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Advocacy, Support, and Education
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Spirit & Breath

from the Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)

feature story

Making D.C. Home *ALCASE Moves Into Its New Offices*

As the boxes make their way from Washington State to Washington, D.C., the critical work of ALCASE continues. Important programs such as the Phone Buddy Program and the Lung Cancer Hotline will continue to provide support to lung cancer patients and their families.

Educational resources such as the website, newsletter and brochures will continue to be provided without interruption.

In addition to maintaining and improving current programs, the new Washington, D.C. headquarters will increase ALCASE's ability to demand more resources for lung cancer.

In 2005, ALCASE will also be introducing a patient-centered information initiative that will continually report on the latest lung cancer data, research, and developments, providing information in a broader

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Caregiver Support

Read Phone Buddy Bill Sonenshine's very personal story about caring for his wife during her battle with lung cancer. **pages 8-9**

Inspire Action During Lung Cancer Awareness Month 2004

One of the biggest obstacles to increasing awareness about lung cancer and its challenges is the stigma associated with the disease. We hope to overcome that stigma by getting people talking about their personal experience with lung cancer.

This November, which is Lung Cancer Awareness Month (LCAM), we encourage you to tell someone — a coworker, a friend, fellow church member, a reporter, your mayor — about your personal experience with lung cancer.

By organizing rallies, distributing educational material, holding fund-raising events, contacting congress, and speaking to the media, those involved in LCAM bring much-needed support and attention to a disease that each year kills more people than breast, prostate, colon and pancreas cancers combined.

Once people understand the challenges and issues that lung cancer patients, survivors and their loved ones face, it will inspire action. This action can take many forms — talking with the media, getting involved in lung cancer advocacy, working with healthcare organizations, funding lung cancer organizations, but the most important is to marshal support to change the current state of lung cancer.

New Web site: www.lcam.org

A new aspect this year is a Web site dedicated exclusively to LCAM. In partnership with many other lung cancer organizations, ALCASE has been able to put together a comprehensive calendar of LCAM events.

You can find additional information about the history of LCAM, ways to volunteer, lung cancer facts, and resources. We hope you will visit the site and encourage others to do so as you share your story and inspire action.

LCAM Kits

Included in this year's kits is a new item — a calendar/advocacy trainer. This 13 month calendar offers tips and strategies to start advocating for lung cancer. The kits also include stickers, an issue of Spirit & Breath, and the 2004 LCAM Poster, which promotes this year's theme.

Awareness Advocates

LCAM also marks the launch of a new volunteer program. We've asked for volunteers from each state to speak to the media in their area and share their personal lung cancer story. We hope to increase awareness by increasing media coverage of LCAM. We still need volunteers! Call or email us today for a "how-to" packet.

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One door closes, another opens

By Cindy Langhorne and Janet Healy

It's only natural that seasonal changes remind us of other transitions in life. Soon, ALCASE's Washington state office will close and we'll open national headquarters in Washington, D.C.

We wish great success to those who will lead and staff the new office. Patient education and personal support programs will continue and advocacy will increase. Your involvement will be vital as we work to increase lung cancer research funding, speed earlier detection of the disease, and provide a voice for lung cancer patients on other healthcare policy issues.

As staff members who won't be moving East, we know that working on your behalf has changed us.

We Heard it on the Hotline

"How can I find the best treatment? Should I get a second opinion on having surgery? My (parent, sibling, spouse) seems to be in shock since the diagnosis. How can I make them to decide on treatment? I was diagnosed last week and don't know what to do next. Something 'suspicious' showed up on my CT scan. It's back. What's next? The medical expenses are huge. Do you have any financial aid? I know I brought this on myself. Can you find me a Phone Buddy? What does your organization do?"...

Over the years, we've heard these and many other comments, some stories that are deeply personal, and some that link to issues of truly national importance. No matter our involvement in carrying out programs such as our Run for the Lungs Team or Phone Buddies, or, publishing the newsletter—the Hotline keeps it all *real*.

We realize that there is no "best" answer to many of the callers' questions and that sometimes listening reveals the true need. All of us are on this Life journey and will face fear, various challenges, and coming to terms with our mortality. We are all in this together. As our late colleague, Scott Rivers, put it, "We're here for each other."

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ALCASE Makes D.C. Home

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context, in much the same way the magazine *Consumer Reports* provides consumers information on cars and appliances.

The new headquarters will be staffed by a newly-hired executive director, who will be joined by a program

manager and administrative assistant, with additional staff to follow.

During the transition, Jane Reese-Coulbourne, a cancer survivor and advocate and corporate strategist, will serve as interim executive director.

Contact the new office:

ALCASE
1155 21st Street, NW
Suite 350
Washington, D.C. 20036
Hotline: 800.298.2436
Email: info@alcase.org



Thank You ALCASE Staff

Board Appreciates Vancouver Staff's Diligence, Dedication

The board of directors of ALCASE extends its gratitude to the Vancouver, Washington ALCASE staff, for their tireless commitment and dedication to the needs of lung cancer patients over these past several years.

Many of you have been with ALCASE from nearly the beginning. The organization is where it is today, in large part, due to your efforts.

You set a precedent for support and education for lung cancer patients. Countless patients and their loved ones have found support and information through your service.

You have our most sincere thanks.

Spirit & Breath

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In My Opinion:

Healthcare Challenges in Mississippi Delta Hurting Area's Rural Residents

By Scott E. Nelson, MD

Few areas of the United States are faced with the healthcare challenges found in the Mississippi Delta, an impoverished area in the northwestern part of Mississippi along the Mississippi river. Here, incidences of disease often lead the nation. Diabetes rates, for example, approach 20 percent in some areas. Lung cancer and other malignancies seem quite prevalent as well.

Why is lung cancer so prevalent? Although the association with tobacco use has long been known by health experts, a mindset still exists in our region of what is tantamount to denial. If someone's mother, father, brother, aunt and uncle all smoke, and no one has gotten cancer, a person all too often concludes he/she must be immune to the risk! I have had many patients tell me so.

Furthermore, the rural southern culture is centered around traditions. Many southerners' idea of a good time is a large (often sugar and fat-laced) meal washed down by a few beers, topped off by a few smokes. A mindset also exists where people think just one or two cigarettes when drinking are perfectly harmless. However, I suspect this notion is not limited to our area!

If prevention fails, early detection of lung cancer is the next best line of defense. Unfortunately, the Mississippi Delta ranks near the bottom in number of healthcare providers per-capita.

Furthermore, access to healthcare, particularly for indigent patients, is limited. If one has a functioning automobile at all, it may be 30 to 40 miles to the nearest doctor's office. Once there, wait times of at least one hour are common. Patients often become frustrated and leave before being seen.

Are there positives? Yes! In the past few years, regional cancer centers have opened in several Delta communities, and a permanent, non-mobile PET scanner is now available. The Mississippi State Department of Health and the Information and Quality Health (IQH) Medicare quality organization have adopted primary prevention programs. The programs even include a tobacco-quitting phone number and office at each state university.

The war against lung cancer and other serious diseases in the rural Delta will rage on. Success will center on improving access to care, raising public awareness, and the most difficult challenge of changing generations-old cultural practices.

We must not forget the relentless push of advertising of tobacco as a cheap, readily available means for the poor to relieve stress — and look cool.

The battles will not be won overnight, perhaps not even in our lifetime. I remain committed to fight for the future in our region.



Lung Cancer Mississippi

The Delta

The American Cancer Society estimates there will be 2,230 new cases of lung cancer and 2,060 deaths in Mississippi this year. That's more deaths than prostate, breast, colon, and pancreas cancers combined.

The Doctor

Dr. Nelson serves on ALCASE's Medical Advisory Committee. He was born and raised in Mississippi and is on the board of directors for the Mississippi Family Practice Foundation.

His articles on diabetes and obesity have appeared in major national magazines and as a cover story in *USA Today*.

In 2003, his television program about diabetes in the Mississippi Delta earned him the Jules Bergman Award for Medical Reporting from the National Association of Medical Communicators.

He reports on health for television and radio stations in Mississippi and edits the Delta Medical Digest. Since 1992, Dr. Nelson has practiced medicine at the Family Medical Clinic in Cleveland, Mississippi. A husband and father, he is also a lifelong enthusiastic fan of Delta blues music.

Related Journal Articles

Rural v. urban aspects of cancer: first-year data from the

Mississippi Central Cancer Registry. Higginbotham JC, Moulder J, Currier M.

Fam Community Health. : 2001 Jul;24(2):1-9

By Charles R. Thomas, MD and Todd Scarbrough, MD

Intensity modulated radiation therapy (IMRT) is a fairly new treatment method in radiation medicine, but one which is showing extreme promise in many cancers. IMRT decreases the long-term side effects of radiation in prostate and head and neck cancer patients and offers many previously “untreatable” patients a chance at safe and effective therapy. While all radiation oncologists have used high-powered X-rays for decades to treat tumors, IMRT involves delivering the X-rays in a totally new fashion.

IMRT is by its very nature extremely precise and targeted. If the target is moving, the worry by many experts is that the impact of IMRT is lessened or the treatment becomes altogether ineffective, or even unsafe. A breathing patient with a lung tumor is an example of a “moving target” scenario.

However, through some very creative study and analysis, researchers at Massachusetts General Hospital/Department of Radiation Oncology (below) counter this worry. Although they found that the expected dose delivered by IMRT during stable respiratory motion could vary as much as 20% on any given day, the dose varied by only 1-2% over the normal course of radiation therapy, if some specific treatment settings were used.

This is some of the first dosimetric pre-clinical research looking at complex IMRT plans for treating lung cancer. IMRT could translate into higher doses to lung tumors (meaning higher cure rates) with fewer side effects (such as lung or esophageal damage) for patients.

Article discussed: An experimental investigation on intra-fractional organ motion effects in lung IMRT treatments. Jiang et al., Phys Med Biol 48:1773-1784, 2003

Radiation to the Lung: How Much & Where?

By Charles R. Thomas, MD and Todd Scarbrough, MD

Intensity modulated radiotherapy (IMRT), a relatively new method of radiation delivery in cancer medicine, has the promise of delivering higher, more curative doses of radiation with fewer side effects than in the past. IMRT has been a natural offshoot of 3-D conformal radiotherapy (3-D CRT), which involves reconstructing the target area's 3-dimensional volumes from CT scans and then directing radiation beams there, while sparing areas from treatment where the clinician wants little to no radiation dose.

With IMRT, the radiation oncologist can work in new ways. Instead of starting with pre-selected radiation beams and then measuring doses in tumors and healthy organs, the clinician can start with desired doses and then allow a computer to design the radiation beams. This allows the clinician to specify “how much of a dose” to “how much of a volume,” whether those volumes be tumors, the lungs, the

heart, the spinal cord, etc.

One problem is that the data regarding “how much of a dose to how much of a volume” is surprisingly lacking in treating lung cancer. If using IMRT becomes more widespread in treating lung cancer, clinicians will need a better 3-D “dosimetric” understanding of the lungs themselves. A first of its kind dose-volume study from Germany (below) helps answer some likely questions. For example, are previously recognized dosing guidelines good predictors of lung damage currently, or are new ways of looking at lung dose-volume measurements needed?

Willner's group suggests a better way to predict lung damage from radiation and that it is better to spread out low doses (less than 20 Gray) to high volumes of lung, if that equals limiting the relatively higher dose/volume areas. While not changing the old ideas about the tolerance of the lung to radiotherapy, it does inform the future, as techniques such as IMRT enter the clinic for use in lung cancer patients.

Article discussed: A little to a lot or a lot to a little? Willner et al., Strahlenther Onkol 179:548-56, 2003

The authors, except for Dr. Scarbrough, are all members of ALCASE's Medical Advisory Committee. Dr. Helen J. Ross is a medical oncologist at the Oregon Clinic Medical Oncology Division and the Earle A Chiles Research Institute of the Providence Cancer Center. She is also Co-Director, Thoracic Oncology Program at Portland Providence Medical Center in Portland, OR. Patricia Juliano Pearce, RN, OCN works at Scottsdale Healthcare Osborn in Scottsdale, AZ. Dr. Todd Scarbrough is a radiation oncologist at Melbourne Internal Medicine Associates in Melbourne, FL. Dr. Charles R. Thomas is a radiation oncologist and professor in the Division of Medical Oncology at University of Texas Health Science Center in San Antonio, TX.

Finding Clinical Trials

Call the National Cancer Institute: 1-800-4-CANCER

Or try these Web sites:

- Clinical Trials.gov
www.clinicaltrials.gov
- National Cancer Institute
www.cancer.gov/search/clinical_trials
- Trial Check
www.trialcheck.org/cancertrialshelp
- Center Watch
www.centerwatch.com/patient/studies/cat34.html
- Veritas Medicine
www.veritasmedicine.com
- Cancer Consultants
<http://patient.cancerconsultants.com/trials.aspx>
- Emerging Med
www.emergingmed.com

Staff Ponders ALCASE's History

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What We've Learned

We've learned that being diagnosed with lung cancer is like waking up in a college course you never signed up for, without books or friends beside you. How to cope and find hope are two of the common themes.

We've learned that everyone's information needs differ and part of our job is to respond appropriately, perhaps by simply helping frame questions to ask one's doctor.

We are often amazed by our Phone Buddies — open-hearted volunteers who realize an encouraging word or an understanding sigh can sometimes transform another person's attitude.

Thank you for the many suggestions and the kind notes you've sent — we call them “feel good” letters. We also appreciate your donations.

Lung Cancer Organizations

ALCASE is still the only national lung cancer patient advocacy organization. We've helped it grow and are proud this has led to working with other organizations on projects such as Lung Cancer Awareness Month and the “Frankly Speaking About Lung Cancer” program.

We value the unique resources other groups offer for people facing lung cancer. We participate in international meetings and were a charter member of the Global Lung Cancer Coalition, which now includes organizations from ten nations.

To support and expand our volunteers' efforts on many fronts, we are especially proud that ALCASE will host the first-ever national Lung Cancer Summit in 2005.

Relationships

From our founding, ALCASE has formed relationships with leading

oncology physicians and supportive care professionals. Our medical colleagues are much more aware, too, of the benefits of patients and their advocates attending and even speaking at medical conferences. We thank our Medical Advisory Committee of family physicians, pulmonologists, oncology specialist, nurses, and social workers for their continuing participation and for helping “translate” medical information into understandable English.

Thoughts

Whatever paths our lives take, our work here has been highly meaningful. Three of us have been on the ALCASE staff for six years. We sum up our thoughts:

“What has been most important to me is trying to help and give hope to people with lung cancer and their families, during the difficult times they are going through. Being part of the ALCASE staff has also helped me grow, developing my skills and confidence.”—Ademira Hadziselimovic, Program Assistant

“I'm honored to have helped patients directly and to have represented ALCASE in many public settings. Volunteers are vital to the work ahead—increasing lung cancer research, informing and supporting people with the disease, and bringing compassion to all the efforts.”—Janet Healy, Senior Program Manger

“Talking with so many people on our Hotline has kept me in touch with the personal impact of lung cancer, even in the toughest times, we've laughed together and seen the strength of people. The staff is dedicated to a smooth transition to our new headquarters. It has been an honor to serve the lung cancer community.”—Cindy Langhorne, Director of Operations

Bookshelf lung cancer reading

- With Every Breath: A Lung Cancer Guidebook by Tina St. John, M.D. c.2003 (not yet in print) Comprehensive, fully annotated, written for lung cancer patients and their families. Available free, for personal use and downloading at <http://www.lungcancerguidebook.org>
- 100 Questions and Answers about Lung Cancer by Karen Parles, MLS and Joan H. Schiller, M.D. c. 2003 Provides a patient's and a doctor's point of view, with authoritative, practical answers about treatment options, post-treatment quality of life, sources of support, and much more. Order online at <http://health.jbpub.com>
- Lung Cancer: Myths, Facts, Choices—and Hope By Claudia I. Henschke, Ph.D., M.D., and Peggy McCarthy (ALCASE founder) with Sarah Wernick Paperback c.2003 An authoritative book with lifesaving strategies for those at risk for lung cancer or already diagnosed. Order online at <http://www.wwnorton.com/catalog/fall03/032498.htm>
- Lung Cancer : Making Sense of Diagnosis, Treatment, & Options By Lorraine Johnston Paperback c.2001 Medical facts simply explained, advice to ease daily life, and advocacy suggestions. Order online at www.oreilly.com/catalog/lung-cancer/

News Lung Cancer

Genetic Link to Lung Cancer

Researchers at the University of Cincinnati Medical Center conducting a National Cancer Institute study with the Genetic Epidemiology of Lung Cancer Consortium found an inherited genetic mutation on one chromosome that gives some people, some families a higher than normal risk for getting lung cancer. This is the first suggestion that lung cancer, long tied to cigarette smoking and other external causes, might also be an inherited disease. The researchers continue to search for families at high risk for lung cancer, especially those with three relatives, living or deceased, who have had lung cancer among their parents, grandparents, aunts and uncles, or their own brothers and sisters. The study is still enrolling. For more information, call 513-558-3120 or see www.eh.uc.edu/gelcc

FDA Approves Alimta

The FDA approved the chemotherapy drug pemetrexed (Alimta), made by Eli Lilly and Co., to treat locally advanced or metastatic non-small cell lung cancer after previous chemotherapy. In a Phase 3 clinical trial comparing Alimta to the previously-approved second-line treatment, docetaxel (Taxotere), Alimta was found to be as effective but with fewer side effects, such as hair loss, lowered white blood cell counts, and hospitalizations for subsequent infection. In February, Alimta was approved, in combination with cisplatin (a common chemotherapy agent), for treating malignant pleural mesothelioma, a cancer linked with asbestos exposure.

ALCASE Steps Up Advocacy Efforts

By Sheila Ross, ALCASE Advocacy Director

We've been asked why ALCASE is moving to Washington D.C. The answer is simple. It's about advocacy. If ALCASE is to make an impact on the legislative agenda for lung cancer, we need to be at the center of where these decisions are made. Our move to D.C. will be accompanied by a formal "Declaration" in which we clearly state our goals for the health policy makers and our commitments to you.

Survivors of breast, prostate, and other cancers have already made their voices heard loud to Washington D.C. healthcare policy makers, as can be clearly seen in the research funding statistics.

The National Cancer Institute's current research budget funds approximately \$1,700 per lung cancer death in the U.S, compared to funding of \$14,000 per death for breast and \$10,700 per death for prostate cancer. The move to D.C. is intended to make the voice of lung cancer heard loud and clear as well.

This Declaration will form the basis of activities for a grassroots effort that will include lung cancer patients, their families, former smokers and their physicians.

Lung Cancer Advocacy Declaration

Goals

- A 50 percent reduction in lung cancer deaths by 2015
- Congressional hearings on lung cancer research
- Funding for the NCI and the Department of Defense to sustain a multi-year research effort to reach the 50 percent reduction goal by 2015
- Expedited review of screening technology and immediate research into safe and cost effective treatment of early lung cancer and pre-cancerous conditions
- More accurate public information on lung cancer and an end to the stigma faced by lung cancer patients, even those who have never smoked

Commitment

- We will work with Congress and federal agencies to achieve these goals
- We will help lung cancer patients, survivors, their families and caregivers become active participants in achieving these goals
- Beginning in 2005, we will issue an annual Report Card on our progress every November which is lung cancer awareness month

Call to Action grassroots advocacy

Lung cancer patients, family members, and others who care about lung cancer. ALCASE needs your help! Our new advocacy initiative will include lots of opportunities for your voices to be heard, in Washington, D.C. and in your local state and community governments. Sign up and we will send you regular Action Alerts via e-mail, letting you know when political action will be taking place and how you can help. To sign up, email us at info@alcase.org and be sure to put "advocacy alert" in the subject line.

American Women and Lung Cancer

By Patricia Juliano Pearce, RN, OCN

Despite increasing public awareness and advertising about the dangers of cigarette smoking, more than a quarter of all women in the United States smoke cigarettes. Since 1987 lung cancer has surpassed breast cancer as the leading cause of death in women in the United States. In comparison, death rates in men from lung cancer have slightly decreased. It is estimated that the mortality rate will continue to increase for women in the coming years, as those most at risk for developing the disease age.

Smoking in women seems to be a more complex issue. It is not just physical satisfaction that is gained; there is also a psychological component as well. It seems that for young women, smoking has become a sign of independence and equality with adults. They also "buy into" the myth that smoking will help with weight loss. Cigarette smoking is three times higher in women with less than a high school education than for women who are college graduates. In other developing countries, despite the increase in lung cancer cases in women, cigarette advertising targets young women. This will have a tremendous effect internationally on the number of new cases as well as the number of lung cancer deaths. Cigarette smoking is still the major cause of lung cancer. Up to 90 percent of lung cancer patients have smoked in their life time. Because of certain DNA markers, a recent study (below) shows that women may be physiologically more susceptible to the carcinogenic (cancer-causing) effects of cigarette smoking.

Although debate continues about the genetic link between women and lung cancer, there is a definite difference in the way the disease appears in women. Of all types of lung cancer, adenocarcinoma has replaced squamous cell carcinoma as the type most frequently diagnosed. It is also the most common type of lung cancer in younger people, women of all ages, and in people who have never smoked.

Women have a greater survival advantage than men, after surgery for early stage lung cancer. But lung cancer will simply not disappear if everyone stops smoking. We have the opportunity to reduce the number of new lung cancer cases and significantly reduce the death rate by educating young people and encouraging those who do smoke to stop now.

Article discussed: *Lung Cancer in US Women: A Contemporary Epidemic* Jyoti D. Patel, MD; Peter B. Bach, MD; Mark G. Kris, MD. *JAMA*, April 14, 2004 Vol. 291, No. 14:1763-1768



Chemosensitivity Assays

By Helen J. Ross, MD

This month, the American Society for Clinical Oncology (ASCO) issued a practice guideline recommending against the routine use of chemosensitivity assays and supporting tests of these assays only in clinical trials. Chemosensitivity assays involve removing a sample of cancer cells from an individual patient and exposing these cancer cells to a variety of chemotherapy drugs in a

tissue culture dish or an animal model. The effectiveness of each drug tested is measured by its effect on the growth of the cancer cells. In theory, this assay could predict which drug combinations would be most effective for individual patients, thus sparing them exposure to ineffective and potentially toxic therapies. In practice, however, chemosensitivity assays have not been shown to predict accurately which drug regimens will work best in a particular patient.

Why might these assays not be accurate? The patient's cancer cells behave differently in a culture dish than in the patient. Culture systems cannot compensate for the natural environment in which the cancer developed—including the patient's metabolism, variation in enzyme activity, rate of drug excretion and vascular (blood) supply to the tumor. Mouse models have similar problems with the addition of a foreign immune system. ASCO has not recommended the routine use of these assays because of these and other problems. The most important obstacle to the routine use of chemosensitivity assays is the lack of randomized clinical trials confirming their effectiveness. ASCO recommends that these trials be done and that their results should determine the effectiveness of the assays and whether routine use can be recommended. Opposition to this guideline has come primarily from groups with a financial interest in the assays in current use. It is of interest to note that these same groups have generally not supported development of randomized clinical trials to confirm the benefit of their products.

Article discussed: *American Society of Clinical Oncology Technology Assessment: Chemotherapy Sensitivity and Resistance Assays.* D. Schrag, MD, et al, *Memorial Sloan-Kettering Cancer Center, New York, NY. Journal of Clinical Oncology (JCO) Sep 1 2004: 3631-3638.* <http://www.jco.org/>

Breathing Motion and Lung IMRT

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Key Highlights Fall 2004

Members of our Medical Advisory Committee discuss recent medical journal articles and topics of interest.

Important Yet Invisible Nursing Tools

By Patricia Juliano Pearce, RN, OCN

Patricia Benner (article below) explores a region of nursing that is more of an art than a science. Being present and available to patients, using comfort measures and gentle touch, are central issues in nursing practice. However, they are rarely recorded on patients' charts, are never suggested in a nursing care plan, and are the "invisible" things that nurses do for patients. Dr. Benner points out that there may be barriers and confusion about the practice of touch and presence in our culturally diverse health care environments.



She states, "Comforting a patient includes providing social, emotional, physical, and spiritual support for the patient. These terms sound soft and tend to get trivialized in a setting focused on highly technical curative techniques; they are life giving and valuable in their own right." They may not seem as important as administering lifesaving drugs, but they are an essential part of evaluating patient needs. Some critical care nurses will use restraints as a last resort for their patients who are pulling out lines or being combative. What they have found is a soothing voice and touch can calm a patient. These "tools" are an essential part of good nursing care and are required for going beyond what the patient is saying, to finding out what their real needs are. These tools are also essential for nurses working with cancer patients. Often a gentle touch of the hand or a reassuring smile will give a patient the courage and support they need to deal with their situation. I know in my job these are just as important as the drugs I give.

Article discussed: *Relational Ethics of Comfort, Touch, and Solace – Endangered Arts?* Patricia Benner, RN, PhD., *American Journal of Critical Care* 13(4): 346-349 2004

Clinical Trials Registration

By Helen J. Ross, MD

This month a group of editors of major medical journals issued a statement favoring inclusion of all patient studies of drug treatments at their outset in a clinical trials registry. This will now be a requirement for

publication in the *New England Journal of Medicine* and other important journals. Many clinical researchers strongly support this requirement.

Why is this new publication policy important? Medical practice depends on evidence of effective treatments as judged by clinical research. Results of clinical trials allow development of treatment guidelines, forming the backbone of evidence-based medicine. These guidelines, and medical practice in general, are changed not by any single study, but by a "body of evidence". Historically, "publication bias" has prevented publication of many negative and equivocal clinical trials, resulting in a body of evidence that may appear to support a new treatment more strongly than would be warranted if all of the evidence could be considered.

Why is that bad for patients and their physicians? Most clinical trials published in major journals are supported by drug manufacturers. Pharmaceutical companies sponsor research to get their new drugs approved and to broaden their uses. Thus, the economic interest of a trial sponsor can come into conflict with the scientific results if a trial does not strongly favor the new treatment over a standard approach. Biased reporting of positive trials with suppression of negative or equivocal ones can make it appear that the new treatments are more useful than older, better known, and frequently less expensive treatments. The end result of this is, at best, overuse of expensive new drugs and escalation of clinical care costs; at worst, overuse of new treatments to the detriment of patients because of lack of effectiveness and unanticipated side effects. As a member of the ALCASE medical advisory board, I urge all of my colleagues and patients to support inclusion of all treatment studies in a comprehensive clinical trials database.

Article discussed: *Editorial: Clinical Trial Registration: A Statement from the International Committee of Medical Journal Editors* C. De Angelis, J.M. Drazen, F.A. Frizelle, and Others. *New England Journal of Medicine* Volume 351:1250-1251 September 16, 2004 Number 12. <http://content.nejm.org/>



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Supporting Others, Writing Book Helps Two-Time Cancer Survivor

Thirty-four years ago, Howard Rubinstein heard his first cancer diagnosis. After an eight-hour operation, for what had seemed to be an infected appendix, his doctor told him he had advanced lymphoma and probably no more than six months to live.

"As you can imagine, this news was sobering and life changing," he remembers. "My son, Ian, was three years old at the time and I believed I would never see him turn four."

Howard was in the advertising business, as creative director for a major national magazine. After completing grueling radiation therapy that hot New York summer, he changed careers and entered the retail pet business.

"It was," he says, "a change in careers which I loved and which probably helped save my life. A while I began to think about my life. I realized that I had gone through a unique and challenging experience. Could I help others who are going through that same nightmare?"

He began volunteering with the American Cancer Society, talking with newly diagnosed patients, and then leading support groups for people with various cancers. He attended college part-time, eventually earning a Master's degree in social work.

He started a support group for the Leukemia and Lymphoma Society and it's now their longest-running group. Since 1998, he's counseled children and families with cancer in New Jersey for the Emmanuel Cancer Foundation.

Howard's challenges were not over. Four years ago, he was diagnosed with lung cancer. He had a lobe of one lung removed and is receiving chemotherapy. Even so, he continued his professional training, becoming a

board-certified oncology social worker last year through the Association of Oncology Social Work.

Howard is also writing a book to explore "lessons I've learned and how my life has been changed by my cancer experiences." Excerpts *The Privilege of Having Cancer* (working title) appear here.

Before the question arises, Howard speaks up, "No, I never smoked." He wonders if the intensive radiation therapy for lymphoma may have left him vulnerable to lung cancer.

But he says the shock of the lung cancer diagnosis didn't derail him. "I continued my work, which really has been a labor of love."

Barely a week after his lobectomy, he was driving to visit a young cancer patient. He still is recovering from some of the effects of surgery, with pain in some muscles and ribs.

"One of the highlights of 'rebuilding' my life is that I'm with Deborah, the greatest wife in the world. This woman, who is the closest thing to an angel on earth, is the most incredible woman I have ever met and has more love in her heart than anyone I have ever met." They married in Las Vegas in 1998 and returned there to do it again after his lung cancer surgery. "This time we went to the Graceland Chapel and 'Elvis' married us!"

"We have shared it all together," he emphasizes. "All the highs and lows of a lifetime and with every day our love for each other grows stronger." Deborah works in hospital management at the medical center where Howard receives treatment; a good situation, he thinks. "She tells my doctor, 'you'd better take good care of my husband, or I'm going to come after you!'"

For a while, Howard attended a lung cancer support group, as a participant,

Profile from where i stand



Howard Rubinstein, who has battled both lymphoma and lung cancer, with his wife Deborah at Niagara Falls.

"Cancer has truly been a privilege of learning and knowledge that has changed my life for the better — forever."

not a facilitator. "It touched me deeply and it was educational," he says, "hearing the different stories the people shared. But maybe the social workers who led it were a little intimidated by me, given my training as an oncology social worker!"

Howard and Deborah's family now includes two adopted daughters, Sarah and Amy. He and Deborah built their "dream house" in northwestern New Jersey. They have four grandsons. Another member of their family is Marvin, a giant blue and gold macaw.

"If I had the opportunity to go back to 1970 and decide not to go through that original battle with cancer, I would go through it all again. The point is that this has really been a lifelong process. Then, too, I have the constant joy of Deborah. What the (previous cancer) battle and this latest one have taught me is how precious every day of life really is."

Support Groups



All Together and Emailing

By Christine Quiry

Christine is co-owner of one of the longest-running lung cancer list-servs on the Internet, through the not-for-profit Association of Cancer Online Resources (ACOR). Being part of the list-serv can help people with lung cancer and their caregivers overcome isolation, share information, and provide encouragement to others — through tapping a keyboard.

Christine tells about her experiences “gatekeeping” the list.

For me, personally, the list has provided a way to help others with lung cancer. My sister died after a very short battle. I couldn’t save her life. Participation on the list was a way to direct and fulfill that frustrated desire to help.

Most members are silent when they join; they’re “lurkers”. Those who write are usually in shock and terrified for themselves or their loved one; questions at this time are usually of a general nature; as if they fell off a ship in the ocean and they’re yelling, “Help!”

Everyone asks the same general questions:

How can this have happened? How long will I live? Where can I find a good doctor or hospital? What is the standard treatment? Can I have surgery? I’ve had surgery, should I also have chemotherapy? Has anyone had <specific treatment> and what was your experience? I’m having this symptom, what can I do about it? I’m looking for a new treatment, has anyone heard of anything promising?

As a co-list owner, sometimes just reading all the messages is the biggest challenge! The list traffic ebbs and flows, and the administrative duties can also be very time consuming. Since this is a volunteer effort, we all put in the time that we have available but we all work well together. This is all behind-the-scenes, so if there is a challenge it is to keep this activity behind-the-scenes.

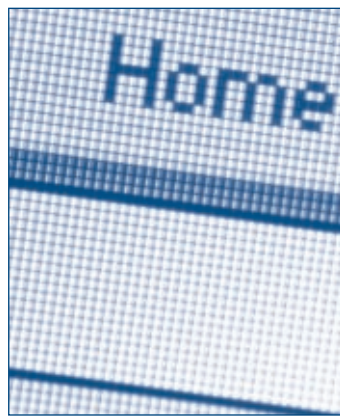
I see no drawback to list participation! I know that, as a caregiver, I derived a great deal of comfort in just knowing that I was not alone and that a cadre of intelligent, informed people was interested in reading what I had to say and would respond to my questions and concerns, either with technical information or by relating their own experience. The list is available 24 hours a day, 7 days a week. It’s international, and plenty of people are up at all hours ... no matter what time someone writes to the list, if someone has have a question or just needs to establish contact with someone else who understands their situation, chances are really good that another “someone”, somewhere, will be reading it and will have something helpful to say.

The list is a vehicle for lung cancer patients and their loved ones to share information and be in touch with others in a similar situation. While I feel we are very lucky to have subscribers and co-owners who are very knowledgeable, even-headed, spectacular at doing research and at keeping their eyes on the news, the list is not a substitute for medical care or advice.

For those who are comfortable with email, I think it works really well. In-person support (for addressing other needs) might be better, but I think the lists work amazingly well as a lifeline and a source of current information, or pointers to current information.

The strength and generosity of those who participate inspires me and I value the sense of connection I can feel to others, even though we’ve never met personally.

For more information, visit <http://www.acor.org>
For other online support, including message boards, see
ALCASE’s Web site:
http://www.alcase.org/support/support_groups_online.html



Volunteer Activity

RFL: Compassionate, Committed Runners

These words come to mind as we honor the amateur athletes who’ve joined our Run for the Lungs Team (RFL). From the Team’s founding five years ago; inspired by Kevin Manley, whose sister-in-law had lung cancer, runners have triumphed in their physical training and fundraising. We are grateful for the money they collect to support ALCASE’s work. And we’re often amazed at the positive effects one person can achieve. For example, contacting a local newspaper to print a runner’s story can increase media interest in lung cancer issues.

We’ve also seen the Team grow as members have more choices. They decide on the event they’d like to run, anywhere in the continental U.S. Although most choose half or full marathons, they can also enter even shorter races. This is a great time to think about joining the Team in 2005!

Some recent RFL members write about their experiences:

Chicago Marathon

Kimberly Campbell: I am running this marathon in memory of my stepfather, Sal. I am running in hopes that someone’s father, mother, brother, sister or friend will have the opportunity to beat lung cancer. Sal was a man so full of life, with a presence so strong and a voice so loud, it is inconceivable to me that it is now silent. I will carry him in my heart always and hear his voice in my head as I cross the finish line. I have dedicated this marathon to him because through him, I have learned the meaning of true courage. I am a different and better person for having known him.

Eric Yates: I’ve always seemed to lack the motivation or commitment to follow through with my goal of completing a marathon. When my mother was diagnosed with lung cancer in October 2000, it was the worst day of my life. After my mother passed, I decided that it was time for me to finally do something important with my life. Then I came across ALCASE while doing a web search for lung cancer. I immediately contacted them and signed up and committed myself to RFL. The Chicago Marathon will be my first marathon and I run it in honor of my mother, Christina Dale. I love you Mom.

Flying Pig Marathon, Air Force Marathon

Becky Garcia: As I reflect on my involvement with RFL, I am saddened by the circumstances that led me to the team, but grateful for the opportunities and new sense of hope that it’s given me. Training for a marathon and raising money for ALCASE in honor of my mom helped to ease the feeling of helplessness that I struggled with after learning of her lung cancer diagnosis.

Runners know that some of the best thinking is done during long runs. During the runs, some amazing transformations occurred. As I slowed to a walk at the end of a route, I realized that sore knees and feet were not the only gifts that running had given me. I was left with a refreshed attitude, renewed strength, and a new sense of clarity and purpose.

San Francisco Half Marathon

Jennifer Norin: Earlier this year, my sister Amy was diagnosed with metastatic non-small cell lung cancer. She is only 44 years old, and is a wife, mother, daughter, sister and friend. She is intelligent, vibrant, and beautiful. Our family was shocked, horrified and devastated by the diagnosis of cancer. It was compounded by the fact that Amy never smoked! I found the ALCASE website and information about the RFL Team. Inspired by Amy’s drive to “keep living”, I joined and began training for a 1/2 marathon in San Francisco. The training has been rigorous. However, it is nothing when compared to the battle that Amy continues to fight. She is the inspiration.

New York Marathon

Diana Boehm: Soon I will join 40,000 runners in the New York City marathon. Unlike many marathoners, I will not be running for a personal record time or to be the winner among women in my age group. I am running the marathon in memory of my mom, Jo Ann Dealing, who passed away this summer—only two months after being diagnosed with lung cancer that metastasized to the brain. I am not just running in memory of my mom. I am running for the thousands of people diagnosed with lung cancer every year and their loved ones. I am running for those currently fighting lung cancer, those who are survivors, and those who have passed away.

Silver Strand Half Marathon

Lisa Moore: I will run these 13.1 miles to show my support for all people affected by lung cancer—people with the disease, their families, and their friends. Last fall, my future mother-in-law was diagnosed with lung cancer. She had one of her lungs removed, underwent radiation and chemotherapy; she is now five months in remission. It was when I saw her strength that I realized I needed to do something to help others who are in similar situations. I was looking for a way to do so when I came across ALCASE. To me, this race is a chance to show my support and hope, while achieving a personal goal as well. It gives me a little push when the miles seem to be getting longer and it means that my push will help others with their struggle dealing with lung cancer.

News Lung Cancer

The Medicare Replacement Drug Demonstration Project

This program allows up to 50,000 people with Medicare, who have life-threatening diseases (such as lung cancer) to get the benefit of significant savings. Depending on income levels, patients could save between 58 percent and 98 percent from the cost of the pill Iressa (gefitinib). This project is unrelated to the Medicare drug discount cards.

There are still slots available. For more information, Medicare beneficiaries should call 1-866-563-5386. The Patient Advocate Foundation is also helping explain the program 1-800-532-5274.

For details online, see <http://www.cms.hhs.gov/researchers/demos/drugcoveredemo.asp>

Tarceva Access Trial Opens

Genentech, Inc. and OSI Pharmaceuticals, Inc. have begun a Phase IIIB clinical study, called the ACT (Access to Care, Tarceva) trial, with the pill erlotinib (Tarceva) in patients with non-small cell lung cancer for whom previous chemotherapy has failed. Designed to allow access to this investigational drug as the FDA considers its approval, the study will eventually enroll eligible patients at about 50 hospitals nationally. People who have already taken either Tarceva or gefitinib (Iressa) will not be eligible. Enrollment will continue until the FDA's approval decision. There will be no charge for Tarceva used in the study, which is intended to measure survival time and response rates. For details on enrollment, other costs, and site locations, call Genentech's Trial Information Support Line at 888-662-6728.

Odyssey of a Caregiver

Continued from Page 9

also did not want to have any regrets. We went and stayed right on the beach. When we first got to our room, she had me pull the sofa to the big sliding glass door and sat there and took in the view and said, "This is just like a dream." I am glad we took that trip.

The toughest part for me as a caregiver was that I wanted to do more, but did not know what to do. I kept calling different sources, to find a new drug or treatment. Cancer is a relentless foe and one has to try and stay one or two steps ahead of the disease. In Marilyn's case, we both knew that since the tumors were still in her body, her life would end sooner rather than later. We had started to run out of drugs and the last one she took, plus the disease itself, finally took its toll.

I knew she was getting weaker and eventually we had hospice come to the house. Marilyn had told me she wanted to stay at home, but if I could not handle it, she would go to a facility. I told her that when we married I made a vow to be with her "in sickness and in health", and I would always be with her.

I had round-the-clock nurses who communicated with the hospice nurses and Marilyn had wonderful care. I remember the words of the social worker, who said "We can help the person on their final journey, but they have to go through the 'door' themselves." I can tell you it was very painful to see her condition the last two weeks, but when she was awake she still smiled.

Farewell

I knew Marilyn had written what I call an "ethical will" in December 1999 to her kids, grandkids, and future grandkids, to be read at the time of her passing. When the rabbi came to us the night before the funeral, he asked our kids if they wanted to write something to be read at the funeral and they all said he could read her "ethical will." It was very sweet, powerful, and inspiring. She also wrote one to me. I suggest everybody should write an ethical will. Don't worry if you are not a writer. Just write what is in your heart. There are also books on ethical wills.

Since Marilyn's death I have done some volunteer work, continued my book reviews, started taking guitar lessons, and joined a grief group. I hope that someone will pick up something in this article that they can use. I know Marilyn would have wanted that. She did journaling and was always saying, "I need to reach more people." I hope I have through this writing. *Bill continues to be a Phone Buddy, especially for spouses.*



Marilyn with grandson Jake, about 1999

First Celebrity Golf Tournament

At press time, all 175 entry slots for the Mark Belanger Celebrity golf tournament, set for October 11th in Aberdeen Maryland, had been taken. Organized by Belanger's son Rob and Rob's friend Chris Federico, the tourney honors the memory of the Baltimore Orioles Hall of Fame shortstop, who died of lung cancer in 1998. This will be an annual outing and already has drawn significant media coverage and the participation of current and former professional ballplayers. Proceeds benefit ALCASE. See details about the tournament at <http://www.markbelangergolfclassic.org>.

First Annual George C. Nisbet Golf Classic

120 golfers and 80 more dinner guests attended the First Annual George C. Nisbet Golf Classic on September 4th, 2004 at Chevy Chase Country Club in Wheeling, Illinois. About \$40,000 was raised to support ALCASE's work.

After Mr. Nisbet ended his brave two and a half month battle with lung cancer last November, his family started the George C. Nisbet Foundation. They expect to receive their non-profit status approval soon. His daughter, Laurie Mitchell, says that the foundation created this golf classic in George's name because, "nothing could have been a more fitting tribute to him. He loved the game of golf. It would have been the perfect day to him... a beautiful day playing golf with family and friends. His hope was that he could help change a diagnosis that can be terminal into one that offers more hope for a healthy future and eventually a cure." The foundation will focus on fulfilling those goals.

Mike Mallare Golf Classic

This fourth annual event, held in July in Salem, Virginia, honored and celebrated the life of pediatrician Michael Mallare, of Roanoke. A health-conscious non-smoker, Dr. Mallare lost his life to lung cancer in 1999, at age 39. The two-day event featured a dinner, cocktail party and dance, a silent auction, golf tournament and family picnic. It was again a rousing success, with proceeds benefiting ALCASE. Many thanks to all, especially to Jennifer Mallare Turner and all of Mike's friends!

Three Walks and a Dance

At press time, Renee Kosiarek expected a great turnout for the 2nd Annual Lung Cancer Walk and Rally in Lisle, Illinois, November 6th. The event, which invites participants to help make "strides against lung cancer," features speakers, food and entertainment, and t-shirts. Renee, an attorney who's also a new mother, learned a lot from last year's Walk and she wrote a terrific "how to" guide for other volunteers who want to plan one. She's launched a website that includes other Walks: <http://www.lungcancerwalk.org>

Also November 6th, the Boardwalk at Virginia Beach, Virginia, is the start/finish line for the first annual Race for Breath, a 5K Run/Walk and 1 Mile Fun Run/Walk. Organizers Kelly Burke Jennings and Stacy Emanuel each lost their mother to lung cancer in the same year. They wanted to bring together others who care about people with lung cancer and want to "go public" with their concern.

November 14th, Virginians Erika Robinson and her mother Karen Jessup put together the 1st Annual Charlottesville Lung Cancer Awareness 5K Walk to raise awareness and public knowledge and support for lung cancer patients and their families.

Mary Kesilewski and her family lost two of Mary's brothers to lung cancer in the last three years. Dancing seemed a perfect way to "help people with lung cancer breathe a little easier". Their 1st Annual Dance for Lung Cancer is November 6th in Wallingford, Connecticut.

Thank you for making things happen and fundraising for ALCASE! We'll review these and other events in the next issue.

Success new support group



Don and Letty Laughery

Letty: "I TRY to keep Don from over-doing things, but oh well!" We just want other patients with lung cancer to realize there is ALWAYS hope!

Phone Buddies/Personal Support

Don and Letty Laughery are one of our Phone Buddy teams—a couple whose decision-making and strong mutual support can help other spouses who are facing lung cancer. Don was featured in our newsletter two issues ago. Now, he's completed treatment and his scans look good. He's out tending to his ranch chores but has also started the first lung cancer support group at Brooke Army Medical Center, at Fort Sam Houston in San Antonio, Texas. The group meets the first and third Friday of each month. It's free and open to lung cancer patients, their spouses and other relatives, and friends. For details, call Don at 830-639-4994 or cell: 830-832-1340

"I am so proud that we are able to do things like this," he says. Letty adds, "God has made a path for us to follow and we're on it, headed in the right direction!"

For other in-person lung cancer groups nationwide, see <http://www.alcase.org/support>

Caregiver Support

Odyssey of a Caregiver

By Bill Sonenshine

Odyssey: a long voyage or wandering, marked by many changes of fortune

You can't do anything about the length of your life, but you can do something about its width and depth. —Evan Esar

Read Bill's Picks

- *The Tibetan book of Living and Dying: The Spiritual Classic and International Bestseller*; Revised and Updated Edition By Sogyal Rinpoche, Patrick D. Gaffney, and Andrew Harvey Harper San Francisco; Reprint edition (April 22, 1994) ISBN: 0062508342
- *How to Go On Living When Someone You Love Dies* By Therese A. Rando, PhD Bantam; Reprint edition (July 1, 1991) ISBN: 0553352695

On May 12, 2004, my wife Marilyn died of inoperable lung cancer. We had been married for 43 years. At diagnosis, her prognosis was not very good — maybe one or possibly two years to survive. She lived for almost six and I began writing a journal that I called “Odyssey of a Caregiver.” Doing this helped me handle my anxiety. I want to say very strongly at the outset, what you are about to read is what my wife and I did, and if there is one thing I learned on this cancer journey, it’s that everybody looks at things differently. I decided to let ALCASE print some of my journal, in the hope that it might help other caregivers.

Changes

Sunday April 5, 1998, my daughter was married. Our family was full of joy and happiness. My wife Marilyn had helped plan the wedding and she was very happy. The next

Wednesday night a horrific tornado swept through our area, toppling 30 trees in our yard. Thankfully, they all fell parallel to our house. We suffered quite a bit of damage, but were only out of our house for a few days. Some people in the neighborhood lost their homes completely and had to rebuild.

But August of that year was the time that forever changed our lives. Since the tornado, Marilyn had a dry cough but she did not have a cold. She told the doctor and he gave her antihistamines, steroids, and finally antibiotics. Nothing seemed to help. Finally, she had a chest x-ray. When the doctor looked at the film, he saw there was fluid in her left lung, but could see nothing else. We then went to a lung specialist (pulmonologist), who drained the fluid. When the lab results came back, it showed that she had lung cancer cells in the fluid.

We were shocked. Marilyn took vitamins, ate a sensible diet, and exercised. She had never smoked, although her father had for many years. He died of cancer, but the doctors could never find the source. His two brothers were heavy smokers and both died of lung cancer.

Opinions

We saw an oncologist the next day, referred by one of Marilyn’s doctors. We did not know him. He was very clinical and unemotional and basically said, “I have looked at your x-rays and other test results and I recommend that you start chemotherapy next week. Any questions?”

You bet we had questions — but we did not know what to ask! In her mind, my wife had been given a death sentence.

We told him we wanted to get a second opinion. I called my internist and he gave me the name of an oncologist he said was excellent. We got an appointment with him and the first thing he said to us was, “I bet you feel just like a ship without a rudder.” I immediately liked him. He spent over an hour with us, using a flip chart to explain our options and what we could expect with the treatments. He said for us to fight this battle, we had to use all manner of healing: physical (drugs, diet, exercise), mental (relaxation tapes, massage) and spiritual.

Our doctor suggested getting another opinion from a group in Nashville, Tennessee, so that we would be sure in our minds of the treatment mode. I liked his thinking. We went to Nashville, where the doctor agreed with the diagnosis and treatment, although he did add one more drug to the protocol.

I know some people will defer to one doctor’s opinion. Everybody’s personality and circumstances are different. I personally feel when we put the entire burden on one doctor; we put too much responsibility on him or her.

No matter how good and empathic your doctor is, he or she cannot possibly know everything about all phases of cancer. What I am saying is that you have to be the CEO of your own body!

Stress Management

How did I continue to handle my anxiety about our situation? I started by doing a great deal of research on the Internet; with magazines, books, and articles; and by talking to people all over the country. Since my job with the state of Georgia for 27 years was in research, I decided to make cancer information a project.

A word of caution: on the Internet, it can be difficult at times to separate well from bad information. Also, you will see statistics about lung cancer survival, and these can be a source of anxiety. I always tried to run information by her doctor when I thought it was relevant. Sometimes he could help me and sometimes not, but I kept digging. At times we

Caregiver Support

could not get a definitive answer and we had to go by Marilyn’s and my gut feelings.

Initially, one mistake I made was telling Marilyn what she should do. My role, as it finally developed, was to give her the information and let her make own decision. If she asked, I would tell her my opinion, but I tried very hard to let her decide.

I also tried to lessen her stress level as much as I could. I took over activities like grocery shopping. She always liked Broadway show tunes, so when we were driving to chemotherapy, I put on music from *Carousel*, *Oklahoma*, or *My Fair Lady* and we sang together. It seemed to relax her. Before bed, we never put on the news (most of the time it was depressing). We’d put on videotapes of the old Johnny Carson shows, Groucho Marx, and Bud Abbott. We tried to go to sleep in a happy frame of mind.

I also tried to answer the telephone most of the time, acting as a screener. She was thankful for all of her calls, but some people wanted to know too much about her treatment and prognosis. People were always asking what they could do and I told them (besides bringing food), they could tell her a joke or something uplifting when they called.

Since I had retired from the state, I had time to take Marilyn to all of her doctor’s appointments. I know many people cannot do that, but I was blessed to have the time. One thing I did at every appointment was tape record the session. I did not take notes, but just listened. When I got home, I went over the tape and wrote down things I wanted to remember. Anyone can do this. Occasionally, someone asked me, what if the doctor had objected? My answer was, we would have gotten another doctor! None ever did.

Attitudes

Back to how I handled my stress. Those of us who are caregivers know that it is not easy. There are stresses on us just in living our everyday lives and sometimes there are situations in life that you cannot control. It is difficult not to worry about a spouse, but you cannot let cancer control your life. Since Marilyn and I had been married for 43 years, it was especially difficult for me, but I had been extremely blessed in that she had such a great attitude about life in general and that truly helped my attitude. Also, our three kids lived in the area and they were extremely supportive and concerned about their mother. Marilyn had many different protocols of treatments, countless tests, and she was stuck many times for blood tests — yet she kept on trucking.

Her tumors were inoperable. I knew she was frightened, but she rarely showed it. We both went to two different

support groups and to a psychologist who had seen many cancer patients. Some people do not want to go to support groups for many reasons and Marilyn and I both respected their decision. However, we got information and inspiration from the groups. Of course, some of the people died and it did make us sad, but the resiliency and courage of the human spirit came through loud and clear. We also shared good news with each other. I can also tell you that, whether you are a patient or a caregiver, there is instant bonding when you first walk into a support group. It is comforting to know that if you need to talk to someone, you can always call someone in the group who will understand.

Helping

It has been said that one way to forget your troubles is to help someone.

PhoneBuddy

- If you would like to speak with a Phone Buddy, or would like to volunteer to be a Phone Buddy, please call us today at 800.298.2436.

I like to read and I facilitate a monthly book club and also do a book review for an assisted living facility. The people at the facility appreciate it so much, and when I leave I feel wonderful.

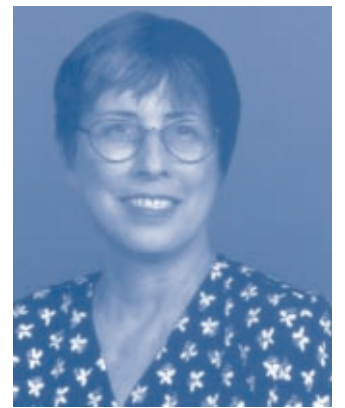
Early in Marilyn’s illness, we came into contact with ALCASE and became Phone Buddies with people all over the county. ALCASE gave people our telephone number and if they wished, they could call us. The

people talked to both of us and we had an instant bonding. We may have talked one day to a country gal in South Georgia and the next day somebody in Florida, New York or New Jersey.

I have read that Mother Teresa said most of us cannot do great things, but all of us can do small things with great love. That is what we tried to do everyday, by being kind to someone or helping somebody in some small way. The Phone Buddy program at ALCASE offered us a great opportunity to try to make someone feel better.

No regrets

We did not talk about death very much. For one thing, Marilyn said, “Whatever happens, will happen” and that she wanted to live life to the fullest. This year, in mid-February, she wanted to go to the beach because she felt that she would probably not see it again. I was very tired and I did not know how she would take the trip. She was in a wheelchair by this time. I really did not want to go, but I



Marilyn Sonenshine

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