; Sheldon TA; Sowden AJ; Watt IS. Supporting consumer involvement in decision making: what constitutes quality in consumer health information? *International Journal for Quality in Health Care, 1996* Oct, 8(5):425-37. Abstract: The promotion of consumer involvement in decisions about individual health care is now high on many health policy agendas, but the structures to support it are not all in place. While it is generally accepted that information to support consumer involvement should be of good quality, the question of what constitutes quality in such information packages is far from settled. Debate around this issue should consider the various theoretical perspectives which relate to the nature and purpose of consumer involvement in health care decision making, and the contexts in which information is used. If we are to judge the quality of information within a consequentialist framework, we need empirical research evidence about the effects of information provision. Until such evidence becomes available, we can only hypothesize about what makes for quality. In this paper we discuss some dimensions of quality which are suggested by a consequentialist perspective.
ComputerLink: Research Related to Consumer Health Information

By Karen Dahlen

Those of us interested in the aging society and CHI should be aware of the recent research conducted by Patricia Flatley Brennan, RN, PhD, FAAN, formerly of Case Western Reserve and currently the Moehlman Bascom Professor of the School of Nursing and College of Engineering at the University of Wisconsin in Madison. Patti’s research supports computer networks as convenient, efficient, and enduring vehicles for delivering nursing services to caregivers of people with Alzheimer’s Disease. The ComputerLink project provided information, decision support, and communication services and studied the behavior of people using the system. The full report is contained in Nursing Research (June, 1995) and the International Journal of Technology Assessment in Health Care (April, 1994). Additional publications coming out of this study include:


Payton FC; Brennan PF; Silvers JB. Cost justification of a community health information network: the ComputerLink for AD caregivers. Proc Annu Symp Comput Appl Med Care. 1995; 566-70


"The secret of caring for the patient is caring for the patient."

Sir William Osler
Book Reviews


Cancer Sourcebook for Women is a compilation of publications issued by the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the Food and Drug Administration (FDA). A number of information sheets from the NCI's Cancerfax service are included in the volume, as well as reprints from the FDA Consumer and extracts from two NIH Consensus Statements. Selected articles from the National Center for Research Resources Reporter, the Centers for Disease Control's Morbidity and Mortality Weekly Report, and Y-Me publications have also been incorporated into the volume.

Focusing primarily on cancers of the female reproductive tract and breast, the information is presented in forty nine chapters, many of which are less than ten pages in length. The chapters are arranged in four parts: major cancers that specifically affect women; the road to recovery: treatments, therapy and coping; prevention; and risk factors and current research. At the end of the interest a wide audience of readers, including patients, patients' families, and health care personnel. However, since the work is a compilation of documents, there is a fair amount of redundancy to be encountered by someone reading through the entire book. For example, the steps involved in a breast self-examination are mentioned in at least fifteen different places in the book. Some of the chapters include references for additional reading, but the majority do not. The names, addresses, and telephone numbers of selected agencies that would be useful for referral purposes are also included, but are buried in the chapters. This type of information would be more useful had it been incorporated into an appendix at the end of the volume.

(Continued on page 14)

Subscriptions

Subscriptions to Consumer Connections are available to non-MLA members for $10.00 for three issues per year. Please send a check or money order made out to CAPHIS to the newsletter editor. See page two for address information.
Book Reviews

(Continued from page 13)

While much of the material in the book, such as reprints from the FDAMA Consumer or Morbidity and Mortality Weekly Report, would be readily available in large public or academic libraries, some of the sources, such as the NCI Cancerfax documents, are not easily accessible in print. The book should not be considered a comprehensive textbook about cancers affecting women, because some cancers that affect large numbers of women, such as lung cancer, are not included, presumably because large numbers of men are also affected. For information on such cancers, the reader is referred to The New Cancer Sourcebook, an upcoming volume in the Health Reference Series. The Cancer Sourcebook for Women does serve a useful purpose, by helping patients and their families understand, detect, and cope with many of the cancers affecting women. Cancer Sourcebook for Women is recommended for public libraries or hospital and academic libraries that collect patient education and consumer health materials.

By Alan F. Carr

This article was originally published in the Spring issue of Medical Reference Services Quarterly, 16(1):86-87, 1997.

<table>
<thead>
<tr>
<th>Current Book Reviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tomlin, Anne C. What Women Need to Know: From Headaches to Heart Disease and Everything in Between. Library Journal Jan, 1997 122(1):134.</td>
</tr>
</tbody>
</table>

This guide provides detailed information on the causes, formation, types, symptoms, treatment, and prevention of kidney stones. The author, Gail Golomb, is a kidney stone sufferer who describes her experience with kidney stone attacks, undergoing lithotripsy, and becoming an informed patient. She also presents extensive documentation on treatments, nutrition and diets for people with kidney stone problems.

In an easy-to-read, non-technical manner, the author assists people in determining their risks of developing kidney stones. She discusses conditions, such as urinary tract infections and hypercalcinuria, and explains how they are associated with kidney stone formation. A large section is devoted to descriptions of the four main types of kidney stones, their formation, and the foods to avoid to prevent their recurrence. Another useful section provides nutrition charts and sample menus for each type of kidney stone.

The chapter on lithotripsy or ESWL (extracorporeal shock wave lithotripsy), a common treatment for kidney stones, serves as a thorough guide to this procedure. The chapter explains what happens before, during and after the lithotripsy experience, and presents other recent technological developments in the field. Describing her own experience in a clear and upbeat manner, the author answers many of the reader's questions and attempts to abate the fears a kidney stone patient may have.

and recovery. Ms. Golomb gives advice on locating a specialist, obtaining medical records and becoming educated about medical conditions. She even includes a section on using medical libraries! A list of resources for patients and a glossary of relevant terms are included at the end.

For the thousands of people who have kidney stone conditions in the United States, and for others who are interested in the subject, this is a valuable source that is recommended for consumer health and patient education collections.

by Laura Sklansky

Available from Four G eeze Press, 911 Douglas Blvd., Ste. 85-131, Roseville, CA 95661


Some interesting controversial issues are brought up, such as the intake of calcium, vitamin C, and cranberry juice. Like other writers of recent patient education materials, this author stresses the importance of the patient's involvement in decisions regarding treatment...
CAPHIS Section Webpage is at: http://www.njc.org/caphis/

Dates of Interest

May 23-28, 1997
Medical Library
Association 97th Annual
Meeting, CAPHIS
Programs: Faster, Better,
Smarter: Providing
Consumer Health
Information and Diverse
Cultures, Diverse
Responses: Meeting the
Challenge of Health
Information for All, Seattle,
WA
http://www.kumc.edu/MLA/MLA97/