

CANCER LIBRARIANS SECTION NEWS



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NEWSLETTER OF THE CANCER LIBRARIANS SECTION OF THE MEDICAL LIBRARY ASSOCIATION

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 Liszczyński, 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.

In closing, the National Cancer Legislation Advisory Committee (NCLAC) released its report, "Conquering Cancer: A National Battle Plan to Eradicate Cancer in Our Lifetime," in September 2001. It has priorities and recommendations for updating the National Cancer Act of 1971. See *Journal of the National Cancer Institute*, Nov 7 2001, 93(27): 1594 for the recommendations.

Best wishes and happy holidays,

Gayle

Gayle Ablove
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MEDICAL LIBRARY ASSOCIATION NEWS



Medical Library Association Annual Conference 2002 Cancer Librarians Section Will Co-Sponsor Two Sessions

Halyna Liszczyński

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."

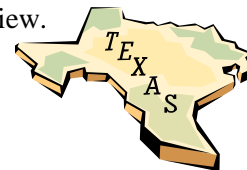
2. Pharmacogenetics

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 NEWS

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 Liszczyński, 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. Another suggestion was made for 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 ask 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 Orlick 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
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Member Updates and Accomplishments



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

Publications:

- Searching for evidence-based oncology: tips and tools for finding evidence in the medical literature. *Cancer Control*. 2001;7:469-75.
- Resources on the Web: searching for information on clinical trials. *Cancer Control*. 2001;8:175-6.
- Commentary on the Informationist: a different perspective. *National Network*. 2001;25(4):20-1.
- 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.

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

Awarded:

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

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.

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.¹ 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.²

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 communication³. 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 truth⁴. 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 decade⁵.

Children may feel guilt because they think the illness is their fault in some way.

Parents who communicate the cancer experience with children do so based on a belief in communication within the family, a desire to keep children's trust and an expectation that communication would lessen children's distress. Studies also show that parents would have liked advice on ways to break the news to their children based on a professional understanding of child development.⁶

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.

¹ Barnes J, Kroll L, Burke O, Lee J, Jones A, Stein A. *BMJ* 2000;321: 479.

² Lederberg MS. The Family of the Cancer Patient. In: Holland JC, ed. *Psycho-oncology*, New York: Oxford University Press, 1998: 984.

³ Kroll L, Barnes J, Jones AL, Stein A. *BMJ* 1998;880.

⁴ Keeley, D. *BMJ* 2000;321:462-3

⁵ Wallace F. *BMJ* 2001;322:355.

⁶ Barnes, op cit., 481.

WEBSITES:



Gillette Women's Cancer Connection: For Families & Friends:

http://www.gilletecancerconnect.org/forfamiliesfriends/for_kids.html

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>

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>

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



Cancer and the Family / Lea Baider, Cary L. Cooper, A. Kaplan de-Nour. John Wiley & Sons, 2nd ed, 2000. ISBN: 0471803006.

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

Cancer in the Family: Helping Children Cope with a Parent's Illness / Sue Heiney, et al.: American Cancer Society, 2001. ISBN: 0944235344.

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.



Cancer Lives at Our House: Help for the Family / Beatrice Hofman Hoek. Baker Books, 1997. ISBN: 0801057353.

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

Cancer: The Whispered Word / Judy H. Swenson. Dillon Press, 1986. ISBN:0875183107.

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.

Good Luck, Mrs. K.! / Louise Borden, Adam Gustavson. Margaret McElderry, 1999. ISBN: 0689821476.

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.

The Hope Tree: Kids Talk About Breast Cancer / Wendy Schlessel Harpham, David M. McPhail, Laura Joffe Numeroff. Simon & Schuster, 2001. ISBN: 068984526X ; (Originally done as Kids Talk for Samsung Telecommunications & Sprint) Using animal characters and wonderful illustrations, the story addresses common fears, concerns and questions young children often have when mom develops breast cancer.

How to Help Children Through a Parent's Serious Illness / Kathleen McCue, Ron Bonn. St Martin's Press, 1996. ISBN: 0312146191.

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

Kemo Shark, Kidscope. <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.

Kids Talk: Kids Speak Out About Breast Cancer / Laura Numeroff and Wendy S. Harpham, Samsung Sprint 1999.

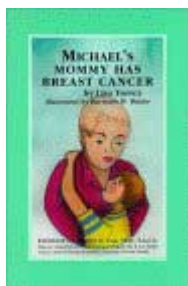
An earlier edition of the Hope Tree, this is available for download at <http://www.sprintpcs.com/speakout/kidstalk/index.html>.

Life Isn't Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer / Peggy Ganz. High Five Publishing, 1996. ISBN: 0965339203.

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.

Michael's Mommy Has Breast Cancer / Lisa Torrey, Charles E. Cox. Hibiscus Press, 1999. ISBN: 0964776367.

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



Mira's Month / Deborah Weinstein-Stern. BMT Newsletter, 1994. (Order from website at <http://www.bmtinfonet.org/> or 847-433-3313) 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.

Mommy's In the Hospital Again / Carolyn S. Parkinson. Solace Pub., 1994. ISBN: 0963028715. 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.

Moms Don't Get Sick / Pat Brack, Ben Brack. Melius Pub Co., 1990. ISBN: 0937603074.

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.

My Daddy's Cancer / Cindy Klein Cohen, John T. Heiney. Promise Pub, 1999. ISBN: 0965649814. 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.

My Mommy Has Cancer / Carolyn S. Parkinson. Solace Pub, 1991. ISBN: 0963028707. 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.

My Mommy's Cancer / Cindy Klein Cohen, John T. Heiney. Promise Pubns, 1999. ISBN: 0965649822. Along the same lines as the author's, My Daddy's Cancer.

Once Upon a Hopeful Night / Risa Yaffe. Oncology Nursing Press, 1998. ISBN: 1890504106. 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.

Our Family Has Cancer, Too! / Christine Clifford. Pfelfer-Hamilton Pub., 1997. ISBN: 1570251444. 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*.

Our Mom Has Cancer / Adrienne & Abigail Ackermann. American Cancer Society, 2001. ISBN: 094423531X. <http://www3.cancer.org/cancerinfo/> 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.



Paper Chain / Claire Blake, Eliza Blanchard, Kathy Parkinson, Elizabeth Murphy-Melas. Health Press, 1998. ISBN: 0929173287.

Beautifully illustrated, the story provides practical steps families can take to help children cope successfully.

Sammy's Mommy Has Cancer / Sherry Kohlenberg, Lauri Cole. Magination, 1993. ISBN: 094535455X. 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.

Vanishing Cookies: Doing Ok When a Parent Has Cancer / Michelle B. Goodman. Benjamin Family Foundation, 1991. ISBN: 0969472404.

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

What is Cancer Anyway? Explaining Cancer to Children of All Ages / Karen Carney. Dragonfly Pub, 1999. ISBN:0966782046.

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

When a Parent Has Cancer: A Guide to Caring for Your Children / Wendy S. Harpahn. HarperCollins Publishers, 1997. ISBN: 0060187093.

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".

When Eric's Mom Fought Cancer / Judith Vigna. Albert Whitman & Co, 1993. ISBN: 0807588830.

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.

Kids Tell Kids What It's Like When a Family Member Has Cancer. Cancervive, 1998.

<http://www.cancervive.org/materials.html>.

My Mom Has Breast Cancer: A Guide for Families. Kidscope, Inc., 1996

Talking About Your Cancer: A Parent's Guide to Helping Children Cope. Fox Chase Cancer Center, 1996.



LITERATURE:

Armsden GC, Lewis FM. Behavioral adjustment and self-esteem of school-age children of women with breast cancer. *Oncology Nursing Forum* 1994;21(1):39-45.

Barnes J, et al. Communication about parental illness with children who have learning disabilities and behavioral problems: three case studies. *Child Care and Health Development* 1998;24(6):441-56.

Barnes J et al. Qualitative interview study of communication between parents and children about maternal breast cancer. *BMJ* 2000;321(7259):479-82.

Buxbaum L and Brant JM. When a parent dies from cancer. *Clinical Journal of Oncology Nursing* 2001;5(4):135-140.

Hilton BA, Elfert H. Children's experiences with mothers' early breast cancer. *Cancer Practice* 1996;4(2):96-104.

Issel LM, Ersek M, Lewis FM. How children cope with mother's breast cancer. *Oncology Nursing Forum* 1990;17(3 Suppl):5-13.

Keeley D. Telling children about a parent's cancer. *BMJ* 2000;321(7259):462-3.

Kroll L, Barnes J., Jones AL, Stein A. Cancer in parents: telling children. *BMJ* 1998;316:880.

Nelson E., Sloper P., Charlton A., While D. Children who have a parent with cancer: a pilot study. *J Cancer Educ* 1994;9(1):30-6.

Rosenheim E., Reicher R. Informing children about a parent's terminal illness. *Journal of Child Psychology and Psychiatry* 1985;26(6): 995-8.

Shands ME, Lewis FM, Zahlis EH. Mother and child interactions about the mother's breast cancer: an interview study. *Oncology Nursing Forum* 2000;27(1): 77-85.

Welch AS, Wadsworth ME, Compas BE Adjustment of children and adolescents to parental cancer: parents' and children's perspectives. *Cancer* 1996;77(7):1409-18.

PATIENT-CENTERED GUIDES

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) <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) : <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/) <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](http://www.patientcenters.com/) 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.

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 *Sabinston 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.

SHARED HOSPITAL ELECTRONIC LIBRARY OF SOUTHERN INDIANA (SHEL SI)

Becky Quinten

Reid Hospital & Health Care Services

SHEL SI 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).

NEW GUIDELINES ON TREATMENT OF PRIMARY BREAST CANCER

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

Full citation: Goldhirsch A, Glick JH, Gelber RD, Coates AS, Senn HJ. Meeting highlights: International Consensus Panel on the Treatment of Primary Breast Cancer. Seventh International Conference on Adjuvant Therapy of Primary Breast Cancer. *J Clin Oncol*. 2001 Sep 15;19(18):3817-27.

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.



LIPPINCOTT WILLIAMS

The subscription-based Lippincott Williams & Wilkins oncology site, <http://lwwoncology.com/> has new content, including the full text of: Diseases of the Breast, 2nd edition, The American Joint Committee on Cancer's Cancer Staging Manual, 5th edition, and The Manual of Clinical Oncology.

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

May 17-23, 2002: Medical Library Association Annual Conference 2002.