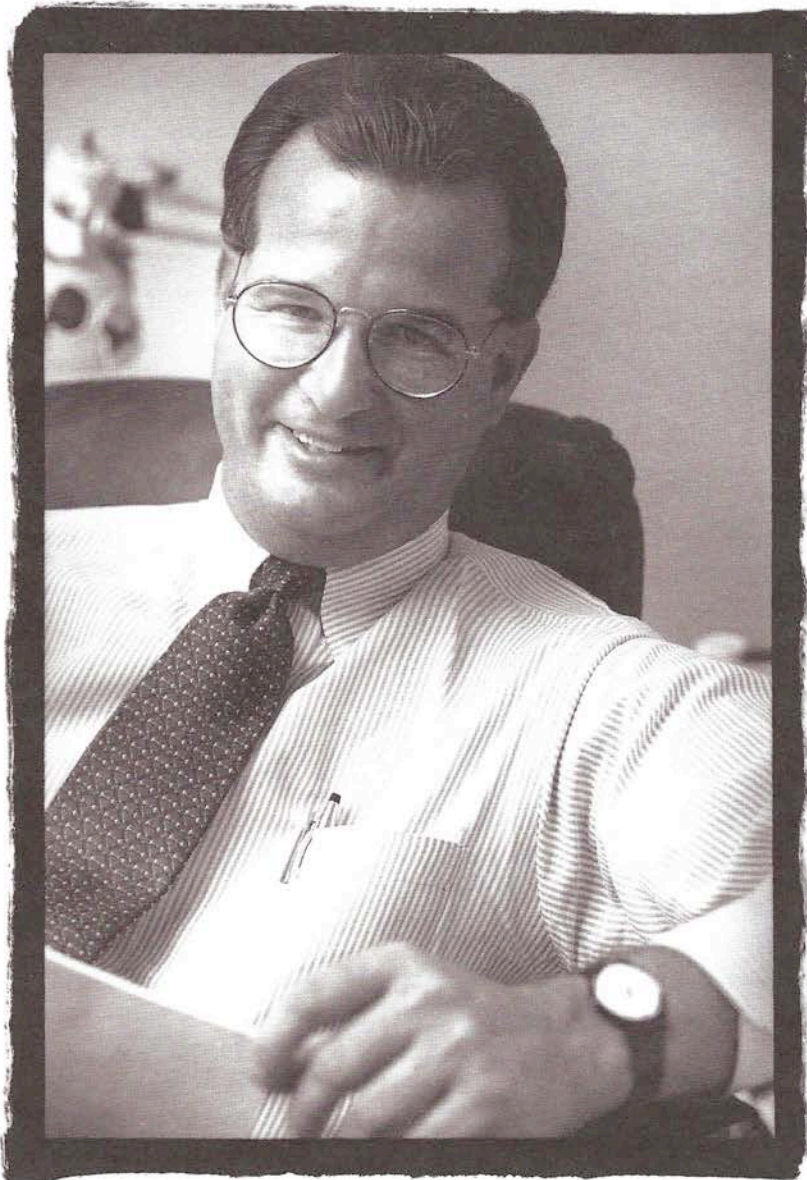


**The future is now**



MICHAEL MCGOVERN

James Zabora heads a program at Johns Hopkins that may point the way to the future of cancer treatment. And quality medical care is only the beginning of the story

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## About NCCS

*The National Coalition for Cancer Survivorship, a nonprofit organization, addresses the needs and interests of people with cancer, their families, healthcare professionals, and cancer organizations. Our core mission is to provide information and referral resources on the physiological, psychological, economic, and social impacts of cancer.*

*NCCS—the only national organization founded of, by, and for individuals with all types of cancer—advocates on issues affecting survivors at the national, state, and local levels.*

*Since our founding in 1986, NCCS has recognized the importance of providing a voice for people who have been diagnosed with cancer.*

*Our philosophy of “the veteran helping the rookie” is intrinsic to our belief that the wisdom of a person’s experience can contribute to responsible advocacy based on that experience. The dramatic growth of the survivorship movement over the past 10 years offers a vivid affirmation of that premise.*

*If you would like more information about NCCS, you can request a general information packet by calling 301/650-8868.*

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NCCS internet home page: <http://www.access.digex.net/~mkragen/cansearch.html>

## Coalition signs court briefing in medical-leave lawsuit

BY BARBARA HOFFMAN, JD

**NCCS** has joined a "friend of the court" brief (*amicus curiae*) filed by the Women's Legal Defense Fund in a lawsuit that may affect how the Family and Medical Leave Act (FMLA) will protect cancer survivors from employment discrimination. The case involves a woman who was denied coverage under the FMLA for medical leave to treat a peptic ulcer.

Kathleen Victorelli began working as a technician for Shadyside Hospital in June 1989. The following year, she started to suffer severe, recurrent stomach pain. In 1992, her doctor finally diagnosed the peptic ulcer. Although he prescribed medication, her ulcer continued to flare up. Victorelli was unable to work during days she experienced nausea, vomiting, and indigestion caused by the ulcer. Shadyside Hospital allowed employees only five sick days a year. The hospital fired her, claiming she had exceeded the allowable sick leave.

Victorelli sued her employer in federal court in Pennsylvania, alleging the hospital violated her right to medical leave under the FMLA. The FMLA requires employers with at least 50 workers to provide up to 12 weeks of unpaid medical leave for an employee with a "serious health condition." FMLA regulations include as a "serious health condition" any illness that requires continuing treatment by a "healthcare provider for a chronic or long-term health condition that is incurable or so serious that, if not treated, would likely result in a period of incapacity of more than three days."

On July 25, 1996, United States Magistrate Judge Kenneth Benson ruled that Victorelli was not covered by the FMLA. Because she missed only four days of work due to her ulcer, the magistrate said, her illness was not the kind of serious medical condition Congress intended the FMLA to cover. United States District Judge William L.

Standish adopted the magistrate's recommendations and granted summary judgment for the hospital. Victorelli appealed to the United States Court of Appeals for the Third Circuit, which will hear arguments in July.

The *amicus* brief says the magistrate erred in ruling that a health condition requiring only an occasional absence of a single day could not be a serious medical condition under the FMLA. The magistrate confused "short-term illnesses," which resolve in a few days, with "chronic illnesses," which may cause short-term absences on a recurring basis. The brief asserts Victorelli's ulcer is the type of chronic condition Congress explicitly intended to cover by the FMLA. As the Senate noted in its report, "the term 'serious health condition' is intended to cover conditions or illnesses affecting an employee's health to the extent that he or she must be absent from work on a recurring basis or for more than a few days."

The Third Circuit's decision in this case will help define how cancer survivors will be protected under the FMLA. Some cancer survivors, especially those with early stage disease, can continue to work with few interruptions in their work schedule. Other long-term survivors experience chronic health problems causing recurring, short-term absences.

Federal courts are currently struggling with how "disabled" a survivor must be from his or her cancer to be covered by the Americans with Disabilities Act (see *Networker*, Spring 1997, p. 3). Through this briefing, NCCS urges the Third Circuit to recognize that Congress explicitly intended the FMLA to protect people like Kathleen Victorelli, as well as cancer survivors at every stage of treatment, from irrational employment discrimination. ♦

*NCCS General Counsel Barbara Hoffman is editor of A Cancer Survivor's Almanac: Charting Your Journey (Chronimed Publishing, 1996) and co-editor of Cancer On Trial, both available from NCCS.*



Hoffman

### MEMO

*Cancer On Trial*, NCCS' new publication, is set for release the first week of August. Features summaries of recent court cases involving cancer-based discrimination. Cost: \$10. Write to the NCCS office or call 301/650-8868.

# NCCS' *Imperatives for Quality Cancer Care*: a key to the future of healthcare

BY DIANN K. AUSTIN, JD

Suppose you were asked to define the building blocks needed to achieve quality care for people with cancer. What would you include on your list? Preventive measures? Referrals to cancer specialists? Access to alternative therapies?

*NCCS believes that quality, not cost, should drive development of standards of care*

As you can imagine, your list could stretch on and on, especially if you tried to cover the

full sweep of the cancer experience, from diagnosis to long-term effects of treatment and beyond.

*Imperatives for Quality Cancer Care* offers such a "list," along with an action plan for turning the guidelines into reality. Cancer survivors, advocates, healthcare professionals, and other experts worked together to create the document, published by NCCS in 1996. It calls for access, advocacy, action, and accountability in three areas critical to the well-being of survivors:

- quality cancer care
- long-term and late effects of cancer treatment
- cancer's psychological and social impacts

Along with detailed recommendations for

## A melting-pot of ideas

To create the *Imperatives for Quality Cancer Care*, NCCS brought together cancer survivors, healthcare professionals, and other experts to write a series of briefing papers.

Their ideas were hammered together at the First National Congress on Cancer Survivorship, an historic gathering of the cancer community hosted by NCCS in November 1995.

At the Congress, delegates from across the country reviewed the papers, which focused on quality cancer care, long-term and late effects, and psychosocial needs. The papers offered recommendations in each of the three areas, and mapped out future research needs and strategies to improve the care experienced by survivors.

The Congress delegates worked in groups assigned to tackle one of the three main issues. Other invited guests met in a Leadership Forum to further define the dimensions of quality cancer care.

The delegates voted to adopt the "Declaration of Principles" at the closing session of the Congress. The declaration makes a concise statement of consensus based on the briefing papers and various working sessions of the Survivorship Congress.

NCCS will continue to build consensus to expand the broad-based principles into more-detailed guidelines for quality cancer care. After seeking ideas from survivors—who know firsthand what people with cancer need—NCCS will open the dialogue to the entire cancer community.

NCCS will present the resulting document to Congress as a challenge to attack cancer for what it is—the most serious public health crisis facing the nation. Watch the *Networker* for developments.

guidelines and future directions in each of these key areas, the document features a "Declaration of Principles" for quality cancer care. Those 12 principles fuel NCCS' challenge to the US healthcare system to maintain, and even strengthen, quality cancer care in a time of stormy change.

Some of the principles address the needs of the public at large. For example, NCCS believes that quality, not cost, should drive development of standards of care. The principles also declare a right to universal healthcare for all, regardless of preexisting conditions, genetic or other risk factors, or employment status.

Other principles, such as the vital importance of participating in clinical trials and obtaining timely referrals to specialists, voice the more specific needs of people with cancer and other serious illnesses. In particular, several principles stress the often overlooked areas of long-term care and psychosocial services.

What does any of this have to do with you? Whether you are a survivor, healthcare professional, or caregiver, the words of the final principle offer an answer:

*Cancer survivors, healthcare providers and other key constituency groups must work together to increase public awareness; educate consumers, professionals, and public policy makers; develop guidelines and disseminate information; advocate for increased research funding; and articulate for and promote survivors' rights.*

To help achieve this action step, over the next several months NCCS will work to refine the ideas expressed in the principles into concrete guidelines outlining quality cancer care. Goal: to provide survivors, policymakers, employers, healthcare providers, and other

## MEMO

To get a copy of NCCS' *Imperatives for Quality Cancer Care*, contact the NCCS office. Single copies are free. You can also find the full text on the Internet at CancerNet, the National Cancer Institute's site. Address:

<http://www.cancernet.nci.nih.gov>.

## If you are a survivor

As part of this campaign, NCCS calls on individual survivors to share your expertise. Tell us what quality cancer care means to you. Send us your suggestions and thoughts. We will integrate a survivors' consensus in a draft guideline. NCCS will circulate the draft to reviewers representing the entire cancer community so that the final version will reflect a variety of insights and opinions. Call 301/650-8868.

pivotal groups with a roadmap detailing the essentials of quality cancer care.

The need for this effort has never been greater. In Congress, legislators on both sides increasingly want to protect the quality of healthcare from erosion in the wake of efforts to control expenditures. Several pending bills would prescribe various standards of care. Meantime, advocacy and professional groups engage in intense debates on what constitutes

---

*In Congress, legislators on both sides increasingly want to protect the quality of healthcare from erosion in the wake of efforts to control expenditures*

appropriate care. And purchasers of healthcare and beneficiaries alike are reviewing their policies to ensure that they offer quality care.

No one can predict what will emerge from the national shakedown of the healthcare system. But NCCS' *Imperatives for Quality Care* offers a key to building the healthcare bridge to the 21st century. ♦

*Diann Austin helped coordinate NCCS' First National Congress on Cancer Survivorship in 1995. She is author of The NCCS Town Hall Meeting Guide: Empowerment Through Advocacy.*

## War on cancer a bust—not!

*The following letter, written by NCCS Executive Director Ellen Stovall, appeared in USA Today (June 2, 1997).*

**T**he study published by Dr. John Bailar in the *New England Journal of Medicine* questioning progress made in cancer treatment does a

*There is no magic bullet to cure cancer. But does this mean the nation's research efforts have failed? Not at all*

great disservice to the 8.1 million cancer survivors in the United States (“\$30 billion ‘War on Cancer’ a bust?” Cover Story, News, Thursday).

As a 25-year survivor of cancer who believes that cancer research has made a significant difference in her life, I think such an unbalanced view of the state of our efforts against cancer deserves comment.

There is no magic bullet to cure cancer. But does this mean the nation's research efforts have failed? Not at all.

Death rates—the subject of the recent study—have declined because of a combination of factors, treatment included, but they are not

the only indicators of success in cancer research.

In fact, progress made over the past 25 years is prolonging the lives of thousands, catching cancer early, when it's most treatable; improving quality of life by reducing pain, fatigue, infections and nausea; and making normal life expectancies a reality for many of the nation's cancer survivors.

Moreover, the introduction of new, more effective agents, recent discoveries about cancer genetics, and the development of entirely new technologies not even envisioned 10 years ago hold promise for patients in the years to come.

In addition, as a member of the National Cancer Advisory Board, I witness many potentially exciting opportunities for cancer research going unfunded, not because of merit but for lack of resources.

If we are failing to win enough battles in the “War on Cancer,” it is not because of too much funding for basic and clinical research, but rather because of not enough funding for all cancer research.

The war on cancer a \$30 billion bust? Survivors like me think otherwise. ♦

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Ellen Stovall chats with

Sen. Edward M. Kennedy (D-MA)

about his managed-care bill and

national cancer policy.



### NOTABLE QUOTABLE

#### How joining a support group can help

Cancer is isolating. It happens to *you*, even though *your* cancer affects the people around you almost as powerfully. And at the same time, it happens to a million and a quarter other people like you every year and to all of *their* families. Support groups have become a helpful way to bring people together to share their experience of a common life crisis. Even if you've never joined a group before, think about it now. It's a tool that can help and that you can put down when you've finished with it.

—Beverly Zakarian in *The Activist Cancer Patient* (see review, page 21)

## Survivors' radio show a natural channel for advocates

Last issue, the *Networker* featured a story on using talk radio as a cancer advocacy tool ("Speaking up on talk radio," pp. 10-11). One such tool seems perfectly suited for cancer advocates: "The Group Room," a nationally syndicated radio talk show devoted to cancer issues.

Selma Schimmel, founder and president of Vital Options, hosts the weekly program broadcast on Sundays. Schimmel, a 14-year breast-cancer survivor, is an NCCS advisory board member.

Schimmel brings together a variety of in-studio guests, including people in treatment, longterm survivors, family members, oncologists, and therapists. They explore a wide range of subjects with each other and with callers to the show.

"The Group Room" explores a balance of medical and emotional issues. So far, the program has examined such themes as what serious illness means, hope and fear, humor, and care for the caregiver. A show on 25th anniversary of the War on Cancer looked at the history of cancer research as well as what the future might hold.

Other shows have offered in-depth discussions on specific treatments such as taxol and tamoxifen, AIDS-related cancers, fatigue, and longterm survival. Forthcoming topics include genetics, employment and insurance, bone marrow transplants, and children and cancer. "The Group Room" broadcast programs on breast, lung, and prostate cancers, and Schimmel expects to do more shows on specific cancers.

Cancer advocates who wish to broadcast their organization's message can either call in to the show through a tollfree number or request to make an appearance in the studio. Call 800/GRP-ROOM (800/ 477-7666) on Sundays from 1-3pm Pacific time, 4-6pm Eastern time.

### MEMO

"The Group Room": For broadcast time and station nearest you call 818/ 508-5657.

### PROFILE

Selma Schimmel knows cancer too well. Her mother and grandmother died of cancer, and Schimmel herself was diagnosed with breast cancer at age 28. These experiences propelled her to devote her energy and attention to cancer survivorship, which she has done since 1984.

Her firsthand experience makes Schimmel the perfect host for "The Group Room," the nation's only nationally syndicated, live call-in radio show for people with cancer. She also serves as executive producer for the program, which offers a new avenue of communication for all persons concerned about cancer.

Schimmel's hectic schedule reflects her dedication to the survivorship movement. In addition to her radio work, she heads Vital Options, a support organization for young adults with cancer. She serves on several committees of California state Senator Hershel Rosenthal's advisory commission dealing with health, environmental, insurance, and other issues. At the UCLA School of Medicine, Schimmel works in a program designed to sensitize physicians-in-training to the human and emotional needs of patients.

Her efforts have gained wide recognition in the cancer community. Among her honors: the NCCS Catherine Logan Award for Service to Survivorship in 1993.

If you plan to be in the Los Angeles area, where the show originates, you can contact "The Group Room" producer to request an in-studio opportunity to participate. Use the tollfree number above or dial 818/508-5657. You can also write to Vital Options, PO Box 19233, Encino, CA 91416-9233.

"The Group Room" radio show offers cancer advocates a new avenue for voicing their messages, and for cancer survivors to get answers to pressing questions.



## Cancer fatigue: more than just plain tired

Everyone knows what it's like to feel occasionally exhausted. But for most people with cancer, exhaustion is a daily fact of life that can drag on for weeks or even months.

Cancer fatigue is the most common side effect of cancer treatment. According to a recent survey released by the Fatigue Coalition, cancer fatigue affects some 78 percent of persons throughout the course of their disease. Its effects cut into every aspect of ordinary life, making it difficult to perform such simple tasks as cooking, cleaning, taking a shower, making the bed—or even getting out of bed.

---

### *Cancer fatigue is the most common side effect of cancer treatment*

Such exhaustion can interfere with mental and emotional well being. Patients can have difficulty concentrating while reading or watching television. They may have trouble thinking clearly and making decisions, which can lead to feelings of frustration, helplessness, and depression.

Says cancer survivor Susan Scherr, a member of the Fatigue Coalition and NCCS director of community and strategic alliances: “Fatigue disrupts family and work schedules, negatively affects personal relationships, cre-

ates a sense of helplessness, and can lead to severe depression for many cancer survivors.”

“For many patients, fatigue is a daily reminder that they have cancer,” says Nicholas Vogelzang, MD. Dr. Vogelzang is professor of medicine at the University of Chicago and author of the Fatigue Coalition's survey. “If we can control or lessen the effects of cancer fatigue,” he says, “we can go a long way toward restoring a sense of normalcy to patients' lives.”

Perhaps most importantly, cancer fatigue can result in stalled treatment. It may limit the number of chemotherapy cycles a person can take, which in turn could limit the treatment's effectiveness.

In many cases, the known causes of cancer-related fatigue can be treated and possibly relieved, at least to some degree. Proper nutrition, vitamin and mineral supplements, antidepressant and anti-anxiety medication, and lifestyle changes can help alleviate fatigue.

Anemia can contribute to fatigue. Traditionally, oncologists have turned to blood transfusions to raise red blood cell levels and quickly restore energy. Trouble is, transfusions yield only temporary results, and doctors try to avoid them because of potential risks. Nowadays, medication for chemo-related anemia can increase red blood cells, reduce the need for transfusion, and possibly boost a person's ability to engage in everyday activities.

“Despite its prevalence and distressing consequences, cancer fatigue is one of the least understood symptoms of cancer,” says Russell Portenoy, MD. Dr. Portenoy, a member of the Fatigue Coalition, is with the department of neurology at Memorial Sloan-Kettering Cancer Center in New York City.

“It's not acceptable to tell patients that fatigue is just something they have to live with,” says Dr. Portenoy. “We need to create greater awareness about cancer-related fatigue and develop approaches for assessing and treating it. For some patients, treating fatigue

### The Fatigue Coalition

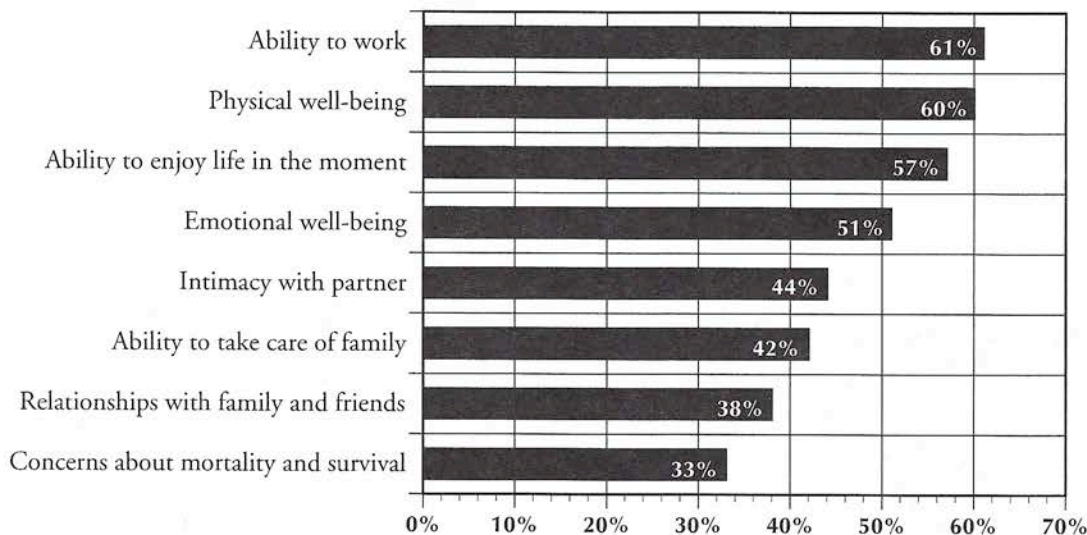
The Fatigue Coalition seeks to promote greater understanding of fatigue in the hope of improving the everyday life of cancer and AIDS patients and their families. Coalition members include medical practitioners, researchers, and NCCS.

Established in 1996, the group will develop a series of educational projects over the next several years to demonstrate the importance of diagnosing and treating debilitating fatigue and to develop successful ways to treat it.

The coalition's survey on fatigue involved 419 people in cancer treatment, 197 oncologists, and 200 caregivers (family members and friends). To receive a copy of the survey, call 908/ 218-6090.



## Impact of fatigue among cancer patients



Cancer fatigue's adverse affects on significant aspects of patients' daily lives

Base: 419 cancer patients. Source: Ortho Biotech Inc.

may be as important as treating the disease.”

While increasing numbers of medical professionals recognize the need for treating cancer pain, researchers are only beginning to study cancer fatigue. To compound the problem, doctors and patients do not communicate well about fatigue.

According to the Fatigue Coalition's survey, nearly one-third of patients claim they men-

tion fatigue on every visit to their doctor. But only six percent of doctors believe it is mentioned that often.

Improved doctor-patient communication, then, is a key piece to the cancer fatigue puzzle. That, and further research and greater awareness, may well yield better treatments that improve the lives—and health—of people with cancer. ♦

## Coping with cancer fatigue

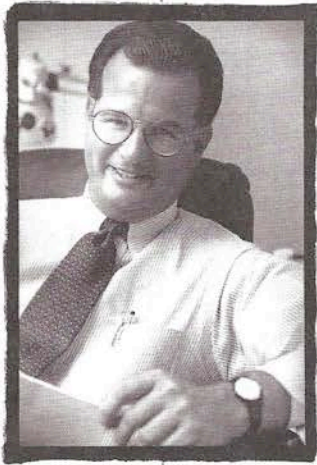
Coping with cancer fatigue may require some self advocacy on your part. Here are some steps you could take:

- Describe your fatigue to your doctor or another healthcare professional. Ask about ways to relieve the symptoms, such as prescription medicines and vitamin and mineral supplements.
- Keep a daily diary of fatigue symptoms. Note when your energy is at its highest and lowest. Watch for trends.
- Plan activities to coincide with times when your energy is highest. Allow time to rest between activities. Short naps and breaks may prove more effective than long rest periods.
- Take short walks and exercise lightly.
- Eat small meals and snacks throughout the day instead of large meals. A nutritionist can help you plan appetizing, nourishing munchies.
- Join a support group. Other survivors can sometimes offer good tips, based on their own experience, that could prove helpful.

# Innovative program at Johns Hopkins sets standard for quality cancer care

BY BETSY CLARK, PhD

In the *Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability*, published by NCCS in 1996, cancer survivors and healthcare professionals challenged the US healthcare system to provide, promote, and protect psychosocial services for persons with cancer. Such services would include adequate insurance, treatment for depression, counseling and education, and training in self advocacy.



MICHAEL MCGOVERN

James Zabora directs Hopkins' innovative cancer care program, which mixes psychological and social interventions with medical care.

They further argued that "psychosocial services that should be provided for every person must emphasize continuity, comprehensiveness, and a multidisciplinary approach."

Yet today's changing healthcare world often views psychosocial care as a luxury, not a need. At first glance, psychosocial services make a tempting target for cost cutters. But an innovative program in Baltimore offering a wide range of services to cancer survivors is demonstrating long-term cost effectiveness as well.

Zabora, LCSW, heads the program.

Any member of the healthcare team can refer a patient or a family member for psychosocial services. A screening process also helps clinicians there to identify enrollees who may need psychological support to cope with cancer.

What sets Hopkins apart from most cancer centers and community hospitals? In a nutshell, the staff does not wait for crises to explode. Instead, they take action to prevent them.

A cancer diagnosis triggers a personal crisis for almost anyone involved, including the person's family. In fact, studies show that 20 to 30 percent of persons newly diagnosed or with recurrent cancer experience significantly heightened levels of emotional distress and could benefit from therapy.

Despite these findings, many cancer survivors do not receive psychosocial services except in severe cases. Those who are referred for services are usually persons with problems so blatant that even the least experienced member of the healthcare team can recognize the need for intervention.

At Johns Hopkins, it's a different story. Specialists there seek to identify psychologically distressed individuals as soon as possible after diagnosis to match them with suitable services. So far, clinicians at Hopkins have collected over 7,000 psychological profiles of persons in cancer therapy through a screening instrument called the Brief Symptom Inventory (BSI).

## MEMO

For more information about the Johns Hopkins Oncology Center, contact James Zabora, LCSW, at the Department of Patient and Family Services, 600 North Wolfe Street, Baltimore, MD 21287. Phone: 410/ 955-5670.

*A cancer diagnosis triggers a personal crisis for almost anyone involved, including the person's family*

The Johns Hopkins Oncology Center has shown that psychosocial care should play a key role in all cancer programs, including those covered by managed care. Hopkins established its department of patient and family services in 1985 to network diverse supportive services for cancer survivors and their families. James R.

Hopkins' staff uses the BSI to rate patients' levels of vulnerability by low, moderate, or high distress.

Patients then receive referrals based on their distress level. A cancer survivor with a low distress level may benefit from educational seminars or a peer support program. Others with a high level of distress on the BSI may do better with psychotherapy or family therapy.

Zabora is quick to point out the need for using a reliable and well-founded screening instrument. He insists measures must come from patient-generated data, not from a panel of healthcare professionals. He stresses the importance repeating the assessments at critical points across the disease continuum.

Zabora and his program go one step further, a step many cancer advocates applaud: they view the patient and the family together as the unit of care.

When family caregiving is prolonged, difficulties may develop late in treatment. The family as a whole may become worn down, depressed, or less functional than at the beginning of treatment. They may need professional help to avoid or relieve family burnout.

Hopkins stands out for the scope of their services and their success in attracting interest from managed care organizations.

The department of patient and family services is a hub of six programs geared toward cancer survivors. Services include:

- oncology social work counseling and discharge planning
- residential living
- psychosocial research
- volunteer services
- career counseling center
- community services program

Elsewhere at Hopkins, the center has created two new programs in the department of oncology social work, headed by Matthew Loscalzo, MSW. The first is a cancer survivors' program. The other is a palliative care program for persons in a terminal stage of illness. These services span the continuum of cancer care and offer interventions specific to the timelines of the disease.

Finally, Hopkins has gathered some impressive data demonstrating that early psychosocial care for persons with cancer can reduce costs over time. Evidence in other disease populations—particularly coronary artery disease—shows that untreated psychological distress increases overall healthcare costs, resulting in poorer health outcomes and lower levels of patient satisfaction. Based on Hopkins' preliminary data, Zabora contends initial investments in proactive care should net cost reduction later. The key, he says, is proactive, not reactive, intervention for survivors' overall health needs.

Cancer survivors also can take the initiative

---

## *Hopkins has gathered some impressive data demonstrating that early psychosocial care for persons with cancer can reduce costs over time*

by demanding adequate support services. Ask your physician—or any member of your healthcare team—for a referral. Or make the call yourself. Talk to your employer and insurance carrier about what types of psychosocial services they offer, or should offer, to you and your family. Don't be afraid to speak out publicly about needed improvements. Not all cancer survivors need psychosocial intervention, but they deserve the option. ♦

*NCCS President Betsy Clark is author of You Have the Right to Be Hopeful, an NCCS publication.*

### **SURVIVOR-LINK**

Marty Lester seeks contact with men with early stage rectal cancer or prostate cancer who have experienced total radiation of the pelvis. Call 212/ 674-8959. Or write: Marty Lester, 274 1st Avenue #7E, New York, NY 10009.

# Coping with cancer in the family: Can we talk?

BY BETSY CLARK, PhD

*This article is adapted from "Family Challenges: Communication, Hope, and Loss," in A Cancer Survivor's Almanac: Charting Your Journey (Chronimed Publishing). Copyright © 1996, all rights reserved.*

**T**he following suggestions can help you sidestep some of the barriers to family communication:

**Try to put cancer in perspective**—Family members need to recognize that cancer is a disease like any other disease. It can be cured, it can be treated, it can be controlled, and it can be managed. Do not let the negative myths and fears about cancer impede communication.

Both the cancer survivor and family members need accurate and honest information about the illness and the treatment course.

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*Knowledge can increase personal control and can help minimize a sense of helplessness on the part of all family members*

Knowledge can increase personal control and can help minimize a sense of helplessness on the part of all family members. Family discussions about the type and extent of treatments and about expected side effects and changes in appearance are useful. Family members should discuss openly within the family worrisome things that they hear from their friends or colleagues. Troublesome comments and questions about suggested miracle therapies, for example, can be brought to your healthcare team for clarification.

Educational materials to help your family understand cancer and its treatment are avail-

able from your hospital, your physician, your oncology nurse, or your social worker.

Booklets related to specific types of cancer can be obtained free of charge from the local unit of the American Cancer Society at 800/227-2345 and from the National Cancer Institute at 800/4-CANCER. Excellent educational resources have been written for younger age groups. Two recommended resources for children include *It Helps to Have Friends When Mom or Dad Has Cancer* from the American Cancer Society; and *When Someone in Your Family Has Cancer*, available from the National Cancer Institute (NIH publication no. 94-2685).

**Discuss needed changes in family roles and activities**—Will a vacation or family event need to be delayed or canceled? Will the cancer survivor need to be absent from work for a period of time, and if so, will this have an impact on family finances? What will remain the same—for example, your love for one another, honesty with each other, valuing family time, and continuing special activities? How will family chores and responsibilities be distributed during the treatment process? Who will be available to help with transportation, shopping, meal preparation, and homework?

The shifting of responsibilities for household tasks, managing family finances, and providing care for the cancer survivor or for children creates stress. Family members can feel overworked, unappreciated, or left out. Discussing these changes and related feelings in an open manner, and being accepting of anger, disappointment, and differences, can go a long way toward stabilizing the situation and helping the family to adapt to the crisis.

Even if a loved one is extremely ill, try not to exclude him or her from the family decision-making process. While some role shifting may need to occur due to the illness, all family members, including the cancer survivor, need to feel that they are a respected and valued part of the family.

## MEMO

Get your copy of NCCS' *A Cancer Survivor's Almanac: Charting Your Journey*. Just use the insert to order. Or call NCCS at 301/650-8868.

Determine what is acceptable to discuss with friends and extended family members about the cancer survivor and the illness—Many friends and neighbors will be curious about the illness and prognosis. Most will ask questions because they want to offer assistance and support. Some people, however, are simply interested in gossip. Keep in mind that the cancer survivor has a right to privacy and that you are not obligated to discuss the situation. It is useful to go over some of the myths about cancer and to help family members form responses to difficult questions that might be posed by others.

**Seek out additional educational resources for the family**—Classes like the American Cancer Society's "I Can Cope" and group meetings can provide education and support to meet the challenges of cancer. Mutual support and self-help groups and special programs designed to help individuals and families cope with family changes and problem solving are readily available in most communities. Let the cancer survivor and other family members know if you are planning to attend a support group or a cancer-related education program. Keeping attendance a secret will not foster family communication. ♦

## Clinical trials: breast cancer

The National Cancer Institute recently opened two clinical trials involving cell transplantation to people with breast cancer.

One study aims to augment T-cell recovery and anti-tumor T-cell responses following chemotherapy to eradicate minimal residual disease. Eligibility: 1) Stage II (5+ nodes), stage III, or stage IV breast cancer; 2) harvest of T-cells before first chemotherapy cycle. Patients can receive chemotherapy treatments from referring physician or at NCI; most standard chemotherapy regimens are sufficient.

The other study involves treatment of metastatic breast cancer. Eligibility: 1) stage III or stage IV breast cancer; 2) those with stage III disease can enroll either before or after other adjuvant therapies; 3) those with stage IV disease are eligible either untreated or treated (with partial response).

*For details, call Daniel Fowler, MD, of NCI, at 301/402-3627.*

## Family checklist

**Are you pressuring the person with cancer to—**

- stop talking about his health because it is morbid?
- stop feeling sorry for himself?
- prove that he is feeling great even when he is not?

**Instead help by—**

- letting him talk about his problems and finding positive topics to talk about
- keeping his interest up about home, work, and world affairs
- being sympathetic but emphasizing the good things about life
- not pressuring him to be a cheerleader for you to keep up your spirits
- letting him level with you about his feelings

*From Morra and Potts, Triumph: Getting Back to Normal When You Have Cancer, 1990: p. 211.*

## ALCASE: Leading the charge against lung cancer

BY SONJA TYLER

Many people believe breast and prostate cancers are the leading causes of cancer-related death among American women and men, respectively.

The facts would surprise them: Lung cancer will kill 94,000 men this year, while prostate cancer will claim just under 42,000. Among women this year, 66,000 will die from lung cancer, compared with 44,000 deaths from breast cancer.

Despite these stark facts, lung cancer has not captured America's public awareness. The Alliance for Lung Cancer Advocacy, Support, & Education (ALCASE) hopes to change that.

ALCASE, founded in 1994 (as Spirit & Breath), educates people about lung cancer and the psychological and social issues facing lung cancer survivors. Among the services:

- *Spirit & Breath: A Newsletter for People Living with Lung Cancer*

- Phone Buddies: A peer-to-peer support program for lung cancer survivors
- Customized information searches based on the needs of the caller, using medical databases and the Internet
- Topic-specific phone support groups, held as issues arise
- Resource and referral list of organizations, videos, and booklets dealing with lung cancer

On November 14, ALCASE will observe the first National Lung Cancer Awareness Day. The occasion commemorates those who lost their lives to lung cancer and acknowledges people living with the disease.

For more information, call: (360) 696-2436. Or visit their web page at: <http://www.teleport.com/~alcase>. Or write: ALCASE, 1601 Lincoln Ave, Vancouver, WA 98660. ♦



## Hope & Cope: Peer support flowers in Montreal

One cancer survivor's vision formed a seed that bloomed into Hope & Cope, a flourishing cancer support system in Montreal, Quebec.

Cancer survivor Sheila Kussner founded Hope & Cope in 1981. Kussner experienced an intimidating sense of aloneness that many survivors encounter in treatment. She sensed that cancer survivors could play a vital role in ending that anxiety and isolation.

Over 120 volunteers (about a third are cancer survivors) pitch in to carry out programs, guided by one volunteer executive and three paid staff.

Hope & Cope seeks to:

- provide a structure of voluntary support services not otherwise offered by the medical

care system provide a framework within which volunteers are recruited, trained, supervised, educated, and recognized for their work

- educate the community and healthcare professionals on the psychosocial impacts of cancer
- promote the value of oncology volunteer programs through research and critical evaluation

"The key to our success is that we are hospital-based," says founding member Jessica Miller. "That makes Hope & Cope highly visible and easy to access by patients in the oncology clinics."

Volunteers work in teams. Each team

*continued on back cover*

# Principal gives students a living profile in courage

BY ANITA BAUMANN

Rarely is it a milestone for a principal to attend the commencement of a high school's graduating class. Rarely does the language of graduation—inspirational words on acting with courage and conquering fears—truly resonate in students' hearts. And rarely do students see before them on the podium an honest-to-goodness hero.

But such was the case at the James Madison High School commencement in May 1996, when principal Robert F. Clark, Ph.D., battling a recurrence of melanoma, saw his senior class for the first time in three months. Students, parents, and guests, stirred by his presence, greeted Clark with an emotional standing ovation.

Though he had the strength for only a brief visit, his words—and the moment—will long live in the memories of the young graduates he addressed.

"I told them that they have to have a hero—someone who has been there and overcome adversity," he says.

Robert Clark knows adversity well. His cancer has recurred several times since its diagnosis 11 years ago. His last bout in 1996 required both radiation and chemotherapy. The chemo took its toll, forcing him to take a leave of absence from his duties at the Vienna, VA, school.

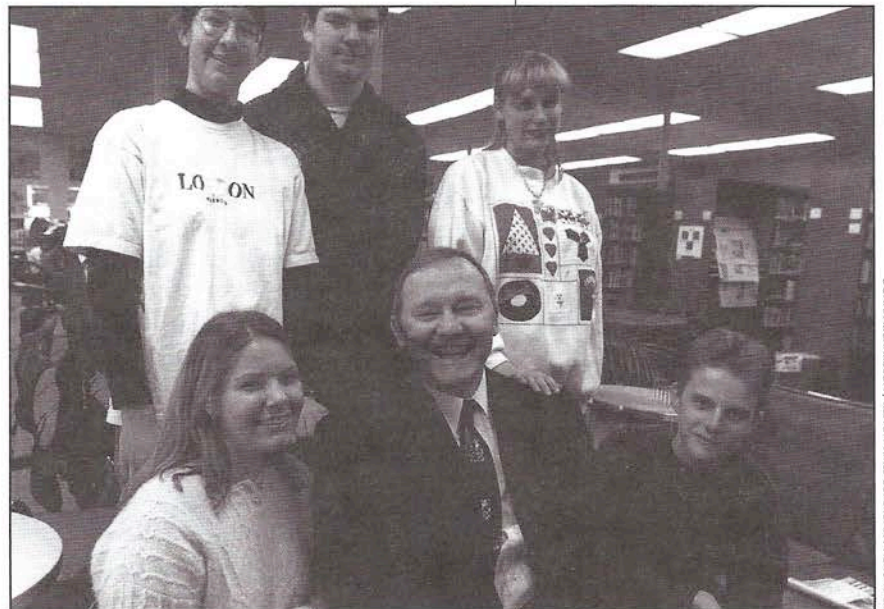
His secretary, Barbara Stinson, witnessed the impact of his departure on the school community.

"The students were devastated, especially the seniors, and would ask about him daily," she says. "Teachers allowed the students to make cards for him—sometimes big, poster-sized cards—and students also brought in their own." Each week students filled a basket outside the office with cards and gifts, which were delivered to Clark twice weekly.

Stinson says the students missed him because they knew him. Since Clark regularly attended extracurricular activities and sports events, his absence was noticeable and painful.

"The students found that giving cards and gifts was a way for them to express their own sadness and concern," says Stinson. "I think it did the students as much good as it did Dr. Clark."

Unlike many survivors, Clark not only had a work environment full of supportive people but also employers who were willing to make the accommodations necessary for his recovery. After 27 years as a teacher and administrator in the Fairfax County school system, Clark was a valued employee. When Clark couldn't work from February to July 1996, the county hired a retired principal to step in until Clark's return.



DONNA RICHARDSON / RESTON TIMES COMMUNITY NEWSPAPER

Clark's wife Edna has been an anchor for him and his two daughters during his long journey with cancer. "She has been my strength," he says. "She never accepted the thought that we couldn't get better." He says his daughters, who were 13 and 9 when he was diagnosed, have gradually learned to accept their father's struggles as a part of their life.

Clark shares his wife's optimism, but cautiously. "Cancer is something that never leaves my mind," he says. "I guess I'd say that I've learned to coexist with it."

Clark says he tends to not want to make long-term plans. Still, he says, "I force myself

*continued on back cover*

Principal Clark, surrounded by students: "They have to have a hero—someone who has been there and overcome adversity."

## Landmark video summit touts lung-cancer research advances, clinical trials

BY SANDRA FOX

**T**he first national videoconference on lung cancer, broadcast May 8, offered updates on advancements in detection and treatment and urged lung cancer survivors to seek the best treatment available, especially clinical trials.

Hospitals, cancer centers, and medical schools picked up the satellite link from the National Institutes of Health to show to a live audience of healthcare providers, advocates, survivors, and their families in 16 cities.

In panel discussions, medical experts and cancer advocates swapped ideas on prevention, research, quality of care, clinical trials, and quality of life issues. Panelists included cancer survivor Ellen Stovall, executive director of NCCS; Richard Klausner, MD, director of the National Cancer Institute; Diane Blum of Cancer Care, Inc.; and many others. ABC TV's Jackie Judd moderated the discussions.

### Who is at risk?

Panelists agreed smoking remains the no. 1 risk factor for lung cancer. Cigarette advertising targets children, minorities, and women, putting those groups at increased risk of addiction and lung cancer. In 1996, lung cancer among women increased 4.6 %, and 3,000 nonsmoking women married to smokers died of lung cancer.

African-American males suffer an alarmingly high death rate from lung cancer, much higher than that for white males. Higher smoking rates or biogenetic factors may be responsible. Two panelists asserted that fewer and later referrals to effective treatment might be to blame, perhaps stemming from social and economic obstacles to healthcare access.

### Treatment advances

Lung cancer has a long developmental phase, so current research focuses on developing ways to diagnose and treat it earlier. Identifying precancerous cells in the lungs offers promise, as

do aerosol drug treatments applied directly into the airways.

The survival rate for advanced lung cancer would increase if patients received the full treatments now available. Relatively few people with lung cancer undergo advanced or comprehensive treatment or participate in clinical trials.

### Quality of care

Oncologists on the panel urged people with lung cancer to ask for the most advanced treatments available. General practitioners, they noted, lack the advantages of a cancer center—such as advanced technology, greater expertise using a variety of medical techniques, and better tracking of lung cancer stages. For the best surgical care, the panel suggested choosing a thoracic surgeon who specializes in lung cancer and has with experience in the appropriate procedure.

### Clinical trials

Panelists stressed that clinical trials offer the best known treatment to people with cancer. Many patients fear they will get poor care if they do not receive the new treatment. But these studies test the most effective, clinically proven treatment against a new treatment considered equal or better.

The first step in learning more about clinical trials is to ask your oncologist. Another excellent source is the National Cancer Institute's (NCI) Cancer Information Service. NCI offers a free booklet describing the different kinds of clinical trials and how to decide if clinical trials are right for you. Call 1-800-4-CANCER, a tollfree number.

### MEMO

ALCASE provides information and support for lung cancer survivors. See page 14.



### Quality of life

Survivors in the audience emphasized that it was important for them to:

- find and use psychological and informational support systems, including community services, family and friends
- build a relationship of trust, confidence and care with their doctor of choice
- learn how to gain and nourish hope and a positive attitude toward the challenges and transitions of cancer

NCCS' Ellen Stovall wrapped up the event. She said, "I was struck by the observation that there are better treatments now for

lung cancer, but so few people taking advantage of them. We have to get the word out about that. We have to give people hope."

"The message should be 'hope', she added. "Not 'cure', and not 'death,' but 'hope.' Cancer is about hope. With the communication we've had today comes understanding. With understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything is possible."

NCCS, Cancer Care, the Cancer Research Foundation of America, and the Alliance for Lung Cancer Advocacy, Support and Education sponsored the videoconference. ♦

*Sandra Fox recently joined the NCCS staff as administrative assistant.*

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## Conference warns of barriers blocking people from care

BY BRAD ZEBRACK, MSW, MPH

**D**r. Elmer Huerta will never forget the Russian woman who once visited his clinic.

The woman spoke no English. She had brought her 12-year-old granddaughter along to translate. As the three people struggled to communicate, a light went on in Dr. Huerta's head. He suddenly realized what a relief his Spanish-speaking patients must feel to have a doctor who speaks their own language.

Dr. Huerta, vice chair of the recent biennial Symposium on Minorities, the Medically Underserved, and Cancer, shared his story at that conference to illustrate a powerful point: language and cultural barriers often stand between people and the treatment they need.

Unfortunately, most minority and low income patients and those for whom English is not their primary language, do not have a Dr. Huerta to turn to. They would benefit from seeing a doctor who shares their social and cultural background, or at least understands the cultural differences they bring to the clinic.

Cultural barriers make a tough problem tougher: namely, the lopsided incidence and

cancer death rates among minorities and persons of low income in the US. For these reasons the symposium stressed the urgent need to:

- exchange the latest scientific and treatment information and strategies for reducing the alarmingly high rates of cancer and cancer death among minorities and the medically underserved
- enhance the competency of healthcare providers, laypersons and survivors in the areas of primary and secondary cancer prevention, early detection, and treatment
- promote culturally competent cancer care and services and ethnically balanced research, especially clinical trials

A constant theme ran through the symposium: solutions to problems in communities lie within those communities. Plenary and workshop presenters described how their efforts at local, regional and national levels have resulted in new ways to deliver cancer treatment, research, and prevention activities at the local level.

However, those presenters also detailed such problems as lack of funding, community distrust

*continued on next page*

of institutions seen as insensitive or ignorant of local cultural practices, and outright fear of cancer. All serve as barriers in attempts to bridge the gap between local people and services.

The symposium explored the role of diet, nutrition, and fitness in health promotion; the relationship of the environment to cancer; and minority access to cancer screening and clinical trials. But speakers representing government, medical institutions, community health centers, social service agencies, and cancer survivors acknowledged the social and cultural barriers remaining.

Disparaging remarks made by insensitive care providers can cause members of minority groups to delay or refuse care. Environmental hazards continue to threaten entire populations in the backyards of this country's poorest communities. And, speakers warned, until valid and reliable scientific data on minority populations are collected, analyzed and translated into direct service and care, cancer will continue to ravage minorities and low income persons. ♦

*Cancer survivor Brad Zebrack, an NCCS board member, lives in Ann Arbor, MI.*

## In Spanish / En Español

### Coming soon: "Teamwork" in Spanish

In August, NCCS will publish a Spanish translation of its most popular publication, "Teamwork: The Cancer Patient's Guide to Talking With Your Doctor."

Maria Elena Leighton, working with the University of Texas M.D. Anderson Cancer Center, translated the text for "Trabajo en Equipo: Hablando con su Medico. Guia Para el Paciente con Cancer."

Like its English cousin, "Trabajo en Equipo" offers practical tips on:

- what your doctor should know about you
- what doctors wish their patients knew
- understanding (and remembering) what the doctor says
- key questions to ask
- resources

Publication of "Trabajo en equipo" is made possible by an educational grant from Lilly Oncology. Watch the *Networker* for publication date!

### Viene pronto: "Trabajo en Equipo"

En Agosto, NCCS publicará la traducción española de su publicación más popular, "Trabajo en Equipo: Hablando con su Médico. Guía para el Paciente con Cáncer."

Maria Elena Leighton, quien trabaja en El Centro del Cancer MD Anderson de la Universidad de Tejas, tradujo el texto de "Trabajo en Equipo: Hablando con su Médico. Guía Para el Paciente con Cáncer."

Como versión Inglesa, "Trabajo en Equipo" ofrece consejos prácticos acerca de:

- lo que su medico debe saber sobre usted
- lo que los doctores quisieran que sus pacientes supieran
- entendiendo (y recordando) lo que el doctor dice
- preguntas claves para hacer
- recursos

La publicación de "Trabajo en Equipo" es posible por medio de una beca educacional de Lilly Oncology. Lea el *Networker* para enterarse de la fecha de publicación!

—translated by Belinda South

## Actor Robert Urich to keynote Anderson Network's conference

Famed TV actor and cancer survivor Robert Urich will keynote MD Anderson Network's ninth annual assembly, which runs Sept. 5-6 at the Doubletree Hotel at Post Oak in Houston.

Urich, who recently completed chemotherapy treatment for a rare soft tissue carcinoma, will share his cancer story and coping strategies. The veteran actor has starred in several television series, including "Vegas," "Spencer for Hire," "S.W.A.T.," and "Soap," and in TV movies and feature films. On April 7 he appeared on "Larry King Live" cable TV show with NCCS Executive Director Ellen Stovall to call for increased funding for cancer research.

Speakers, panel discussions, and workshops will explore a wide range of survivorship issues. Judy Gerner, Anderson Network's administrative director, will open the event with an address on "The Power of Hope." Deforia Lane, PhD, will explore "Music and Medicine," a look at the effects of music on the mind, body, and spirit.

### Attention assembly lovers

Since NCCS is not holding an assembly this year, members may want to consider attending the MD Anderson event. A number of NCCS members will attend. Anderson's meeting is similar in format and scope to typical NCCS assemblies. It's an opportunity to see old friends, make new ones, and get that special feeling that comes with hanging out with fellow survivors, caregivers, and friends. Remember, the number to call for more information is 800/ 345-6324.

Workshop topics include pain management, guided imagery, cancer and the Internet, genetics, nutrition, caregiving issues, and much more.

The event also features a book fair and book signing, gala banquet, and a "Celebration of Life" birthday party. Cost: \$50 (includes all activities and meals). For more information call: 800/ 345-6324. ♦

The National Cancer Institute (NCI) is calling for nominations for a new initiative: the Director's Consumer Liaison Group.

### NCI seeks nominees for advocacy group

The new group will help NCI increase representation of the cancer advocacy community on NCI advisory committees. It will also ensure wider involvement in NCI programs and policy development.

NCI will select 15 persons who reflect the diversity among those whose lives are affected by cancer. The panel will work directly with the scientific community at NCI on a wide range of programs and issues.

Organizations (local, regional, or national) or individuals may submit nominations. To receive a nomination package, send your name, organization (if any), and address to:

Office of Liaison Activities  
NCI c/o Palladian Partners  
7315 Wisconsin Avenue, Suite 440W  
Bethesda, MD 20814

Or fax your request to 301/ 986-5047. Nominations must be postmarked by September 15, 1997.



## From victim to activist

*The Activist Cancer Patient* by Beverly Zakarian. New York: John Wiley & Sons, Inc., 1996. 225 pp, \$14.95 (pb); \$20.95 Canada.

REVIEWED BY HOLLY A. COLLETT, MS

In 1985 Beverly Zakarian was diagnosed with ovarian cancer. She became an activist first in her own treatment and later in thousands of others as cofounder of CAN ACT. In *The Activist Cancer Patient*, she has written an inspirational book that serves as a step-by-step guide in moving individuals from patient status to active participants in the public arena. The book contains invaluable information about clinical trials, including the origin of new treatments. While strongly acknowledging that clinical trials are not perfect, Zakarian advocates the position that failing to conduct trials clearly deprives society of knowledge that could benefit the next generation of patients. Also included for discussion are treatment, consent, and ethical issues.

Zakarian suggests that patients become activists at the time of diagnosis and, as survivors, take charge of their treatment. Her concept of "empowerment" is clearly illustrated when she defines activists as individuals who speak for themselves in a more direct manner. Taking charge requires researching treatment options and choices, including clinical trials. Cancer Survivors also need to acquire skills for speaking intelligently with their physicians and making informed decisions.

She further encourages people living with a diagnosis of cancer to "see activism as more than taking charge of your own treatment. It means actively taking charge of your life. Killing cancer cells is only part of restoring yourself to health. You have to go after what you need in other parts of your life with the same determination."

Zakarian defines "The Empowered Patient" as one who desires to effect change for themselves and others. "The Empowered Patient" has three agendas. The first is a personal agenda, described as the most intimate and urgent, that is confined to the space of the body.

The second agenda is the environment in which we are fighting cancer. It includes people who offer support, information and conditions that shape personal growth.

The third agenda is the political agenda, "the largest box containing the other two. It is the wider context of cancer, in which your cancer is part of what 'cancer' means to society. And this is the one in which you don't get anything—you give."

The survivorship movement in the United States has already opened the doors for many new possibilities, from treatment choices to improved research methods in the war against cancer. But more voices are needed. Zakarian asks: "Where are the patients? Where are you? Ten million people who have cancer should have the collective clout of the largest interest group in the country."

*The Activist Cancer Patient* is a gift from Beverly Zakarian to cancer survivors and their friends. Shortly after its release Beverly Zakarian died. Her book tells her story and her dreams, but more importantly, it portrays

## Cheers!

The Robert Wood Johnson Foundation has named NCCS Executive Director **Ellen L. Stovall** to chair its national advisory committee for Promoting Excellence in End-of-Life Care. The program funds innovative projects of national significance geared to improving quality of care for terminally ill persons and their families. Stovall's other recent honors include appointments to the National Cancer Advisory Board and the National Cancer Policy Board at the Institute of Medicine.

The Society for the Advancement of Women's Health Research has honored **Amy Langer** with its 1997 Advocacy Achievement Award in Women's Health Research. Langer is executive director of the National Alliance of Breast Cancer Organizations. The award recognizes her contributions to the 1990 Consensus Conference on the Treatment of Early Stage Breast Cancer, the National Mammography Advisory Committee, and the National Action Plan on Breast Cancer Steering Committee.

The W. K. Kellogg Foundation named **Susan L. Scherr** to take part in its Experts in Residence program in June. Scherr, a cancer survivor, is NCCS' director of community and strategic alliances. Lifeguards, a local support group in Battle Creek, MI, hosted Scherr's visit. She spoke to survivors' groups, nurses, and doctors during her three-day tour.

her courage and dedication to the cancer survivorship movement and provides a blueprint for others to follow. ♦

*Cancer survivor Holly Collett chairs the legislative committee at the Greater Capital District Coalition for Cancer Survivorship in Albany, NY.*

## Stubborn hope

*When a Parent Has Cancer: A Guide to Caring for Your Children* by Wendy Schlessel Harpham, MD. New York: Harper-Collins Publishers, 1997. 164 pp, \$24 (\$34 Canada) hb.

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### REVIEWED BY RUTH PENNEBAKER

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When I was diagnosed with breast cancer two years ago, the landslide of advice and homilies began. *Be positive! Fight it! Your attitude is everything!* Being around emotional cheerleaders like that practically made me develop a severe facial tic. These people meant well, I knew, but they didn't know what they were talking about.

Wendy Harpham, a cancer survivor, internist, wife, and mother of three, could not be more different from those T-shirt optimists. *When a Parent Has Cancer* is a heartfelt, invaluable book about the difficulties of being a parent with cancer and the potential for transcending your hardships. The book is accompanied by *Becky and the Worry Cup*, a paperback for children that insightfully presents a child's-eye view of a household when a parent has cancer.

Certainly, Harpham is an optimist who persists in finding as much joy and promise and beauty as possible, even in the roughest circumstances. But hers is a pragmatic, stubborn optimism that acknowledges how hard it is to live with a cancer diagnosis, treatments, and an uncertain future. From that realistic base, she offers approaches and suggestions for caring for our children and ourselves the best way we can.

More than anything, we have to tend to our children now, since this is the only childhood they'll have. Even in the midst of treatments, disabilities, or illness, we can still love them and teach them, and reassure them that

they'll be taken care of, no matter what.

When we can't meet their immediate needs, we must find family members or friends who can help. Equally important, we must be honest with our children, Harpham says—which isn't to say we have to tell them absolutely everything. Even when we have to tell them news that isn't good, though, we can still show them we're hopeful and that they can be, too. "The greatest gift you can give your child is not protection from change, loss, pain, or stress," she writes, "but the confidence and tools to cope and grow with all that life has to offer them."

We have choices, Harpham emphasizes again and again, *even if they're not the choices we want*. We can choose to live as well and as fully as we can, and to teach our children as much as possible, even if our time is short.

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*We can choose to live as well and as fully as we can, and to teach our children as much as possible, even if our time is short*

Like Harpham, we can choose life and hopefulness, rather than bitterness and despair, as the legacy we leave our children.

Harpham's book is remarkable for its unflinching honesty, warmth, and empathy. Her answers aren't easy or magical, because she knows too well the medical, physical, and emotional world she's writing about. Skip the emotional cheerleaders on the sidelines. Skip the T-shirt optimists. Buy this book for yourself and your family. It's like having a wise, understanding friend to lean on and comfort you—and challenge you to be a better parent than you've ever been. ♦

*Ruth Pennebaker is a cancer survivor, writer, and mother of two. Her work has appeared in the New York Times, the Dallas Morning News, and Parents magazine. Her first novel, Don't Think Twice, was published in 1996.*

## MEMO

This column is provided as an information service with no endorsement implied.

*"Insights Into Cancer" series*—presentations by leading professionals to help women and their families live with and learn about cancer. Aug 12: Vincent Hung, MD, on "Skin Cancer Update: Early Detection, Prevention & Treatment." Sept 9: Beth Meyerowitz, PhD, on "Impact of Cancer & Menopause on Women's Sexuality." Oct. 14: Linnea Chap, MD, on "Understanding Cancer Treatment: Chemotherapy & Radiation." At UCLA's Rhonda Fleming Mann Resource Center, RPB Auditorium. Free. Call 310/ 794-6644.

*New Medicines in Development for Cancer*—a survey of 316 new medicines undergoing testing in clinical trials. Lists drug names, purposes, manufacturers, and status of research. Includes glossary, cancer facts, and a description of the drug approval process. Contact PhRMA, 1100 15th St NW, Washington, DC, 20005. Phone: 800/ 762-4636.

*New from Cancer Care*—single-page information sheets on coping with cancer. "Cancer Care Briefs" cover such topics as finding resources in your local community, practical tips for dealing with appetite loss and nausea, "Don't Be Afraid of Clinical Trials," effective self advocacy, HMOs and other managed care plans, and more. Free.

*Also:* "Professional Briefs," offering information on a variety of clinical and educational

topics, including: "How to Help Your Patients Make Decisions About Clinical Trials," "Working with an Older Person Who Has Cancer," "How to Start a Cancer Support Group," "Developing a Breast Health Awareness and Mammography Program," "How to Implement a Teleconference Workshop Program," and "How to Work with the Bereaved." Free. Call 800/ 813-HOPE. E-mail: [info@cancercareinc.org](mailto:info@cancercareinc.org). Website: <http://www.cancercareinc.org>.

*Helping family caregivers help themselves—The Resourceful Caregiver*, a 148-page information guide for both family and professional caregivers, features over 500 listings for hotlines, helplines, newsletters, respite services, support groups, and more. Written by the National Family Caregivers Association. \$12.95 plus shipping/ handling. To order, call: 800/ 426-4545.

*For kids whose parents have cancer*—Kids Konneted publishes *Konnections*. Features "Kids in the News," chapter updates, letters, poems, books to read, and "Parents Page." Written mostly by kids, for kids. Contact: Kids Konneted, PO Box 603, Trabuco Canyon, CA 92678. Phone: 714/ 380-4334. Website: [www.komenkids.org](http://www.komenkids.org).

*Influence your elected officials*—"The Health Advocate's Guide to the US Congress," by

## ONLINE

*New ovarian website*—features information about ovarian cancer, updates on the ovarian quilt project, chat room, and the National Ovarian Cancer Coalition newsletter. Online address: <http://www.ovarian.org>.

*Reducing cancer risk*—the Cancer Research Foundation of America (CRFA) has launched a new website focusing on cancer prevention. It provides prevention and early detection information about breast, cervical, colon, lung, prostate, and skin cancer. Includes exercise and nutrition facts and tips for children. Address: <http://www.preventcancer.org>. For information about CRFA, call 800/ 227-CRFA.

*BMT Newsletter's new e-mail address*—to reach the Blood and Marrow Transplant Newsletter by e-mail, input: [help@bmtnews.org](mailto:help@bmtnews.org). On the web: <http://www.bmtnews.org>.

Families USA, lists names of all US senators and representatives and describes jurisdictions of key committees involved in health-care issues. Describes effective ways to communicate with national leaders, how to get copies of bills and committee reports, how to communicate with the White House. \$4 (DC residents add 5.75% sales tax).

*Also from Families USA: Medicare Managed Care: Securing Beneficiary Protections* outlines policy changes needed to ensure adequate protections for Medicare beneficiaries. Covers marketing, enrollment and disenrollment, the HMO appeals process, access to providers, quality of care, and much more. 66 pages, \$15 (DC residents add 5.75% sales tax). Send check payable to Families USA Foundation to: Medicare Report, Families USA, 1334 G St NW, Washington, DC 20005.

*Smith Farm Cancer Help Program*—this center for the healing arts offers weeklong retreat programs starting this fall. Based on the Commonweal program, sessions offer participants an opportunity to seek physical, emotional, and spiritual healing in the face of cancer. Explore issues, choices, feelings, and concerns with an experienced and concerned staff. Cost: \$1,480 (includes full program, lodging, and meals; partial scholarships available). Next sessions: Sept 15-21 and Nov 10-16. Call 202/ 338-2330 or write Smith Farm, 1501 32d St NW, Washington, DC 20007.

*Free peer counseling*—The National Cancer Hot Line matches callers with trained volunteers who have survived the same types of cancer, helps with overcoming the initial shock of diagnosis, and helps callers find other resources. Practical and inspirational. No medical advice. Established by the R. A. Bloch Cancer Foundation. Call tollfree 800/ 433-0464. Note: This service seeks volunteers who wish to share their experiences with other people with cancer. ♦

## MEETINGS

*"Between Two Worlds: Striving for Normalcy in an Abnormal Situation"*—the Well Spouse Foundation's 1997 annual conference runs Oct. 24-26 at Country Inn & Conference Center in Waukesha, WI (outside Milwaukee).

Workshops and speakers on caring for the chronically ill, bereavement, relationships, poetry, relaxation and more. Cost: \$258 for members (includes lodging, registration, and meals). Call 800/ 838-0879 for more information.

*Cancer rehabilitation*—"Innovations in Cancer Rehabilitation: Pathways to the 21st Century," a comprehensive oncology rehabilitation conference for nurses, specialists, social workers and counselors, and other health professionals. Runs Nov 3-4 in Columbus, OH. Call 614/ 293-6428.

*Managed care*—"The Impact of Managed Oncology Care: Integration or Disintegration?" runs Sept. 17-20 in San Diego. Experts will explore such issues as legislative and reimbursement matters, home health care, the changing culture of American medicine, creating effective pain management programs, and more. Aimed at healthcare professionals. Contact the Association of Community Cancer Centers at 301/ 984-9496.

## On TV

"A Question of Genes: Inherited Risks" airs September 16 at 9pm on PBS. Explores the weighty ethical, moral, and medical issues surrounding genetic testing. Features comments of patients (including people with cancer), family members, doctors, and researchers. Examines the personal side and personal questions raised by the genetic dilemma. Check local listings for details.

## SPECIAL THANKS

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## Hope & Cope

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provides services in a specific area such as clinic support, companions for others with similar diagnoses, library and office operations, transportation, self-help groups, hospital visits, bereavement, education, and the bilingual newsletter.

This comprehensive support system reaches survivors, relatives, young adults, women newly diagnosed with breast cancer, women

with breast cancer after treatment, and people in bereavement.

It's a long way and many years between Kussner's vision and this thriving program in Montreal. For the cancer survivors served by Hope & Cope, the journey was well worth the effort.

For more information, call: (514) 340-8255. Or write: Hope & Cope, Jewish General Hospital, 3755 Cote Ste. Catherine, Montreal, Quebec H3T 1E2. Website: <http://www.mcgill.c/jgh/hc/hope.html>. ♦

*Sonja Tyler is an information specialist at NCCS.*

## Principal gives students a living profile in courage

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to make them, because you need something to look forward to, to grow toward."

That statement is a far cry from the day he was diagnosed. On that day, all he wanted to do was hide. "When the call came in, we didn't leave the house for three days," he recalls.

"I guess we thought if we could hide from cancer, it couldn't find us."

But he could hide only so long. Clark ultimately faced his cancer, drawing strength not only from his family and community, but also

from his steadfast religious faith.

Not to mention golf. In the weeks before the 1996 commencement, Clark remembers watching golfer and cancer survivor Paul Azinger return to the tour circuit after completing chemo.

"As I watched, I thought, 'Surely I can get well enough,'" he says. "That's the message I wanted to share with the students. Life isn't always going to be about positive things. You have to keep fighting."

After so many years and so long a struggle, Robert Clark knows where he stands, with his students and with cancer: "I expect the best, and I've never been disappointed." ♦

*Cancer survivor Anita Baumann is a former staff member of NCCS.*

### National Coalition for Cancer Survivorship

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