From the Chair

Hello Everyone,

As I write this, I feel that many of us are probably of two minds. The first feels relatively secure at home and at work, and the second wonders if we are really safe anywhere since September 11, 2001. Let me extend my heartfelt condolences to all those who lost relatives, friends, or acquaintances as a result. As has been said, we must unite across differences of nationality and faith in order to create a world free of injustice, violence and terror.

On a more upbeat note, my skepticism about having the MLA 2001 meeting at Disney World was completely erased by its superb convention facilities. All the meeting facilities and hotel rooms were close to each other! Of course, the rest of Disney World was just plain fun, the meeting was good, and yes, we really missed everyone in the Section who was unable to attend!

I am excited that this is the very first issue of the Cancer Librarians Section News that will be published only electronically (first by email and then by Internet)! Congratulations and thank you to newsletter co-editors Tanya Smith and Helen Flitton and Webmaster Anne Marie Clark. I must admit that I had Internet stage fright about writing this column.

At MLA 2001, the Cancer Librarians Section co-sponsored three successful programs on gene therapy, bioethics and genetic counseling, and DNA chips. The speakers were able to explain gene therapy and DNA chips, as well as pertinent information resources, in layman’s language.

For MLA 2002 in Dallas, Halyna Liszczynskyj, our section’s program planner, is working on two cosponsored programs, “Delivering Genetics Information to Health-Care Consumers” and “Pharmacogenetics.”

Our other goals for 2001-2002, include completing the revision our section’s bylaws, updating the Core Cancer Library bibliography, and publishing two issues of this newsletter. Thank you to Karen Albert, past Section Chair, for her continuing work on the bylaws.


Best wishes and happy holidays,

Gayle

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Gayle Ablove
Roswell Park Cancer Institute
Chair, Cancer Librarians Section
gayle.ablove@roswellpark.org
Medical Library Association Annual Conference 2002
Cancer Librarians Section Will Co-Sponsor Two Sessions

Halyna Liszczynskyj

1. Delivering Genetics Information to Healthcare Consumers
The invited speaker is Angela E. Scheuerle, MD, Clinical Director, Texas Birth Defects Research Center at the Texas Department of Health. Dr. Scheuerle teaches Clinical Ethics in Medicine in Dallas at the University of Texas, Southwestern Medical School in Dallas and is an adjunct Faculty member in Management and Policy Science at the School of Public Health, University of Texas - Houston.

The other two speakers for this session will be librarians Kristine Alpi (Weill Cornell Medical Library) and Gail Hendler (New York University School of Medicine), speaking on the topic of "DNA Demystified: Online Genetics and Cancer Genetics Resources for Patients."

2. Pharmacogenetics
The invited speaker for this session will be Corinne C. Aragaki, PhD, Assistant Professor, University of Texas Health Science Center at Houston, School of Public Health, Dallas Satellite MPH Program. Her research interests include: gene-environment interactions, cancer epidemiology, genetic epidemiology, molecular epidemiology. Her websites are: http://myprofile.cos.com/caragaki and http://www2.utsouthwestern.edu/publichealth/Aragaki/

Two invited librarian speakers will be chosen based on submitted abstracts that are presently under review.

3. The Joint Informal Session
This program is still being planned and further details will be sent to members as they are set.

**Grant Opportunity**

Dear Colleagues:
You are invited to apply for the Medical Informatics Section/MLA Career Development Grant. Medical Informatics Section has just generously increased the grant amount from $1000 to $1500 this year to support a career development activity that will contribute to advancement in the field of medical informatics. Up to two individuals will receive awards up to $1500 each and will be honored at the MLA Annual Meeting. The description of the grant and the application form are available online (in PDF format) at: http://www.mlanet.org/pdf/awards/medinfoapp_032000.pdf. Please submit a completed application and all related materials by December 1, to the Professional Development Department at the Medical Library Association, 65 E. Wacker Place, Suite 1900, Chicago, IL 60601; 312/419-9094, Ext. 28; Fax: 312/419-8950; mlapd2@mlahq.org.

Submitted by:
Jie Li
Medical Center Library
University of South Alabama

**Student Abstracts: "Debuting Fresh Perspectives"**

The Medical Library Education Section (MLES) is sponsoring a contributed paper session at MLA '02 designed to attract new colleagues to attend and present at an MLA annual meeting and to showcase the work of newer members. Current students or recent graduates of library and information science or related programs may submit papers, if they have not presented at a previous MLA annual meeting. Paper subjects may cover any aspect of medical librarianship, health information management, medical informatics, etc. Papers may be co-authored works, but the first author must be a student or recent graduate.

The deadline for student abstract submissions is December 3, 2001.

For more information, visit MLANET at http://www.mlahq.org/am/am2002/participate/index.html
Cancer Librarians Section
Business Meeting Minutes
MLA Annual Meeting in Orlando
May 29, 2001

Attendees: Gayle J. Ablove, Nina F. Galpern, Christine Fleuriel,
Beth Lewis, Ann Marie Clark, Seungja Song, Nancy Peterson,
Jan Orlick, Sue Felber, Sharon A. Lezotte, Annelie Sober,
Halyna Liszczynskyj, Tanya Smith, Sherrill Olsen.

The meeting started at 12:30 with a pizza buffet luncheon and
was called to order at 1:00 by Gayle Ablove. Copies of last
year’s minutes and an agenda for today’s meeting were
distributed to all attendees.

Gayle asked if there were any corrections, and/or additions to
last year’s minutes, which were distributed, and there were no
comments. The minutes were then approved.

Chris Fleuriel, treasurer, gave her report. We have a balance of
approximately $6000 in the checking account, and this includes
$250 that was taken out for our joint program with the
Molecular Biology SIG.

Gayle remarked that we owe Michele Tennant (from the
Molecular Biology SIG) a great deal of gratitude for pulling this
year’s program together. Michele contacted the speakers and did
the fundraising for the program. Funds of approximately $2000
were obtained from Swets Blackwell and Nature Publishing.

Halyna discussed next year’s program. The theme is The Big D
because the national meeting will be held in Dallas; therefore a
big D must appear in the title. Some of the suggestions that were
offered include: knowledge management, electronic record
management, minority health, pharmacogenetics, and Healthy
People 2010 cancer directives and goals. Sharon suggested that
we could possibly have a joint program with the Consumer
Health Section involving the Healthy People 2010 cancer
directives. Sharon suggested that we could possibly have a joint program
involving pharmacogenetics. Gayle then explained the details of
how a program is chosen and developed with another section.

Ann Marie Clark discussed the section’s website. Since April,
we have had 484 visitors to the website, and the newsletter
recently went up on the website for the first time. This was
popular and all responses to the e-newsletter were positive.
Questions to ask are whether we should restrict access to the
newsletter, and, what other features we want, such as a list of
members, etc. Discussion ensued and it was decided that it
would be preferable to have the newsletter in PDF format and
restricted parts of the website that only members could access.
Members prefer to have just one id and password instead of
individual id’s and passwords. Another suggestion was to e-mail
the newsletter to members and then put it up on the website after
an appropriate length of time, perhaps a month. We can try it
and then reassess the situation with the next issue. Gayle
thanked Ann Marie for all her work on the website.

We were treated to seeing snapshots of Helen’s twins! Helen
will be moving back to England but will help Tanya with the
newsletter. Tanya needs more contributions to the newsletter!!

Annelie Sober gave a thorough Section Council report and
explained what section council is and why it’s important. There
is a new special interest group (SIG) focused on the Internet.
Cheryl Warren is our nominee to Section Council. Section
Council now has its own website on MLANET. We should be
monitoring the information on their website for accuracy and
currency. The manual for section officers has recently been
updated and this is only available online. A question was asked
as to whether section council should develop a logo for a
website; our group didn’t go for it. A suggestion was made to
take Chapter Council if we could vote by e-mail; Gayle says
mailing the ballots is costly and this would save us money.

Cheryl Warren was unable to attend, but a friend of hers is
making a quilt square for a quilt that Section Council is putting
together.

Updating the Core Cancer Library list was brought up. Most
members expressed that they do not have the time to put into it.
Perhaps a list of titles could be maintained on the website, but it
was decided not to update the annotated bibliography.

Nina Galpern recently updated the Cancer Librarians section
brochure. Copies were available at the section table at the
annual meeting and Beth brought extras to the business meeting.

New business involved revising the bylaws to reflect the new
three-year structure of Chapter Council Representative. Jan
Orick suggested a reciprocal interlibrary loan agreement among
cancer libraries. It was decided to think about this suggestion.

The meeting was adjourned at 2:25

Respectfully submitted by

Beth A. Lewis
Talbot Research Library
Fox Chase Cancer Center
Philadelphia, PA 19111
Member Updates and Accomplishments

Sue H. Felber, Coordinator-Medical Library at H. Lee Moffitt Cancer Center & Research Institute.

Publications:
- Serving as Information Specialist for Evidence-Based Oncology journal.

Presentations:
- Poster presentation on *Pilot Project in Evidence-based Oncology Literature*, Southern Chapter/MLA, Mobile, AL, October 2000.
- Invited speaker on evidence-based oncology search skills at *Ensuring Quality Cancer Care*, Chicago IL November 2001. This was the second presentation on this topic to a physicians' conference.

Becky Quinten, Reid Hospital Libraries, Reid Hospital & Health Care Services, Richmond, Indiana.

Awarded:
- Quinten and her volunteer staff were recipients of the "The Helping Hands Award" for Patient Satisfaction in August 2001. Nominated for their contributions to the Pharmacy Department's research needs for immediate patient care.

Presentation:
- *Medical Reference Sources*. District 8 ALA Conference, October 2001. The presentation covered tips on evaluating web pages and providing information on the "best" medical references sources for the public and patients.

Addajane (Midge) Wallace, Medical Librarian at Halifax Medical Center, Daytona Beach, Florida.

Awarded:
- Recipient of the MLA Consumer Health Credential (Level I).

Margaret Vugrin, Reference Librarian at Preston Smith Library, Texas Tech University Health Sciences Center.

Presentation:
- *Librarians of the 21st Century - Presenting Better Professional Images*. South Central Chapter of MLA Conference, New Orleans, LA, October 2001. This presentation visually showed how librarians could enhance their professional image one photograph at a time. Images were analyzed using basic photographic techniques, followed by evaluation and discussion of how to give ourselves a 21st century look compatible with our 21st century profession.

Updated Core List for the Cancer Library

Cancer Librarians Section of MLA has updated the Core List of Cancer Materials. CLS developed this core list of cancer materials in an effort to identify up-to-date titles that would be basic and useful for the small to medium library. The purpose of the list is to aid in selection and collection development. CLS does not propose that this is a definitive list that meets the needs of all institutions. The list can be found on the CLS web site at http://www.selu.com/cancerlib. Comments or updates can be directed to Cheryl Warren at cherylw@valleycare.com.
Communicating the Cancer Experience to Children

Sue H. Felber, AHIP  
H. Lee Moffitt Cancer Center & Research Institute

Cheryl Warren, AHIP  
ValleyCare Health Library & Ryan Comer Cancer Resource Center

Communicating cancer information is not an easy task, even for physicians. It can be especially difficult for newly diagnosed cancer patients to tell their children, while dealing with their own feelings and coming to terms with the implications of their diagnosis. When a parent or other family member has cancer, children in the family often feel left out of the communication loop. These children are at a higher risk for various social and psychological problems.

Cancer in the family is highly stressful for all members, and particularly so for young children who do not understand the terminology, treatments, side effects, and various ramifications of the disease. These children may develop such conditions as vegetative disorders, psychological symptoms, acting-out behaviors, and school problems along with long-term changes in cognitive performance and unsuitable personality traits, especially low self-esteem.

Children may feel guilt because they think the illness is their fault in some way. They may experience grief and yearning for lost parenting from one or both parents, fear for their own future, and anger at being pushed aside by the pressures that cancer brings to family life. Disruptions in routine can be particularly unsettling and disturbing.

Children’s anxiety levels are related to whether they are told about a parent’s cancer and the quality of that communication. Children must be told about matters causing pain and anxiety to parents, because if they are not told and feel unable to ask, they may fantasize explanations that can be more distressing than the truth. To be excluded from family concerns may undermine a child’s trust in parents and even the entire adult world. Clearly a child needs to be included in the family’s communication loop, using techniques and language appropriate to the child’s age and developmental stage.

Parental decisions to withhold information from a child may be based on the rationale that avoiding questions about cancer and death will prevent distress in the child. One survivor of a parent who died from cancer says that all children deserve to know the truth. She was not told about her father’s cancer. She reasoned that if it was something as serious as cancer, someone would tell her. No one did. She continued to think everything was all right. When her father died, she suffered emotional problems for over a decade.

The following resources were compiled from an online discussion with Consumer Health and Cancer Librarians. To keep the topic manageable, resources dealing with grief and death were excluded as well as those dealing with childhood cancer. Only resources dealing primarily with communication of cancer to the child and young adult were included.

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6 Barnes, op cit., 481.
WEBSITES:


This web site is based on strength in knowing and support in sharing, and provides particular articles for children’s needs and support.

**KIDSCOPE:** [http://www.kidscope.org](http://www.kidscope.org)

The goals of this site are to improve the chances that a child will successfully cope with the diagnosis and treatment, hopefully not the death, of a parent with cancer and to look at the problem of having a parent with cancer from a child’s viewpoint.

**Kids Konnected:** [http://www.kidskonnected.org](http://www.kidskonnected.org)

The Kids Konnected program is based on the premise that when a parent gets cancer, the entire family is affected and children’s needs must be addressed. At this site, kids help other kids deal with the cancer experience.

BOOKS:

This list includes books written for both the parent and the child. While the titles aimed at children vary in illustration and depth of content, all help open up the lines of communication for discussion of the cancer experience. Some titles may be out of print or in limited supply.


A professional source, the book contains an excellent section on communicating with children.


This new title by the ACS covers a broad range of ages. Included are common questions to expect from children and activities that can be done to help the child express his feelings.


The author, a teacher and cancer survivor, delivers helpful suggestions and insights based on her experience.


This is an older title geared more for the middle school child. Book provides a nice, simple overview of cancer terminology within the story of a family whose mom develops cancer. Includes suggestions for the parent or adult, activities, glossary, and recipes that are suitable for the child to help prepare.


On the 1999 Parents' Choice Recommendation list, this nicely illustrated story deals with a teacher that gets cancer and how the children cope with her hospitalization and recovery. Could be useful for talking to children about their adult friends and acquaintances experiencing cancer.


Using animal characters and wonderful illustrations, the story addresses common fears, concerns and questions young children often have when mom develops breast cancer.


Although not cancer specific, this very informative book offers practical suggestions from a child-life specialist.

*Kemo Shark*, Kidscope. [http://www.kidscope.org](http://www.kidscope.org)

Comic book style story features a shark hunting down the bad cancer cells. Provides an imaginative approach to explaining chemotherapy to the very young child.

Written by a pediatric oncology counselor, this workbook combines drawing and writing with open-ended questions as a coping technique for children with cancer as well as those whom have parents or friends diagnosed with cancer. Provides an interesting approach for children dealing with cancer issues.

Small book with pleasant pictures relates the story of a boy’s experiences and feelings during his mom’s breast cancer journey.

Bold colorful full-page illustrations are the hallmark of this book, designed for the young child whose parent is about to be hospitalized for a bone marrow or peripheral blood stem cell transplant.

Lovely illustrations add to the story of a mother’s continuing cancer treatment. Deals with the child’s fear of seeing a parent return to the hospital. List of practical suggestions for parents are included.

Written by a mother and her son in a diary-like format with each recording his or her feelings and thoughts during the cancer journey. The story is for the older child.

A simply told story of a boy’s feelings and experiences during his dad’s cancer, this paperback is in an activity style format that can be colored and includes a few activities. Good for relating the idea that the parent might not feel well for a very long time.

This is a nicely illustrated, sensitive, upbeat story for the young child. Presents a realistic idea of what the parent will look like in the hospital with equipment and tubing.

Along the same lines as the author’s, My Daddy’s Cancer.

Written in verse, the story is illustrated in a soft monotone color. Gently introduces many of the issues facing young children of a parent with cancer, such as anger, sadness, fear and hope, giving parents a way to start communication and discussion.

Using cartoon style illustrations and humor, this book offers older children the chance to explore their feelings and concerns. Glossary, tip sheets and suggestions are included in this pocket-sized book by the author of Not Now – I’m Having a No Hair Day : Humor and Healing for People With Cancer.

Written by two young girls whose mom had breast cancer, the book features crayon-like drawings and relates the experiences they had during their mom’s treatment.
Beautifully illustrated, the story provides practical steps families can take to help children cope successfully.

Winner of the "Best Book of 1994" award from the American Medical Writers Association, this is a comforting, easy-read story for the young child that includes suggested activities.

Discusses some of the problems, fears and anxieties that children might experience when a parent is ill.

Using dog characters, the book explains in simple language cancer, radiation, chemotherapy and other cancer terms.

Excellent book by a cancer survivor and physician, this title provides practical advice on caring for children of all ages. Includes a story for children called "Becky and the Worry Cup".

This is a story of a young boy’s fears and frustrations at his mother's sickness and how his family reassured him. Nicely illustrated, the story imparts an upbeat feeling.

When Someone in Your Family Has Cancer / National Cancer Institute
Free pamphlet available online at: http://cancernet.nci.nih.gov/peb/family

VIDEOS:
Hear How I Feel. Northeastern Ontario Regional Cancer Centre, 1996.

LITERATURE:
PATIENT-CENTERED GUIDES: AN INTRODUCTION

Cheryl Warren, AHIP
ValleyCare Health Library & Ryan Comer Cancer Resource Center

The Patient-Centered Guides, a collection of book titles on various cancers and related topics, have consistently been given excellent reviews and appear on numerous recommended lists. Several of the titles have been updated on a regular basis. Librarians working with cancer patients, or family and friends affected by the cancer experience, are probably more than aware of this series. Few of us, however, know of the history behind the beginning of this publishing effort. Recently Linda Lamb and Nancy Keene provided their fascinating story of dedication and personal interest in bringing needed information to the cancer patient and concerned public. Be sure to check out their web site at http://www.patientcenters.com/.

THE BEGINNINGS OF PATIENT-CENTERED GUIDES

Linda Lamb
Nancy Keene
Editors, Patient-Centered Guides

Nancy Keene and Linda Lamb, co-creators of the Patient-Centered Guides series, began working together in 1995. They had both been impacted by cancer.

Nancy’s daughter, Katy, had been diagnosed with acute lymphoblastic leukemia (high risk) in 1992, when she was three years old. Nancy spent years helping her daughter through treatment. When Katy’s treatment ended, Nancy had amassed not only a library of medical information but scores of first-person accounts of how individual parents coped.

“It saddened me to think that most parents of children with leukemia would, like me, have to expend precious time and energy to collect, assess, and prioritize information vital to their child’s well-being. After all, parents are busy providing much of the treatment that their child receives. They make all appointments, prepare their child for procedures, buy and dispense most medicines, deal with all of the physical and emotional side effects, and make daily decisions on when the child needs medical attention.”

[Read more of Nancy’s story: http://www.oreilly.com/catalog/leukemia2/chapter/ch00.html]

At her brother’s insistence (and with his gift of a computer), Nancy dug through her filing cabinets of medical background and stories, to put the information together. As the material began to take shape, Nancy contacted her best friend from high school, publisher Tim O’Reilly, to see what his advice was for getting the material published. He encouraged her to keep working on the book, and said he would help find a publisher for it.

Tim had Nancy send the early chapters to one of O’Reilly’s editors, Linda Lamb, who was going through chemotherapy for treatment of breast cancer. Linda remembers:

“I would sit on the floor of my office, reading Nancy’s chapters and tears would pour down my face. I could keep a stiff upper lip about undergoing chemotherapy myself, but thinking about children going through it bypassed all my defenses. Nancy was a really good writer. Her directness and the inclusion of parent stories were powerful. I would wipe my tears, then call her up to start talking about the structure of a chapter, parallel wording in lists, or the style of headings.”

Linda’s response to the experience of cancer had been similar to Nancy’s: she had read everything she could get her hands on. They respected similar authors and sources. And they had both found cancer online support groups http://www.acor.org/ to be a lifeline.

At that time, books for cancer patients were of two general types:

- Books written by MDs (or in some cases a team of MD and RN) for patients, giving them advice
- Books written by patients, telling their own experience

The books by MDs were often paternalistic and assumed the reader did not know much or want to know much.
They offered a sense of medical surety, but often did not look beyond standard treatments to either treatments in research trials or to complementary treatments that could ameliorate side effects or improve quality of life. Sometimes, an MD’s bias of geography or training institution prevented readers from getting the whole range of available treatment options. Patients could get the equivalent of very extensive consultation with a doctor, but would not get the benefit of a “second opinion”, a doctor with differing viewpoints, or the “anecdotal evidence” and emotional validation they might get in a good support group.

The books by patients were interesting in that they illuminated the emotional terrain, but the perspective was very specific to one person’s experience. Readers would gain in-depth exposure to only one person’s story. Linda recalls:

“I remember reading Treya Wilber’s journal entries in Grace and Grit. Some of it rang true and some didn’t apply at all. I remember wondering questions like, how does my cancer compare to hers? What happens to the people who don’t have the full-time support of a husband or the money to fly to Europe for an experimental treatment? What if I don’t have the discipline to meditate every day?”

With agreement from Tim, Nancy and Linda published Childhood Leukemia with O’Reilly & Associates and began a small consumer health press. They agreed that what was needed by themselves and by patients they knew were books that:

- Focused on a single disease or condition
- Had in-depth medical information, reviewed by MDs
- Talked about treatment controversies (giving both sides on a question)
- Put topics in the order in which patients encountered them
- Included topics that were important to patients, not simply the “medically significant” topics
- Featured the voices of patients/families, telling what something felt like to the person to whom it was happening
- Assumed that patients and families didn’t have a lot of medical background, but that they were motivated to learn and could be treated as intelligent participants
- Contained comprehensive resources so interested readers could continue to research their disease or condition

For authors, they looked for persons who were involved with emerging patient communities and who had a broad perspective about a particular disease. One early writer on the subject of advanced breast cancer was Musa Mayer. Linda had met Musa on the breast cancer listserv and found her especially compassionate, knowledgeable, and connected with other patients. Musa is currently a contributing editor to the women’s cancer magazine MAMM (http://www.mamm.com); a graduate of Project Lead, the National Breast Cancer Coalition’s advocacy training program; a speaker at conferences; and leader of workshops on writing and healing.

A recent author of a book on adult leukemia is Barbara Lackritz. Barbara frequently speaks to government, research, and patient groups. She is a patient advocate on the NIH Director’s Council of Public Representatives and sits on the Board of Directors of ACOR and the Chronic Lymphocytic Leukemia (CLL) Foundation. She is also an advocate and list owner on several online support groups and coauthor of the well-respected GrannyBarb and Art’s Leukemia Links: http://www.acor.org/leukemia/frame.html

Although modern medicine is the foundation of books in the series, complementary therapies and psychosocial topics are covered where applicable. Another recent author, Bill Buchholz, is an oncologist with a holistic approach. This is evidenced in his cancer practice (with his psychotherapist wife) and writings such as The Medical Uses of Hope: http://www.buchholzmedgroup.com/hope.htm

Cancer books are still a major focus of the series. Nancy Keene has continued to write and edit books on childhood cancer. Her most recent effort was co-authoring Childhood Cancer Survivors. This book was also born out of the experience of her family and countless others. Children who have survived cancer and its treatments usually have to cope with emotional and physical long-term effects. For example, a child treated with cranial radiation may have to develop coping strategies for cognitive difficulties; a child treated with certain chemotherapy drugs needs to have regular tests for cardiac function. There are a limited number of Follow-Up Clinics who have this specialized knowledge and do the testing. Nancy is now editing a book on pediatric brain tumors, in addition to other titles.

In marketing materials, Nancy and Linda strive to keep materials informational and useful. For example, the Cancer Bibliography (http://research.acor.org/biblio/) (hosted online by ACOR) annotates 110 best books from all publishers. A site for oncology nurses (www.onconurse.com) provides free patient fact sheets. Patient Centers web site (http://www.patientcenters.com/) includes excerpts from the books.

Providing information for patients facing life-threatening or life-changing conditions continues to be rewarding for the staff. If you have questions about the series, you can send email to health@oreilly.com.

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Cancer Librarians Section Newsletter - 10
RESOURCES FOR THE CANCER LIBRARIAN

MERCKMEDICUS

Karen Albert  
Director of Library Services  
Fox Chase Cancer Center

MerckMedicus [http://www.merckmedicus.com] is an excellent new site provided free to all licensed health professionals thanks to the support of the pharmaceutical company, Merck and Co., Inc. A comprehensive web site with authoritative medical information from a variety of full text journal and book, this resource is one you’ll want to publicize to your patrons.

Besides including MDConsult, which usually requires a hefty subscription fee, the site also provides access to Harrison’s Online, Cecil Textbook of Medicine, DxPlain, Braunwald’s Atlas of Internal Medicine, Best Practice of Medicine by Praxis, and Dorland’s Medical Dictionary. The site also features an independent resource for Continuing Medical Education (CME) courses. Access to MDConsult and the major full-text medical sources require registration and input of a state professional licensure number.

There is a wealth of information here for doctors, nurses, and other health professionals. In MDConsult, a search on “merkel cell carcinoma” retrieved entries from texts such as Abeloff’s Clinical Oncology, Cotran’s Robbins Pathologic Basis of Disease, Behrman’s Nelson Textbook of Pediatrics, and Townsend’s Sabiston Textbook of Surgery – all the latest editions. In addition, 147 journal article references were retrieved, and sorted with full text selections appearing first. For this search topic, full-text articles were available from: J Am Acad Dermatol, Ophthalmol Clin NA, Surg Clin NA, Ann Surg, Dermatol Clin, and Hematol Oncol Clin NA.

Merckmedicus.com is intended to be a one-stop medical Internet site providing MD’s and other health professionals with high-quality references, clinical information, literature searches, in full text along with medical news, technology reviews and diagnostic tools.

The search engines within it are relatively unsophisticated, so that complex searches could be problematic; however, the range of full-text content is impressive, making this an extremely useful tool for health professionals. It would helpful if Merck permitted health sciences librarians to access this resource as well, especially for teaching/training purposes. As with many trial electronic resources, the duration of this free access is unknown.

NEW GUIDELINES ON TREATMENT OF PRIMARY BREAST CANCER

Highlights can be found in the Journal of Clinical Oncology, Sept 15 2001, pages 3817-27.


SHARED HOSPITAL ELECTRONIC LIBRARY OF SOUTHERN INDIANA (SHELSI)

Becky Quinten  
Reid Hospital & Health Care Services

SHELSI is designed to assist professionals in their search for online healthcare information. The home page is [http://birch.palni.edu/~shelsi] It is a nice introduction to full-text professional resources such as MDConsult, National Guidelines Clearinghouse, ProQuest, INSPIRE, PubMed and MedlinePlus. The project director is Peggy Richwine at IU School of Medicine (mrichwin@iupui.edu or 317-274-2292).
To Live Until I Die: Conversations with Six Hospice Patients  
Producer: Jay Shefsky of WTTW National Productions  
Cost: $19.95 + shipping & handling  
To order, call 773-509-5586  

Reviewed by:  
Tanya Smith  
Huntsman Cancer Institute  

Although there are over three thousand hospice programs in the United States, few Americans understand what hospice is or for whom it is available. This hour-long video takes the viewer on an incredible journey into the hospice experiences of six terminally ill individuals and their caregivers. The discussions in To Live Until I Die serve to provide reassurance that it is possible to have more control over how one spends his or her last days and to show how hospice programs can assist with those desires.

The video opens with the narrator, Jay Shefsky, sharing how he, his wife, and his children were able to care for his terminally ill father-in-law in their home. Though brief, this portion of the video shows how his children reacted to the experience, and may provide reassurance to viewers who are concerned about how children could be impacted by having a dying loved one in the home. After his experience with his father-in-law’s death, Shefsky put together the To Live Until I Die video to help others learn more about hospice and about how other Americans are gaining control over their own end-of-life decisions.

Of the six individuals whose experiences with hospice are discussed, four were dying from cancer, one from emphysema, and one from ALS (Lou Gehrig’s Disease). Each of the six utilized hospice services in ways that best met their end-of-life care needs and desires, whether at home or in an inpatient unit. The discussions in this video illuminate how hospice is a philosophy of care, the goal of which is the relief of pain and suffering and the improvement of quality of life. The fears of dying in pain and of dying alone have been well documented in research about Americans’ thoughts and concerns about death. To Live Until I Die shows the many ways that hospice care can relieve those fears by giving the dying an active role in deciding where they want to be, whom they want with them, and the type of medical care they do or do not want as death approaches. It also shows how hospice programs and staff support and assist the loved ones of the individual with the terminal illness. By including perspectives of the physicians, nurses, chaplain, and other hospice staff, the viewer has a better understanding of the holistic approach that hospice takes to end-of-life care.

To Live Until I Die is an excellent resource for consumer health and cancer resource centers. The video will be most beneficial for those who have a terminal illness and their caregivers, those who want to understand the philosophy and dimensions of hospice care, and hospice workers and volunteers who are new to the field.

December 1, 2001: Medical Informatics Section/MLA Career Development Grant Application Due. (page 2)  
April 1, 2002: Cancer Librarians Section Newsletter Articles Due. Forward articles to Editors Helen Flitton and Tanya Smith at tanya.smith@hci.utah.edu  