NEWSLETTER OF
THE CONSUMER AND PATIENT HEALTH
INFORMATION SECTION
OF THE MEDICAL LIBRARY ASSOCIATION

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Spring, 1993

News From The Chair

Having written the annual report for our section already, I feel sad that my year is
almost over. I have had contact with quite a sizable number of you, as well as
inquiries from people outside our section. While I wouldn't say "E-mail has
arrived," it has been the medium in which a lot of communication has been
transacted. Although not terribly exciting news, our bylaws are in great shape.
By voting for them at our meeting in Chicago (Sunday, May 16, 4:45 p.m. in
Parlor A, Sixth floor) we will satisfy MLA's requirements at least for a few
years, I hope.

I wanted to let you know about some problems that we are still ironing out since
MLA took over the role of collecting dues for the sections. One is that we are
working on a membership information sheet to recruit new members. By the
time of the MLA annual meeting this year, we should again have a nice brochure
to attract new members. Because MLA sends us new members' names
throughout the year in paper copy, a membership directory has been difficult to
implement. Inputting all the new names, keeping track of the old was done
differently when we did it ourselves. MLA's new computer system may change
how we handle this. So hopefully next year, we will have a member directory.
On another note, an exciting project the membership committee is working on,
is a directory of programs and centers that members are involved in. This should
be a useful resource for our members.

Once every three years, MLA asks CAPHIS to name a representative to the
Patient Education in the Primary Care Setting Annual Conference. This
individual attends the annual meeting and prepares a report that is published in
the MLA Annual Report. Carolyn Ruby has been our representative for the past
three years. At our business meeting in May, I am proposing that, as long as the
representative is a member of our section, CAPHIS contribute a small amount
towards the expenses of that meeting. I am suggesting $100.

Our upcoming MLA program on "The Good, the Bad and the Ugly, Comparing
the Canadian and U.S. Health Care Systems" is a very timely topic considering
the Clinton administration will be hopefully implementing health care reform.
Canada's Eugene Vayda, and Quinton Young from the U.S. are our speakers.
Please come prepared to ask insightful questions of our speakers.

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CAPHIS Annual Meeting Program Announced... Mark Your Convention Calendar!

The Good, The Bad And The Ugly: Comparing The Canadian And U.S. Health Care Systems

Canada spends about 8.5% of its GNP on health care. The United States spends 12% of its GNP or 50% more per capita than Canada. At the same time everyone in Canada has access to health care. In the U.S., there are over 40 million people uninsured. What can the U.S. learn from the Canadian system? Is the Canadian system as good as it sounds? What about waiting lists and problems in accessing services in Canada? How will changes made by the Clinton Administration impact the U.S. health care system? Dr. Eugene Vayda, Professor Emeritus, Department of Health Administration and former Associate Dean of Community Health, University of Toronto and Dr. Quinton Young of Physicians for a National Health Program will share insights with us on this timely subject.

This program will be presented at the MLA annual meeting in Chicago on Monday, May 17 from 1:00 p.m. to 3:30 p.m. in the Adams Ballroom on the sixth floor of the Palmer House Hilton. Make plans now to attend!

Medical Library Association Testifies In Support Of The National Library Of Medicine

To encourage continued federal funding for the National Library of Medicine (NLM), the Medical Library Association (MLA) submitted testimony on March 2, 1993, before members of the House of Representatives. Speaking on behalf of MLA and the Association of Academic Health Sciences Library Directors, Sara Jean Jackson requested $240 million for NLM for fiscal year 1994.

Addressing the House Appropriations Subcommittee on Labor, Health and Human Services, and Education, Ms. Jackson described how information provided to physicians positively impacts their diagnoses, choice of tests and drugs, prescribed length of hospital stay, and advice given to their patients. She testified for continued support of NLM Outreach Programs, such as the National Network of Libraries of Medicine, which ensures that health care professionals, especially those in medically underserved rural and minority communities, have access to the most current federally funded National Institutes of Health (NIH) research.

President Clinton was commended in this testimony for his proposal to increase 1993 NIH programs by $9 million to develop applications of advanced computer and networking technology for health care, such as the National Research and Education Network (NREN). NREN will provide more timely access to the world's biomedical literature for health sciences librarians and the health care providers, students, and researchers whom they support in the delivery of health care.
The Librarian's Role in the Provision of Consumer Health Information and Patient Education

Previous CAPHIS chairman Alan Rees formed a subcommittee to draft this statement and we would appreciate feedback from the CAPHIS membership on its content and usefulness. In particular, we are interested in knowing whether such a statement, approved by CAPHIS, would be useful to librarians who are trying to explain their CHIS role within their institution or region.

Comments and suggestions will be incorporated in a second draft to be distributed at the MLA Annual Meeting in Chicago. Send comments to:

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Draft Statement for Discussion
Prepared for the CAPHIS/MLA Annual Meeting 1992

Consumer health information (CHI) is information on health and medical topics provided in response to requests from the general public. In addition to information on the symptoms, diagnosis and treatment of disease, CHI encompasses information on health promotion, the determinants of health and accessing the health care system.

Patient education is a multidisciplinary field whose aim is to impart knowledge, attitudes and skills with the specific goal of changing behavior, increasing compliance with therapy and, thereby, improving health.

CHI and patient education overlap in practice, since patient behavior may change as a result of receiving informational materials, e.g. change in diet, smoking cessation, lowering cholesterol, etc. Patient education and CHI often differ in terms of the setting in which the process occurs, e.g. a hospital compared to a public library or community organization, rather than in terms of the subject matter.

Health librarians, because of their knowledge and training in the identification, selection, organization and dissemination of informational materials, have an important role to play in both CHI services and patient education. The following roles are appropriate for librarians in these two areas:

1. Identifying available CHI/patient education materials for review and possible purchase.
2. Selection of CHI/patient education materials for the organization, including books, magazines, audiovisuals, pamphlets, computer databases, etc.
3. Building of an authoritative and balanced collection of CHI/patient education materials in print and electronic form that meets the needs of the institution or community being served.
4. Networking with other individuals, organizations and agencies to facilitate resource sharing of CHI/patient education materials.
5. Consulting on the identification, selection and organization of patient education materials in health care settings, e.g. hospital nursing units, ambulatory clinics, etc.
6. Serving on institutional committees, e.g. patient education, community health education, quality assurance, medical ethics, etc., to encourage and support the development of CHI/patient education resources.
7. Working with the institution and the community to develop informational and educational programs related to health issues, e.g. living wills, CPR, weight control, nutrition, stress management, etc. The librarian can play a special role in identifying printed materials, locating speakers, etc.
8. Supporting and encouraging the development of self-help groups by providing resources, making referrals to facilitate networking and suggesting contact persons by names for programs, etc.
9. Acting as a consumer/patient advocate to:
   a. protect the individual's right to unrestricted access to medical and health information. The ALA Administrative Policies and Procedures and the Library Bill of Rights promote such access.
   b. protect the individual's right to confidentiality when requesting information from the library (ALA Statements on Professional Ethics and state laws which make a library user's question confidential).
   c. encourage the gathering of information on all sides of a question and on various types of procedures, both medical and non-medical, as a means of contributing to informed choice in health care decision-making.
10. Acting as a resource for health professionals who wish to develop consumer health/patient education resources in their practice settings.
11. Acting as advocates on the local, national and international levels to promote open access for the public to health information.
12. Sharing the results of their CHI/patient education experience with other professionals, both in the library field and outside, in order to improve these services.
13. In cases where the institution has a patient education program, working as a member of the interdisciplinary team to meet the informational needs of the program. In such situations, the librarian should also advocate the right of consumers to access information independent of the patient education program.
14. Extended roles for the librarian in CHI/patient education may include: sending information to hospitalized patients or community members who are unable to visit the library; creating a current awareness service for health professionals about new CHI/patient education materials; making rounds on hospital wards to determine information needs; creating health information centers with pamphlets; developing subject file collections on current topics of interest to consumers, etc.

While librarians are experts in identifying and providing information, they are not practicing health professionals who interpret information and give advice. It is important that librarians avoid suggesting diagnoses, recommending particular health professionals or procedures. The librarian role is to provide access to a range of authoritative materials, but he or she cannot be held responsible for the scientific accuracy or currency of all materials in the collection. Librarians should adopt the view of the World Health Organization in defining health as a complete state of mental, physical and social well-being and not simply the absence of disease. Librarians activities should be oriented towards the goal of producing a health society as well as assisting the individual to make more informed health decisions.

Respectfully submitted,

Joanne Marshall, Chair; Members: Margaret Bandy, Kathy Lindner, Lisa McCormick, Janet Schneider, Alan Rees

May 1992

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**Americans Change Their Expectations As Consumers**

American consumers no longer buy to impress others . . . there's a new emphasis on owning products that are personally satisfying . . . reports a recent study released by Yankelovich Clancy Shulman in Adweek. Among the findings:

- Buying the “best” is no longer as important as value at every price level.
- Consumers are sophisticated marketplace strategists.
- Comfort and utility are important selling points. Products must deliver on the basics—performance, reliability, ease of maintenance, and price.
- Consumers are not interested in technology per se, but in how technology makes the product better and their lives easier.


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**Healthy Computing...**

...Read All About it!

If you use a computer often or manage people who do, the library has a new book worth your attention. Published by the American Management Association, Healthy Computing is a concise, practical, and well-written collection of explanations and advice on preventing and solving the myriad ailments that can afflict computer users.

One author is a chiropractic physician and industrial consultant who specializes in computer-related health problems; the other is a computer industry journalist who has himself suffered repetitive stress injury (RSI). They emphasize practical preventative measures in today’s workplace.

The book informs and advises on the well-known maladies that can develop in the eyes, neck, and arms, but also explores lesser-known threats to digestion, circulation, and mental and emotional health. Attention is paid to exercise, diet, posture, movement, equipment positioning, lighting, and sound - all factors in health maintenance for computer users. Do-it-yourself treatments of minor problems that can become major are interspersed throughout the text in 27 “Quick Fix” boxes - ideal for skimmers - while the text offers more in-depth advice as well as some interesting background information, such as the reasons that most sufferers of RSI are female, the emotional aspects of human-computer relationships, and the new hardware, software, and workstation technologies that prevent health problems. One chapter also addresses the specific issues faced by managers of computer users.


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**Contribute for a Better Section...**

...and a Better Newsletter!

All Section Officers and Committee Chairs are asked to send their committee roster and news items about their committee business to Carolyn Ruby. If you can, send it on diskette in an ascii or text format.
Consumer Health Library Opens In Delaware

By Gail P. Gill  Director of Library Services
Delaware Academy of Medicine, Inc.
1925 Lovering Avenue
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Delaware's only Consumer Health Library opened to the public in June 1992. This community service is the most recent project sponsored by the Delaware Academy of Medicine and is housed in the Academy's Lewis B. Flinn Library. The Consumer Health Library's objective is to provide the public with access to current health care information in order to promote health education. As health care costs increase, prevention and wellness are emphasized; consumers are urged to take participatory roles in their own health care. Individuals not only seek information during times of illness, but also research topics in preventive care to maintain healthy lifestyles. The Library will provide information on the following: diseases, injuries, drugs, procedures, nutrition, exercise, treatments, support groups, prevention.

The Library resources include books, health newsletters, medical journals, and referral and clipping files. A user-friendly computerized database, InfoTrac's Health Reference Center, is available to the public. The database provides a combination of references to popular and clinical journals, abstracts, and full text of selected articles and pamphlets.

Circulating books cover such topics as aging, AIDS, allergies, chronic fatigue syndrome, drugs, environmental health, heart disease, neurology, and men's, women's, and children's health. Spanish-language and children's books are also available. Reference materials include directories of national and local health oriented organizations, physician directories, guides to prescription and over-the-counter medications, medical dictionaries and encyclopedias. Clipping and referral files are compiled from newspapers, clinical journals, health newsletters and pamphlets. The resources of the Lewis B. Flinn Library's clinical book and journal collection are available for reference use by the public.

All Consumer Health Library materials, including items which reflect diverse points of view within the medical profession, are selected and reviewed by Library Committee and staff. The collection is intended for educational purposes and will enable consumers to make informed decisions in conjunction with their health care providers. The Library staff does not interpret materials or offer any medical advice.

The public may use consumer materials in the Library free of charge. A patron who submits a request by phone, mail or fax is mailed one relevant article at no cost. There are nominal fees for other services: e.g. photocopying, searching the Medline clinical database and interlibrary loan. The Consumer Health Library is currently open Monday through Friday with a toll-free number for statewide access.

The Library staff works with individuals and organizations throughout the state. The reference staff trains public librarians in the techniques of conducting a medical reference interview and informs them of the resources available to their patrons. The Library exhibits at health fairs, sponsors public service announcements, and present programs for organizations. The Consumer Library will be a vendor at the annual meeting of the Delaware Academy of Family Physicians on March 27, 1993. In addition to the Delaware Academy of Medicine's support, the Library has received continuing funding from the New Castle County Medical Society Auxiliary for the Health Reference Center database.

The Delaware Academy of Medicine is a private, nonprofit organization founded in 1930. Its mission is to promote professional and lay health education, maintain a medical library and archives, provide a meeting place for the medical/dental professions and related organizations, and give financial support to medical and dental students. The Academy is supported by membership dues, library fees, contributions from local health care organizations, and tax-deductible donations from the community.

Since 1981, the Academy has supported consumer health education with TEL-MED, an automated system of 400 recorded messages on medical, dental and other health-related subjects available statewide. Currently, TEL-MED receives over 10,000 calls per month. The demand for information has continued to increase. However, funding for public libraries in Delaware has not kept pace with this demand. The Academy realized this problem and made a commitment to fund a Consumer Health Library to help meet these needs. A new health-conscious public demands information. The Academy of Medicine, in supporting the Consumer Health Library, is ensuring that all Delawareans have access to reliable and accurate health information in order to take an active role in their health care decisions.
National Wellness Institute to Host The First National Conference on Consumer Health Informatics

A new breed of patient-centered computer programs, which will allow lay folk to manage more of their health care, will be showcased at the First National Conference on Consumer Health Informatics, to be held July 17-18 in Stevens Point, Wisconsin. The conference is sponsored by the National Wellness Institute and Healthwise, Inc in conjunction with the 18th Annual National Wellness Conference.

More than a dozen of the nation's leading experts on patient centered systems will describe their work and discuss the role of lay health systems in cutting health costs and improving the quality of medical care, says conference coordinator Dr. Tom Ferguson. Tom Ferguson, M.D., is a trustee of the National Wellness Institute and editor of the new industry newsletter, Consumer Health Informatics, which will be available at the conference.

The July conference will offer hands-on demonstrations of several innovative programs and an opportunity to meet and talk with leading developers and researchers. Participants will be invited to organize small group breakout sessions on topics of their own choosing and to network with other participants and faculty members who share similar interests.

Dr. Ferguson and his colleagues are pioneering a new breed of patient-centered computer applications in health care -- home health workstations, psychological spread sheets, online self-help, fax-on-demand, medical videos for interactive decision support, and many more. The first prototypes of these new computer, telecommunications, and multimedia programs are already beginning to be used in work places, hospitals, homes, and communities across the nation.

"Preliminary studies suggest that these new consumer-centered systems can help cut costs, improve access, and improve the quality of health care," Dr. Ferguson says. "From health information databases to computer therapy, from self-help bulletin boards to telephone medicine, consumer health informatics systems are emerging as powerful tools for the health-active medical consumer. AIDS patients can use them to send e-mail to their doctors -- or to get advice and support from other AIDS patients. People with a rare or serious disease can search the medical literature for the latest current research and therapies. By providing health consumers with access to (1) health information, (2) self-help medical and psychological applications and (3) electronic networks for both consumer-consumer and consumer-professional communication, we will be taking the first giant steps toward a real Information Age health care system.

"These new patient-centered systems will lead to interesting changes in the roles of both consumers and providers," Ferguson says. "They will help turn patients into providers.
Articles From The Literature


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Dudden Resigns As Newsletter Co-Editor...

...Newsletter Committee will play more active role in '93-'94

By Carolyn Ruby

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Due to increased responsibilities in other areas, Rosalind Dudden, Consumer Connection co-editor for the last two years has resigned effective with the publication of this issue. Please join me in thanking Roz for her invaluable help over the last two years in getting information for the newsletter and doing the layouts for each issue.

I have given some thought to how to handle the editorial responsibilities of Consumer Connection over the next year. I will retain editorial responsibility for the newsletter but will rely heavily on the Newsletter Committee to help gather information for each issue. This will be a departure from the last two years as Roz and I did not utilize the Newsletter Committee the way we could have. In addition to gathering information to be published in each issue, we will be looking into placing ads in the newsletter as way to offset some of the cost of publishing it. We will also be considering the feasibility of increasing the number of issues per year from three to four issues.

I would like to see some regular columns in the newsletter. Alan Rees has given us a start on this with his reviews of patient education software. With the increasing number of consumer health books being published we need to start a book review column. Those interested in reviewing books are encouraged to contact me. Reviewers can either review a new book they have or contact me and I will arrange to have a book sent to them. I would also like to see the newsletter continue to profile various programs that our members are involved with. The proposed directory from the Membership Committee will help us find possible contributors on that topic.

As you can see, there is a lot of opportunity to get involved with the publishing the newsletter. Let our new CAPHIS chair, Andrea Kenyon, know you are interested at the May meeting or contact me directly.

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CALVIN & HOBBES

HELLO, COUNTY LIBRARY? REFERENCE DESK, PLEASE. THANK YOU.

HELLO? YES, I NEED A BOOK ON PAINTING THEORY AND TECHNIQUE.

SPECIFICALLY, I'M INTERESTED IN GRAFFITI. IS THERE A BOOK THAT EXPLAINS THE PROPER USE OF MATERIALS AND LISTS POPULAR, DIRTY WORDS AND SLOGANS?

WHAT ON EARTH DO THEY SPEND THEIR MONEY ON OVER THERE?

Bill Watterson
Medical Library Association Supports Texaco Appeal

The Medical Library Association (MLA), in coalition with six other organizations, has filed an amicus curiae (friend of the court) brief in support of Texaco's appeal of a recent ruling of the Honorable Pierre N. Leval of the United States District Court for the Southern District of New York. In American Geophysical Union et al. v. Texaco, Inc., Texaco was sued by American Geophysical Union, and five other publishers for making photocopies of copyrighted information. Texaco maintained that because the photocopying was necessary for the purpose of advancing science and was not for commercial gain, it was in compliance with the fair use principles of the Copyright Law. Judge Leval ruled that the purpose of Texaco's scientific research was "to create new products and processes for Texaco that will improve its competitiveness and profitability," and therefore did not comply with the principles of fair use.

In the amicus brief, MLA and the American Association of Law Libraries, the Association of Research Libraries, the Special Libraries Association, the American Council of Learned Societies, the National Humanities Alliance, and the Association of Academic Health Sciences Library Directors challenged the U.S. Court of Appeals for the Second Circuit to reconsider the district court's position on fair use:

The decision of the lower court, if upheld, threatens a long-standing, reasonable, and customary practice in for-profit and nonprofit institutions alike - the spontaneous photocopying of single copies of published scientific, technical, and other research and scholarly journal articles, notes, and comments by researchers, scientists, and scholars for their own research use. The lower court's rejection of Texaco's "fair use" claim would impose substantial, additional costs on researchers and their employers or institutions, hampering scientific, medical, and scholarly research in the United States. It would thus impair, not promote, the constitutional objective of the Copyright Act, "the Progress of Science and Useful Arts."

Carla J. Funk, MLA's executive director, explains, "MLA has a strong interest in the issues involved in the Texaco appeal, because the lower court's ruling could ultimately affect patient care by impairing the ability of our members to collect and disseminate health care information to researchers, health care professionals, and scholars."

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Medical Library Association Urges Congress To Review Copyright Reform Act Of 1993

The Medical Library Association (MLA), as part of a coalition of organizations concerned about copyright law, recently issued a statement on the Copyright Reform Act of 1993 (H.R. 897). Executive Director Carla J. Funk declares

MLA remains committed to its mission to ensure that information vital to medical education, research, and the health needs of our nation can be accessed by health care professionals and the general public. MLA, in coalition with the American Association of Law Libraries, the American Library Association, the Association of Research Libraries, the National Coordinating Committee for the Promotion of History, the National Humanities Alliance, and the Special Libraries Association, urges Congress to conduct a thorough investigation of the impact and cost of implementing H.R. 897.

H.R. 897 would reorganize government operations related to copyright policy, the acquisitions policy of the Library of Congress, and judicial administration. If the bill becomes law, two of the three incentives for registration and deposit of copyrighted materials would no longer exist: the convenience of depositing materials in collaboration with the registration process would be eliminated; and the comprehensive nature of the collection, partly a result of convenient depositing procedures, would be jeopardized.

Also, the register of copyrights would be appointed by the president rather than the librarian of Congress, and the authority of the librarian of Congress over Copyright Office regulations and staff would be removed.

The coalition's statement, issued March 3, 1993, was submitted to the House Judiciary Committee Subcommittee on Intellectual Property and Judicial Administration and expresses concern that H.R. 897 could result in a more expensive, less timely, and less-than-comprehensive acquisitions program for the Library of Congress.
How to Submit Articles to the Consumer Connections

Anyway you want!!! That's the answer to an interesting, relevant, and useful newsletter. Membership participation is a necessity!!! Although the editors will accept tidbits and articles for review, it would be easier if the reporting member wrote the article review or item for the editor to edit, perhaps enclosing the article also. And don't forget cartoons and interesting quotes!

Send your news items by these various means:
U.S. Mail: Articles and items to:
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...Many Thanks!!!

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What about YOU?!?!?!

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v10 n2 Summer issue: August 1, 1993
v10 n3 Fall issue: November 1, 1993
v11 n1 Spring issue: March 15, 1994

Be creative! Send in your articles and news!

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