



NETWORKER

NATIONAL COALITION FOR CANCER SURVIVORSHIP

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NCCS Congress: Learning Advocacy From the Inside Out

by Terrence Campbell

There was no shortage of star power at the First National Congress on Cancer Survivorship. During its four-day run (November 11-14) in Washington, DC, such luminaries as Gen. H. Norman Schwarzkopf, Michael Milken, and Richard Klausner, MD, director of the National Cancer Institute, all paid visits to the podium. Congressman Jim Moran of Virginia stopped by, as did ex-NFL great Rosey Grier.

Still, the presence of cancer survivors and their supporters from every corner of the nation created perhaps the brightest spark. They came because they care about the issues confronting people with cancer, and because they care even more about the people affected by those issues.

During those four days they learned about advocacy from the inside out—beginning with advocacy for themselves as individuals, advocacy in support of others facing cancer,

ANNETTE PORTER



Moderator Robert Mittman takes comment from survivor Bobbi de Cordova-Hanks at SpeakOut.

and advocacy for the wider community of survivors and caregivers.

The Congress was peppered with "firsts":

- a joint reception with the American Society of Clinical Oncology and NCCS that gave survivors, oncologists, and other care providers a rare opportunity to mingle and share ideas;
- a general session on death and dying that marked a new awareness and acceptance of the "final season" as part of the survivorship agenda (see story page 12);
- an on-line information fair sponsored by the National Cancer Institute that gave attendees a tour of cancer resources available on the information superhighway;
- a general session on cancer prevention focusing on the role of environmental influences on cancer and cancer control (see story page 7);
- working groups in which cancer survivors and supporters helped draft principles and priorities for NCCS to pursue; and
- an historic SpeakOut in which cancer survivors and cancer community leaders debated and affirmed an NCCS declaration of principles (see page 3).

The program offered 14 workshops spanning a wide array of survivorship concerns, including effective communication, building successful programs at the local level, and spiritual and psychological aspects of the cancer experience.

Mary P. Lovato received the Catherine Logan Award for Service to Survivorship in recognition of the

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What We Carry Forward



Letter from the President

Betsy Clark, Ph.D

It is with great pleasure that I prepare my first message to you as president of NCCS. Having assumed my new role at the start of the First National Congress on Cancer Survivorship, it seems fitting to highlight what we achieved together at the Congress, and what we will carry forward from that event into the coming year.

A torrent of ideas and activities animated the Congress. Workshops empowered participants with strategies for improving communication and community networking. Plenary sessions tackled such tough topics as terminal illness and late effects of treatment. The Celebration of Hope gave everyone a strong sense of emotional connection. Distinguished speakers inspired standing ovations. And survivors and providers engaged in a powerful dialogue throughout the three days.

The NCCS Town Hall program—going into local communities to hear firsthand about survivorship concerns—played a major role in setting the stage for this event. The 10 Town Hall meetings held throughout the country provided a forum for over 1,000 people to express their views about survivorship issues.

These meetings have proven so valuable that we will continue Town Halls as an ongoing NCCS program in 1996.

The Town Hall meetings provided another crucial resource: data. Participants filled out surveys about survivorship, which were collected during the Town Hall meetings. Local Town Hall hosts can use this information to improve services to survivors, and NCCS will use it to develop our advocacy efforts.

In addition, NCCS solicited broad input for position papers on quality cancer care, long-term and late effects,

and psychological and social needs of survivors. The findings were compiled and presented for discussion and debate during the Congress.

The resulting principles, endorsed by cancer survivors and the healthcare community alike, were adopted during the Congress SpeakOut as the NCCS survivorship agenda through the year 2000. NCCS will further develop these principles in formal white papers, which we will publish in early 1996.

NCCS will move forward to build on the groundwork laid at the Congress. Speaking with one voice, we will translate the survivorship agenda into action.

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The *Networker* is a quarterly publication of the National Coalition for Cancer Survivorship. NCCS is a network of organizations, institutions, and individuals working in the area of cancer survivorship and support.

The primary goal of NCCS is to generate a nation-wide awareness of survivorship, showing that there can be a vibrant, productive life after the diagnosis of cancer. NCCS facilitates communication among people involved with cancer survivorship, promotes peer support, serves as an information clearinghouse, advocates the interests of cancer survivors, and encourages the study of survivorship.

The *Networker* is delighted that so many organizations want to use material from our pages. Please remember to request permission from NCCS to reprint any items.

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New NCCS Agenda Set at Congress SpeakOut

by Anita Baumann

They had gathered for four days, some 300 cancer survivors, family members, health care professionals, and researchers. Drawn together by common bonds and a shared interest in survivorship, they came from near and far, representing small grassroots organizations and large nationwide networks. They were young and old; rich and poor; black, white, Asian, Native American, and Hispanic; newly diagnosed "rookies" and veteran survivors—a living, breathing, moving picture of this nation's survivorship community.

Many were tired after four exhausting days of workshops and plenary sessions, where they learned about advocacy—for themselves, for their family members and loved ones, and for their communities. Now they had gathered together—one last time before returning home—to raise their voices in a SpeakOut designed to discuss, shape, and vote on the future of NCCS' advocacy efforts, focusing on three areas of critical importance to survivors—quality cancer care, physiological late and long term effects, and psychosocial needs.

The objective of the SpeakOut was to report on the issues raised and conclusions drawn during the Congress plenaries, workshops, and working groups and to vote on a declaration of principles on quality cancer care, which had been debated and discussed during Monday afternoon's working groups.

These issues had also been the subject of three separate questionnaires that had been sent to leaders within the cancer community last summer. NCCS compiled their responses into draft briefing papers which were then developed and debated during the Congress working groups. The coalition will release final white papers reflecting the principles in early 1996.

Richard Klausner, MD, director of the National Cancer Institute, set the tone for the evening by couching his vision for the institute in words that

would become the rallying cries of the evening: "reduce the burden of cancer," "provide outreach," "health care reform," and "research funding."

Dr. Klausner sees long-term value in the SpeakOut. "I think what has been most important to me [about the SpeakOut] is how well articulated the issues of survivorship now are," he said after the event. "The SpeakOut represented a clear articulation of an agenda of issues that the survivorship community can work on together."

And perhaps the most fundamental imperative of the evening was

"choice." In all three reports from the working groups, the value of choice, coupled with a multi-disciplinary approach to care, was stressed as critical to survivors during the full continuum of care.

The quality cancer care groups, represented by NCCS board member Debra Thaler-DeMers, RN, and NCCS Public Policy Co Chair Al Siu, MD, pointed out the need for informed access to specialized care that is both affordable and portable.

The question of managed care as a

(continued on back cover)

THE BASIC PRINCIPLES

Quality Care

NCCS should continue to call for universal access to healthcare. "Everybody needs to be covered, especially for lethal disease," declared Harold Freeman, MD, chair of the President's Cancer Panel.

Quality care recognizes the need for access, throughout the continuum of cancer, to specialists, clinical trials, and a multi disciplinary team approach to treatment. Access to specialists may prove a common challenge as more and more people enroll in HMOs.

In addition, managed-care "report cards" should be driven by standards that measure quality care, not only cost. The report cards should focus on care throughout the cancer continuum, include participation in clinical trials, and quality of life considerations.

Psychosocial Needs

With the seachange in healthcare, NCCS must work to build its successes in raising awareness about the need for psychological support along the continuum of care. Adequate healthcare includes assessment of survivors and their support systems across the survivorship spectrum. NCCS must educate the public by clearly defining what is meant by psychosocial care, promote psychosocial interventions and other supportive services as integral to comprehensive care, and work with key constituencies to ensure adequate funding for survivorship research.

Physiologic Long-term and Late Effects

Cancer survivors should receive continued medical follow-ups and systematic long-term follow-up care. The healthcare system should establish specialized clinics that promote health, prevent disease, provide psychosocial and rehabilitation services, and coordinate care with survivors' primary care professionals.

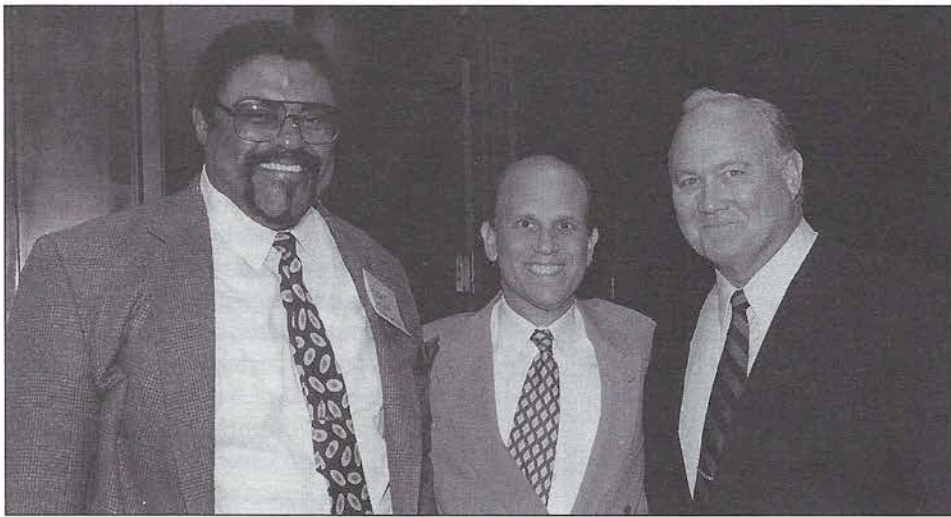
NCCS should increase public awareness of the physiological long term and late effects of cancer; educate consumers, healthcare professionals and policymakers on this issue; provide guidelines and information on long-term and late effects; promote research funding in this area; and articulate survivors' rights to long-term care.

—Terrence Campbell

Marching Orders

Schwarzkopf Urges Survivors to Speak Out

PHOTOS: ANNETTE PORTER



Milken and Schwarzkopf with former football great Rosey Grier, left.

The following excerpts from General H. Norman Schwarzkopf's keynote address have been edited for fit. A complete version is available on video from NCCS. See insert for details.

I'm here because I won a battle. But it's not the battle everyone associates me with. They associate me with another battle where we indeed won the battle and we won the war. In my case, I won the battle, but the war's still going on out there.

A year and a half ago, I went to the hospital for an orthopedic problem. I had tendinitis in my left knee.

I went in, got a cortisone shot, and I thought, while I'm here, I'll just go see the urologist. Not that I felt any great need to, because I had a PSA test just a year before, and it was normal.

So I went by the urologist, and he said, "There's something just a little unusual there. I think we ought to run a series of tests on you and we ought to do a biopsy."

I, of course, panicked. But he said, "Don't worry about it, I do thousands of these examinations and can always tell when it's cancer. It's not cancer, but there's something there we need to look at."

They ran the tests, and called me up about two weeks later and said, "By the

way, your PSA test came back at 1.8. Just like we thought. Nothing to worry about."

I went in for the biopsy. First they did an ultrasound on me. The doctor said, "Looking at this ultrasound, there's no question about it. There's no problem here. There's a small stone there. That's the only problem we have."

He left the room and the technician said, "General, you don't have a thing to worry about. I've done thousands of these tests. And I can guarantee you that your results [from the biopsy] will come back negative." I said, "Of course. My PSA is very low, I'm in perfect health, and besides, generals don't get things like prostate cancer."

Five o'clock, Friday afternoon—I remember exactly when it was, because at 5:15 I was taking my son to Orlando, from Tampa, to see *Man of La Mancha*. Five o'clock, Friday afternoon, the phone rang. The doctor said: "I don't know how to say this. Other than to say, you—have—cancer."

I said, "Wait a minute! I can't have cancer. I don't have cancer! Other people get cancer. I don't get cancer! All my tests were negative! My PSAs were low—that [ultrasound] technician told me. I don't have cancer!"

I just thank God that I had to take my son out that evening. We had two hours to drive to Orlando, and I wasn't going to tell him about it yet. I wasn't ready for that. Because I couldn't have cancer! It wasn't right! Why me?

Around the middle of *Man of La Mancha*, about the time where Don Quixote sings "The Impossible Dream," I said to myself: "Wait a minute. Maybe there's a reason you have cancer. You can't let this get you down. You've fought every battle, and you've won every battle. What are you feeling sorry for yourself about? You're gonna win this battle, just like you've won every other battle. And not only that: maybe there's a reason why you have cancer. Maybe there's something that you can do with this cancer that you have." And that kind of turned me around.

Very next morning, I went out to my shooting club. A fella there had prostate cancer. We all knew about it. But we whispered about it: "Poor Judge. He's got prostate cancer. Poor son of a gun. Terrible! God! I never wanna have that. Thank God it isn't me."

I went right up to him and said, "Judge, I have prostate cancer. Let's talk. Tell me everything ya got!" We talked and I felt better about it.

My successor at central command had prostate cancer. I called him up that afternoon. I said, "Tell me about prostate cancer. I need to know!" And he told me more, and I felt a little bit better.

Then I went around asking for literature, but I couldn't find any! There wasn't anyplace for me to go to get my hands on something that would tell me about prostate cancer. Finally I called some friends, and they started sending me magazine articles. I started reading and studying and I learned everything I could.

Shortly thereafter we scheduled surgery. Now, something interesting happened. My administrative assistant came to me and said, "General, I hate

to bring this up, but you're about to go into the hospital, and the press will know it. What should we tell them?"

I didn't even hesitate. I said, "We'll tell them that I've got prostate cancer. We're going to make it very clear. We're going to make it very clear. Maybe that's what this is all about. Maybe instead of whispering about this, it's time to start talking openly about it. We're going to make a public announcement."

That's exactly what we did. And it got a lot of [media] play. [Senator Robert] Dole came to my hospital bed and said, "Well I guess you're going to replace me as the prostate cancer poster boy!"

I went home from the hospital and there were all sorts of letters for me from all over the country by people who found out I was going to have surgery and wanted to make me feel better. Some of the letters said lovely things like, "The day they removed the catheter, I have had no control ever since." Another one said, "Your biggest problem will be your trouser size, because you're going to have wear a *diaper* for the rest of your life!"

But I never forgot one letter. It said, "I had prostate cancer, just like you. But I am fully recovered and the only after-effect is that it has just slightly slowed down my sex life. But that's not bad when you're 78 years old!" I said, "I'm gonna be like that guy!"

I got out of bed and started walking. By the time I got back to the hospital to take out the catheter I was walking 5 miles a day. I went back home and I was walking 8 miles a day. My surgery was at the end of May. By the middle of July, I was standing in the middle of a rushing river in Alaska fly fishing. In August I was bouncing around on a safari in Africa. And I feel like a million bucks.

There's a moral to this story. First of all, why didn't anybody talk about prostate cancer? You have no idea what a difference those two individuals made to me when I could talk to them about that cancer less than 24 hours after I found out I had it. And if I hadn't had them to talk to, I probably would have gone a little bit crazy. And why wasn't any literature immediately available for me to get my hands on?



Milken and Schwarzkopf receive "warrior" awards from Immediate Past President Susan Leigh, RN.

I found out that 400,000 more people will get prostate cancer every year. And 40,000 will die of it this year.

Every man out there pay attention to what I'm gonna tell you: If you are over 50 years old, go in every year for a checkup. And don't just have the PSA test—that's the easy part. Go to a urologist who knows what the hell he's looking at and say, "Doc, bring me to my *knees* if you have to!"

And if you are an African American, or if you have a history of prostate cancer in your family, then start when you're 40 years old.

You see, I was damn lucky. I went in with a bad knee, and I was just lucky that they found the cancer when they did, and as a result, I'm a survivor. But it only happened because I had the digital rectal exam—that's what it's called, guys—in addition to PSA. Go in and have a complete exam every year.

Listen, we're at war, but I'm convinced it's a war we can win. There are 8 million of us out there. We need to start talking. We need to start being open about our cancer. We need to advocate. Stand up like I do and tell a man to go have digital rectal exam—or anything else that needs to be said. Stand up and advocate it—become an advocate in your community, wherever it is. Rally other people to become advocates in your community. *Talk* about cancer.

Number 2: Be available to other people right away who find out they

have cancer. Make yourself available. I get calls from all over the country now, every week from people who discover they have prostate cancer. My West Point roommate called me less than a month ago—he has prostate cancer. But see, he has somebody he can call, somebody he can talk to. So make yourself one of these people that people can talk to.

A TIP OF THE HAT

The editor extends warm thanks to those good souls who helped with reporting at the NCCS Congress:

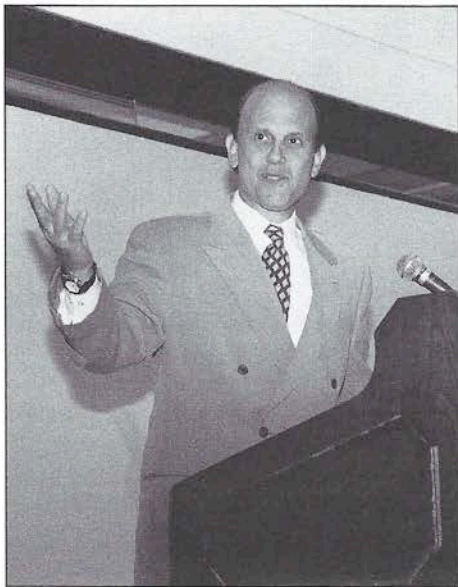
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Deborah K. Ash
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Michael Milken's 10-Step Plan For a Cure

ANNETTE PORTER



Milken: "The cure is visible."

by Anita Baumann
and Terrence Campbell

In his heyday, Michael Milken was arguably the most innovative financier on Wall Street. These days, Milken is investing heavily in a different field: cancer research.

Milken was diagnosed with prostate cancer in 1993, but he was active in cancer research long before his own diagnosis.

"I was drafted into the war on cancer in 1976 when my father was diagnosed with malignant melanoma," he said. Since that time, he has lost 7 more members of his family to cancer.

Today, Milken's prostate cancer research foundation, CaP CURE, is the largest private funder of cancer research in the nation.

Despite CaP CURE's enormous contribution, Milken feels the best hope for a cure lies in cooperation among many organizations, and on an international scale. In a special address at the NCCS Congress, Milken counted off 10 actions he feels would lead to a cure.

"First, internationalize the war on cancer," he said, noting that 90 percent of those who die of cancer live outside

the United States. "This is a world problem, a problem of the human race against cancer, not Americans against cancer."

He said the world should share the burden of financing cancer research. The United States now funds more than 95 percent of all research worldwide.

"Investing in cancer research, treatment, clinical trials, prevention, and detection is one of the best investments any country can make," Milken declared.

Next, Milken envisions a "world class scientific cancer team," made up of physicists, biologists, computer scientists, chemists, engineers, clinicians and survivors. He advocated using advanced technology—computers, video conferencing, virtual laboratories—to accelerate communication among researchers worldwide.

He called for public and private partnerships because "neither public nor private sectors will solve this problem alone."

He wants to arm scientists with the best technology available. "The military, NASA, for-profit companies—the technology they use is more advanced than the technology used by cancer centers....How can we hope to compete?"

Another action: Create an organic chemical library, which would enable testing of every one of the over 10 million recorded chemical compounds within one or two years.

Turning to the government, Milken urged an accelerated approval process for new drugs. "Today, a pharmaceutical company must spend \$400 million and 14 years to bring a drug to market," he said. "We have got to find a way to shorten this process....The sheer thought that if someone invented or identified a potential cure for cancer that it would take 15 years to get it to patients in wide distribution is mind-boggling."

He said the government should adopt a more businesslike, realistic approach to funding by shortening the

length of grant proposals and speeding up the approval process.

Finally, "Mobilize the human race," he said. "It's not just money, it's people....The cure is visible. The technology is available. But our cost cutting and lack of incentive to private industry are about to cause us to seize defeat out of the jaws of victory—to push back the solution possibly a generation—another 10 or 15 million Americans dying when we could solve the problem in the next few years."

THE PLAN

Michael Milken feels that these 10 actions would lead to a cure for cancer—

- 1 Internationalize the war on cancer. It's a world problem; every country needs to be a part of the solution.
- 2 Invest heavily in research, treatment, clinical trials, prevention and detection.
- 3 Build a world class scientific cancer team.
- 4 Use cutting-edge communications technology to foster worldwide communication.
- 5 Forge public and private partnerships.
- 6 Make cancer centers as technologically advanced as the military and space programs.
- 7 Create an organic chemical library to accelerate testing compounds against cancer cells.
- 8 Streamline and shorten the approval process for new drugs.
- 9 Take a businesslike, realistic approach to funding.
- 10 Mobilize the human race.

Cancer Prevention: Can We Get There from Here?

by Kate Nagy

Fact: An estimated 60-80 percent of breast cancer cases in the US cannot be explained by genetic or lifestyle factors, suggesting that environmental factors play an important role in its cause.

Fact: Exposure to contaminants such as DDT has been correlated with increased incidence of breast and prostate cancers, although causation remains unproven.

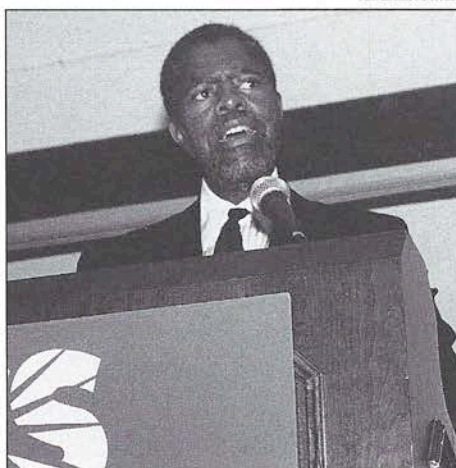
Fact: Higher rates of leukemia, soft tissue sarcoma, and brain cancer have been observed among children in homes where pesticides are used.

Mounting evidence implicates a variety of environmental toxins in the development of cancer, particularly among poor and underserved populations. But while the evidence seems convincing, it is not yet conclusive in most cases. That makes it difficult to regulate toxic substances, according to panelists at the NCCS Congress plenary session "Prevention: Can We Get There From Here?"

Panelists included moderator Jay Feldman, MA, executive director of the National Coalition Against the Misuse of Pesticides; Kenneth Olden, PhD, director of the National Institute of Environmental Health Sciences (NIEHS) and the National Toxicology Program; and Gerald Poje, PhD, coordinator of minority health activities at NIEHS.

Understanding the carcinogenic properties of environmental substances and regulating those substances where appropriate are crucial steps in preventing cancer. For example, if environmental factors cause as few as 10 percent of all cancers, eliminating or controlling those factors could prevent 125,000 cases of cancer each year.

Olden defined "environment" broadly to encompass industrial and agricultural chemicals, byproducts of combustion and other industrial processes, food, prescription drugs, lifestyle choices (such as substance abuse), various other physical agents, and diverse social



Olden: "We need to regulate for populations that are most susceptible."

and economic factors.

He said that all diseases are caused by genetic or environmental factors, or a combination of them. But while our understanding of the genetic causes of cancer continues to grow, we still don't fully understand the environment's role.

"We spend an awful lot of money in the government to investigate the genome in the etiology of disease," said Olden. "A similar commitment has not been made for environmental factors."

Olden introduced the concept of "environmental justice," which holds that environmental health risks are borne disproportionately by certain segments of society, especially the poor, who work and live in the most hazardous environments.

"Regulatory agencies regulate as though we were all equally susceptible," said Olden. "But we need to regulate for populations that are *most* susceptible."

In February 1995, President Clinton signed an executive order that requires federal agencies to take steps to incorporate environmental justice into their missions. Congress, however, has not been as friendly to environmental interests, especially recently. Turning the tide may prove difficult. Many groups whose actions clash with environmen-

tal and public health agendas (such as the tobacco industry) are well organized, well funded, and well established on Capitol Hill.

Still, Olden noted, lawmakers tend to vote their constituents' will. If the American people were to demand environmental regulation, he said, Congress would pass it. But before that can happen, we need proof that such regulation is necessary.

"Science is not in place to make intelligent regulatory decisions," he said. "We have to convince policymakers and the American people that research that emphasizes prevention is the best approach."

Panelists said that public health research should focus on:

- developing and using new research models among different populations, communities, and industry;
- studying exposures and diseases among small populations, exposures to low levels of hazardous materials, and multiple and cumulative exposures to hazards; and
- the development of new biological markers.

The panel encouraged cancer survivors to play a key role in the search for environmental causes of cancer. Said Feldman: "Survivors should be at the forefront of the environmental movement."

Poje recommended that concerned citizens contact their state health department for information about combatting environmental hazards locally. He suggested involving religious leaders: The Catholic Church recently sent information on environmental justice to every diocese, educating millions of people.

The speakers emphasized that individuals can make a difference. Poje urged that individuals gain expertise to partner with regulatory agencies and to promote the environmental health of their communities.

"Beware of 'experts' coming from Washington, DC," said Poje. "They'll be gone tomorrow, and you'll be stuck with the problems."

Kate Nagy is a technology transfer fellow at NCI, where she edits the newsletter ProtoCall and occasionally writes for the Journal of the National Cancer Institute.

PEOPLE-WATCHING AT THE CONGRESS



Top Left: Immediate Past President Susan Leigh, RN, moderated panel on late effects of treatment.

Above: Book lovers thronged at the NCCS book fair.

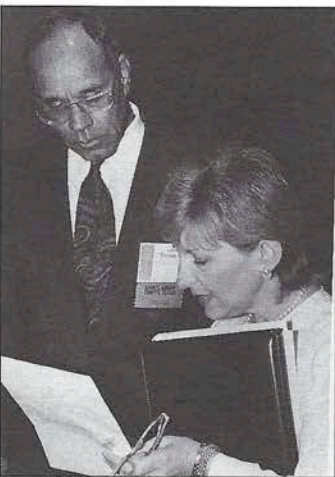
Left: "Do doctors always eat like this?" That was the question of the night at a joint reception with the American Society for Clinical Oncology (ASCO). From left: Sam Turner, vice president for strategic planning; Ellen Stovall, executive director; John H. Glick, MD, president of ASCO; and Diane Blum, vice president for development.



Far Left: Richard Knox of the Boston Globe receives Natalie Davis Spingarn Writer's Award from Spingarn herself.

Left: Mary P. Lovato, left, who heads A Gathering of Cancer Support in Santo Domingo Pueblo, NM, receives Catherine Logan Service to Survivorship Award from Logan, a cofounder of NCCS and director of People Living Through Cancer. PLTC will co-host NCCS' 10th Anniversary celebration next October in Albuquerque.

PHOTOS BY ANNETTE PORTER

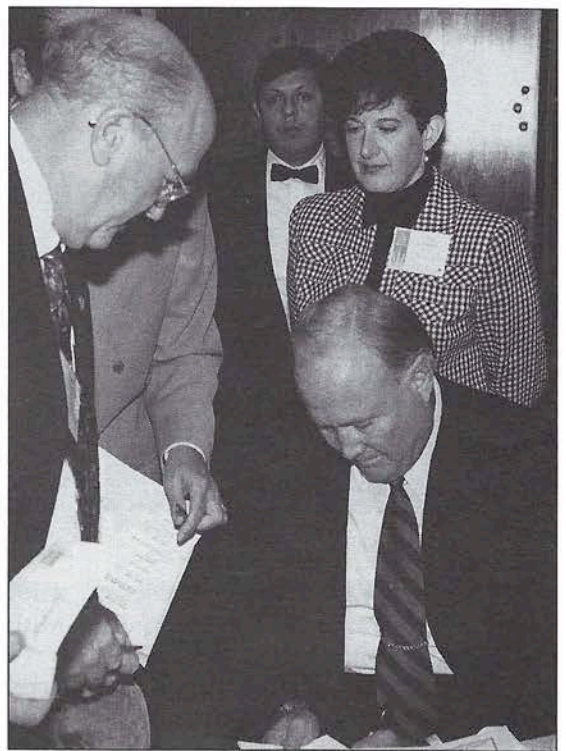


Top Right: Admirers press General Schwarzkopf for his autograph.

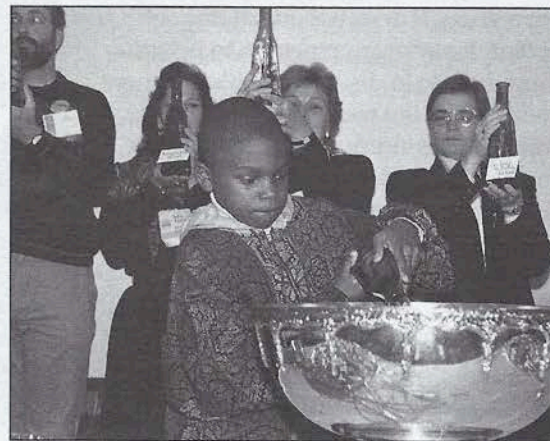
Top Left: Congress participants tour the information superhighway courtesy of the National Cancer Institute.

Middle: Brad Zebrack (left) and John Campbell during a workshop on men's cancer issues.

Above: Harold Freeman, MD, co-chair of the Honorary Congress Committee, consults with NCCS Executive Director Ellen Stovall.

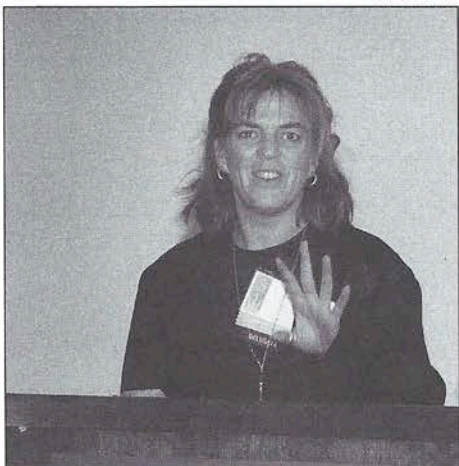


Passing the Flame of Hope—Hundreds of cancer survivors and supporters gathered for what many considered the emotional peak of the Congress: "A Celebration of Hope." The nonsectarian spiritual service was a mosaic of gospel music, meditation, a symbolic burning of fears, and a ceremonial mixing of healing waters from all over the world. A moving candlelighting sequence, in which survivors passed the "flame of hope" from one to another, closed out the celebration. Patricia Gilner, MS, a 15-year survivor and founder of the Institute of Renewed Hope in Baltimore, created and organized this evocative ceremony.



Voices From the Congress

DEBORAH ASH



Annette Porter

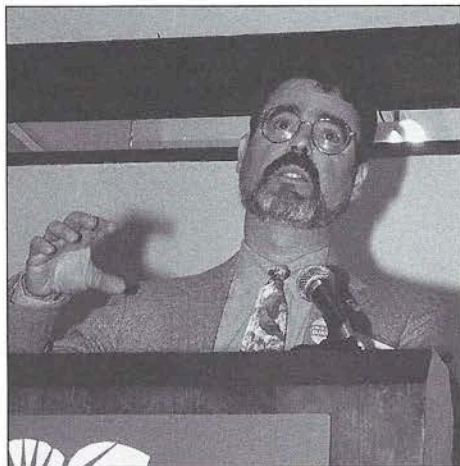
You'll see in between the tents something that was very important to us: the prayer flags we carried. It's a Tibetan tradition, to fly the flags on the mountain, the belief being that as they deteriorate in the sun and the wind, they send prayers out for the people whose names are on the flags. And when the flags are completely gone—they've disintegrated into the sun, the elements, the winds—then all the prayers for that person are sent.

We carried flags with us with names of hundreds of people. Women who have had cancer, breast cancer, men and women with different kinds of cancer, people who have been impacted in various ways. It was the first thing we took out of our packs. We all had them in our packs. First thing we took out every time we stopped, first thing we put up. These were important symbols to us.

At night they would flutter in the wind. I would wake up and go and look out at the stars...and I'd just sit and listen to them for awhile. They started cracking and popping when the winds got up to 60 miles an hour, higher up on the mountain.

—Annette Porter
Activist, cancer survivor

[Some years ago, after addressing a conference in Baltimore,] a woman came up to me, and kind of looked over one shoulder, then the other, and



Fitzhugh Mullan, MD

said, "I know I shouldn't be here, Dr. Mullan, but can I ask you a question?"

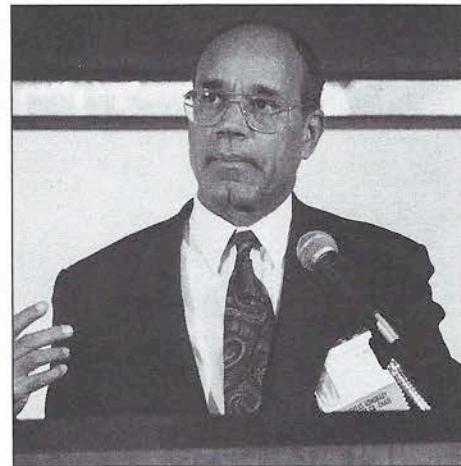
I said, "Why shouldn't you be here?" She answered, "Well, I've only been in treatment three months." She was apologizing for not being cured. Well, what's a cure? When do you know you're cured? What both of us were doing, her at three months and me at seven years, was: We were surviving. We were putting one foot in front of the other, trying to deal with all of the issues, physical, medical, psychosocial, vocational, that are part of surviving. And that was the reality—not either the hoped-for cure or the dreaded death.

[NCCS has] labored, since that time, to change the vocabulary and the mindset of the country, to talk about this path, this journey, that people with this diagnosis travel. It does not end at five years. It does not end at any set point. It varies from person to person, and disease to disease, but it's out there with us for the rest of our lives. And that is the concept—for bad, and very importantly, for good. That is the journey of survivorship. And that is the journey we are all on.

—Fitzhugh Mullan, MD
NCCS Chair, cancer survivor

I want to tell a story about a man I heard of, who was middle aged, and who was admitted as an emergency to a hospital in St. Louis. He was very

PHOTOS: ANNETTE PORTER



Harold Freeman, MD

sick and required immediate surgery. The hospital was run by the Little Sisters of the Poor, Catholic Sisters.

Three days later, he was doing well. The Sister responsible for collecting money came to his bedside. She said, "Sir, you've had a good post-operative course. I want to talk to you about some practical things. Do you have any health insurance?"

The old gentleman said, "No, I don't have any health insurance."

So she said, "Well, do you have any money saved up in the bank? You know, the hospital needs to support itself. We're really running a very tight budget."

"No, Sister, I don't have any money saved up in the bank."

She finally asked him, "Do you have any relatives who might help you? We really have to find a way to support the hospital."

"Yes, Sister, I have a sister who lives in New Hampshire. She's a spinster-nun."

The Sister recoiled. She reflected a minute and said, "Sir, with all due respect, there is no such thing as a spinster-nun, because all nuns are married to God."

And the gentleman reflected too, and said, "Then, Sister, we have no problem. Send the bill to my brother-in-law."

It would be good if we could solve our problems miraculously like

that...but I don't think that's in the offing. We're in a watershed time in American life. There has been a tremendous shift toward budgetary considerations, some of which are probably reasonable. But we must not allow the shift to occur in such a way that the American people will be harmed, particularly those who are most vulnerable.

—Harold Freeman, MD
Chair, President's Cancer Panel



Debra Thaler-DeMers, RN

I am a 15-year veteran in the battle against cancer. After my battle against cancer and taking care of my sister who was diagnosed with the same kind of cancer, I became an oncology nurse and a licensed

public health nurse. This battle should also enjoin the more than 37 million people in this country who do not have access to healthcare because they have no health insurance. Some of them are cancer survivors who have been denied coverage because of a pre-existing condition.

In my work as a public health nurse I have to meet many veterans in fast-food restaurants to give them their medication because they're homeless, and they don't have a refrigerator to store their medications. And I have to give them their medications at these fast-food places, assess them and send them on their way. We need to help these veterans also.

—Debra Thaler-DeMers, RN,
NCCS Board Member, cancer survivor

It's very, very important that we integrate psychosocial care into routine medical care. It's not an adjunct. It's not an afterthought. It's not something that we think of only if a person is in a crisis. It has to be a systematic part of how a physician takes a history of a patient.

—Patricia Ganz, MD
Professor, UCLA School of Public Health

In the past, psychosocial services were based on observations. We would wait for a problem to happen. We would wait for a patient to become so depressed, or so distressed, or suicidal, then suddenly we would begin to react to that patient's concern.

Our belief is that we can no longer do that. We cannot wait for patients and families to reach a point where they are so distressed. We believe that [psychological] care should be actively integrated into medical care. And it should begin the first day that patient or family walks into our cancer center.

We do not treat patients, we treat families. Every patient that walks into our center comes as a member of an active family unit. And we have to be equally concerned about what happens to that family as they go through the disease continuum.

—James Zabora, MD, Director of
Patient & Family Services
Johns Hopkins Oncology Center



Richard Klausner, MD

It is important that scientists speak to the American people, that we let the American people know what an enormous treasure they have in the biomedical, research and clinical enterprise that has been built in this country and is the envy of the world. It has been built with federal funds and it represents, in this era of questioning what government should do, the expression of the rightful role of government in providing for the public good.

We must assure that the changing healthcare system does not leave out

clinical research, for if we cannot continue to discover and to translate discoveries into new avenues of prevention, of detection, of diagnosis, and of therapy, we will be stuck with the same inadequate approaches 10 and 20 and 30 years from now.

—Richard Klausner, MD, Director
National Cancer Institute

We have a responsibility to offer comprehensive care to survivors of cancer. I'm so tired of going across the country and hearing statements like, "Well, it would be nice if we had the money." It is not a money issue. We cannot just treat people with medicine and then say, "Okay, call us when there's a problem." You deserve it, and you should have it. And by following longterm survivors in a systematic way, we can identify effects of therapy.

—Wendy Hobbie, RN, PNP
University of Rochester School of
Nursing

Healthy survivorship means focusing all our resources on those things that we can do to prevent or minimize late effects, and adjusting to late effects that are unavoidable or unalterable. And as the serenity prayer advises, health survivors find serenity over things they cannot change, such as the unalterable risks associated with the best available effective treatments for their primary cancer, find courage to change the things they can change, such as taking steps to decrease their overall risk of developing late effects, and have the wisdom to know the difference.

—Wendy S. Harpham, MD, cancer survivor
Author, *Diagnosis Cancer and After Cancer*

I Never Have a Bad Day by John Robert McFarland

I have nauseated days and frightened days.
Tired days and hurting days.
Long days and short days.
Silent days and alone days.
Mouth sore days and swollen days.
Bald days and diarrhea days.
Rainy days and sunny days.
Cold days and warm days.
But no bad days.

—quoted by Betty R. Ferrell, PhD, FAAN
City of Hope National Medical Center

Facing Death With Hope

by Terrence Campbell

"On occasion NCCS has been criticized for focusing on survival and neglecting those of our ranks who do not achieve cure or longterm survival," said coalition President Betsy Clark, PhD. Clark moderated the panel discussion, "Learning a New Language: How to Talk About Death and Dying."

Clark described our society as "not death denying, but death avoiding." She noted that we use death-related phrases in everyday speech (deadbeats, dead ends, dead on our feet, etc.). But when we speak of actual death, we use euphemisms (expired, passed away, went to their maker, or just "gone").

We use death to sell movies, magazines, and television shows, creating what Clark termed "the pornography of death." Just as sexual pornography implies "an obsession with the sex act abstracted from its natural human emotion, namely affection," the pornography of death describes an obsession with death without its natural human emotion: grief.

Death and grief avoidance creates a kind of "conspiracy of silence." There are several versions of this conspiracy: the medical team knows death is imminent, but doesn't tell the patient; the patient knows but doesn't discuss it with family; or all parties know that death is coming, but no one talks about it.

This silence destroys trust and creates confusion, suspicion, and anger. It robs us of the chance to put things in order and make peace with others. Finally, it blocks hope and the therapeutic benefits of hope.

"Hope can never be false," Clark declared. "There is always something to hope for." Even in the face of death, Clark noted, one can hope for comfort, relief of pain, or even a good death—that life can be lived as fully as possible until the time of death.

Betty R. Ferrell, PhD, FAAN, discussed several studies (some with NCCS members) in which cancer survivors expressed their concerns about

recurrence and death. Ferrell, an associate research scientist at the City of Hope Medical Center, focuses her research on such issues as pain management and quality of life.

From her research, Ferrell shared many moving comments by survivors on cancer and death, including this one:

"My illusion of eternity is gone. And in its place is the reality of now. Holding death at arms' length has forced me to look into its face. No more turning back. But at the same time, I'm looking past death, right over its shoulder, into life."

Many of those surveyed said they were able to come to terms with their mortality and no longer feared death. The cancer experience, they reported, helped them to learn to enjoy every moment of the day, to set priorities, and to work on the things that truly mattered to them.

Naomi Stearns, MSW, urged NCCS to include death and dying as part of its agenda. "To contemplate death is not opposed to survivorship," said Stearns, a consultant for several cancer organizations and former director of social work at Dana Farber Cancer Institute. She is also a one-year cancer survivor.

Stearns asserted that it is not necessary to "learn the language" of death and dying. "Every survivor, every provider, every family member knows that language, whether or not it is expressed," she said.

Healthcare professionals have traditionally resisted learning about death. Years ago, one doctor told Stearns that "people come to us for a cure, not to die." She reminded him that, despite advanced technology and all our best efforts, "patients sometimes died."

In her 20 years in oncology, Stearns has observed some improvement in that outlook. Gradually, survivors, families, and doctors have developed means to deal with death in a realistic yet humane way.

There remains much to do, Stearns said, "but rather than criticize the movement, we should expand the

vision of the movement to include death."

Ken Miller, MD, medical director of Montgomery Hospice Society in Maryland, reported that "in 10 or 12 years of professional education, I heard one lecture on pain control and no lectures on hospice care." Doctor and patients alike have tended to view hospice as giving up hope.

But "hospice care does not mean giving up hope," said Miller. Instead, hospice focuses on autonomy, comfort, dignity, quality of life—the same things NCCS values. Hospice allows people to fulfill goals and to continue to make choices.

Miller described hospice as a team effort, in which social workers, home health aides, physicians, and pastoral counselors work together to attain optimal quality of life for their clients.

Miller shared a story about a woman with lung cancer in his care. After several relapses, she had a final recurrence. She came to Miller with a question: "Dr. Miller, tell me, do I really have a chance, or am I going to die of this?"

Before Miller could reply, she blurted out: "But don't tell me any bad news!"

Miller was tongue-tied for a moment, then remembered a question a social worker taught him. "How can I best be of help to you?" he asked. This question opened the way for the survivor to express her needs, and for Miller to "share honest information and also share hope."

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CELEBRATION

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A Tragedy's "Hidden Treasure"

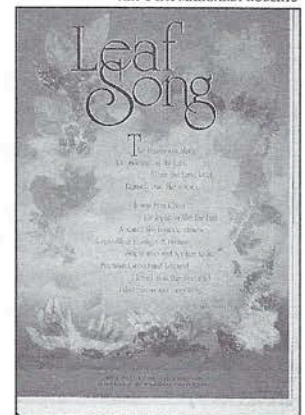
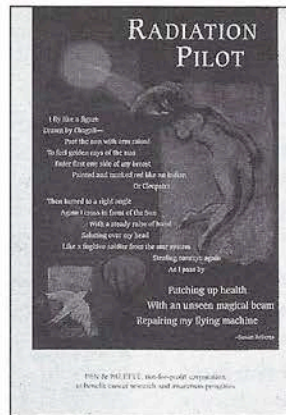
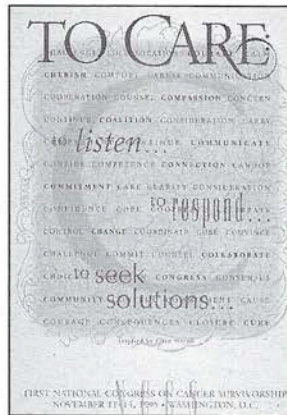
by Anita Baumann

As children growing up, we often read of treasures hidden in houses—in secret hiding places, attic trunks, or hollow spaces under floorboards. Sometimes, in these stories, the treasure turns up in a more obvious place where no one thought to look, like a desk. And sometimes these stories come true, and real life mirrors fiction.

Such was the case for Margaret Roberts. Her hidden treasure came in the form of deeply personal poetry stowed in a desk in an upstairs room in her sister Susan's house. Susan had died of breast cancer in September 1992. Unbeknownst to everyone, she had written the poems during her three year struggle with the disease. Margaret discovered them when she settled her sister's estate in the months after her death.

"Hidden treasure—that's how I described it to people after I found it," says Roberts. "It was like Susan was still talking to us."

But hearing Susan's voice in the poetry added to the ache Margaret felt at losing her second and only remaining sister. Another sister, Linda, had died in 1988 from lung cancer. Susan's poetry described her reactions to her own illness, to Linda's death, and to the natural world, for which she gained a new appreciation during her illness.



Three survivorship posters: "To Care," left, created especially for NCCS; "Radiation Pilot," center; and "Leaf Song."

"Reading her poetry made me sad and a little angry," says Roberts. "Why didn't she share these with us when she was alive?" Seeking an emotional outlet for her grief, Roberts, in a project she says was "conceived to help me out of depression," created a series of paintings that amplify her sister's poetry.

She then founded Pen & Palette, a non-profit organization that seeks to support cancer research through the sale of posters based on the paintings. After receiving a grant from the John Anson Kittredge Fund in Maine, Roberts was able to have the first series of four posters printed.

Roberts plans to contribute close to two-thirds of the price of each poster to cancer research. She hopes that hospitals, clinics, and doctors' and therapists'

offices will purchase the posters to help brighten waiting rooms and treatment areas.

One of these posters, entitled "To Care," has a list of positive "C" words superimposed over a large letter "C." Roberts says that the poster was inspired by Ellen Stovall's comments about the cancer community at the NCCS Town Hall meeting in Albany.

Roberts sold copies of the poster at the First National Congress, along with three others that illustrate her sister's poetry.

Surprisingly, one of the most well received posters was "Radiation Pilot" which depicts a nude woman lying on a hospital table, engulfed in a beam of light. Roberts considers the accompanying poem by her sister especially powerful because it transforms radiation treatment into a positive, almost magical experience.

NCCS President Betsy Clark says of Margaret Roberts: "She has taken a tragedy and made something positive come from it. Her work is a gift to others who have had similar tragedies."

To order the "To Care" poster, see the insert in this issue or contact NCCS. For more information on the other posters, write Pen & Palette, 29 Ver Planck St., Albany, NY 12206.

Anita Baumann, a 10-year survivor of leukemia, serves as Information Services Coordinator for NCCS.

Keep on Dancing!



Frogs just wanna have fun. At least, that's how it looks on a colorful greeting card from NCCS.

The whimsical card shows a frog dancing on a lily pad with a trio of salamanders, a butterfly, and a gaggle of dragonflies. On this lily pad, the joint is jumpin'.

The image bears the legend, "Keep on Dancing." Because it is blank inside, you can use the card for a variety of occasions, or simply as a notecard.

Immediate Past President Susan Leigh, RN, commissioned artist Carolyn Schmitz of Phoenix to create the card especially for NCCS. A share of proceeds from sales goes directly to the coalition.

To order a set, see the insert in this issue, or contact NCCS.

ART © 1996 CAROLYN SCHMITZ

Stretching a Ribbon of Hope Across America

by Anita Baumann

"There is no such thing as false hope."

"I hope everything turns out fine."

"Well, we can always hope."

"Hope does not equate with denial. True hope is based in reality."

As reflected in these statements overheard in conversations, general sessions, and proudly displayed on buttons, hope was in the air at the First National Congress on Cancer Survivorship. Hope is a cornerstone of cancer survivorship, and it is an attitude that NCCS fosters among our members and those we serve.

NCCS unveiled a vivid symbol of that important concept at the survivorship Congress: The Ribbon of Hope. The display—which is actually an arrangement of ribbons shaped like a radiant sun—symbolizes hope and new life. Cancer survivors and their supporters will affirm that message by signing the sunburst as it tours the nation.

That process got off to a strong start at the NCCS Congress as participants lined up to sign throughout the event. First Lady Hillary Rodham Clinton boosted the project with a signing at the White House attended by a delegation from NCCS. In so doing, Mrs. Clinton became the first person outside the NCCS Congress to sign the Ribbon of Hope.

The NCCS delegation included coalition President Betsy Clark, PhD; Deputy Executive Director Susan L. Scherr; Catherine Logan, executive director of People Living Through Cancer and an NCCS co-founder; Mary P. Lovato, director of A Gathering of Cancer Support; and Jack Sheahan, director of the Greater Washington Coalition for Cancer Survivorship.

During their 10-minute meeting with her, the delegation told Mrs. Clinton about the NCCS Congress and the coalition's work in the survivorship movement.

"Mrs. Clinton was very gracious," said Clark after the meeting. "She told us



First Lady Hillary Rodham Clinton met with NCCS delegation at the White House to sign the Ribbon of Hope. Here she inspects NCCS poster, "To Care." With her (l-r): NCCS President Betsy Clark, Deputy Director Susan Scherr and GWCCS President Jack Sheahan.

that the work we do is worthwhile and that she was personally glad that our group was there to help survivors. She mentioned that her mother-in-law had died of breast cancer and that she understood the need for groups like ours."

The "sunbeam" signed by the First Lady was later signed by Harold Freeman, MD, Chair of the President's Cancer Panel and director of surgery at Harlem Hospital; Richard Klausner, MD, director of the National Cancer Institute; the NCCS Board of Directors; and numerous Congress participants.

The Ribbon of Hope is the brainchild of artist John Feight, director of the Foundation for Hospital Art in Atlanta. Feight, who conducted last year's "Paint-In" at the ninth annual Assembly, created the display onsite at the Congress.

Throughout 1996, Feight will take the ribbon to hospitals around the nation, gathering cancer survivors' signatures at paint-ins and other special

events. In October, he will present it at NCCS' 10th anniversary celebration in Albuquerque, NM.

NCCS hopes to have the ribbon signed by people in every state, with the Congress ribbon representing the District of Columbia. A group in Canada has also expressed an interest in signing the ribbon.

After the Albuquerque meeting, the Ribbon of Hope will go on permanent display at a site to be determined.

"It will stand as a lasting legacy of hope to cancer survivors," says NCCS Executive Director Ellen Stovall. "It signifies that, even after the shock of a cancer diagnosis, a new rich life may be possible."

"The significance of the ribbon is compelling," says Clark. "The ribbon, as it travels throughout the country, and once it is fully formed, will call national attention to the survivorship movement in a highly visible, hope-filled way."

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and the staff of the
Washington Court on
Capitol Hill

NCCS Congress: Learning Advocacy From the Inside Out

(continued from page 1)

innovative program she developed at Santo Domingo pueblo in New Mexico, A Gathering of Cancer Support. The Natalie Davis Spingarn Writer's Award went to Richard Knox of the Boston Globe for his series on the Dana-Farber tragedy. Senators Nancy Landon Kassebaum and Edward M. Kennedy were jointly honored with the NCCS Public Service Leadership Award.

Cancer survivor Annette Porter's wowed the audience with her vivid slide presentation of Expedition Inspiration, in which she joined a team of activists to climb Mt. Aconcagua in Argentina.

Other highlights included an uproarious and rollicking performance by comedian Scott Burton and a moving "Celebration of Hope," organized by Patricia Gilner, MEd, a 15-year cancer survivor.

New NCCS Agenda Set at Congress SpeakOut

(continued from page 3)

viable option was not debated. As Dr. Sui put it: "It is not whether we have managed care or not, but how to deal with some of these considerations in the context of the emerging managed care system."

Julia Rowland, PhD, member of the NCCS board of advisors and co-author of the definitive *Handbook of Psycho-oncology*, presented the report on psychosocial needs. Like the quality care group, the psychosocial group urged for access to and coverage of psychosocial services for all cancer patients and their families.

NCCS Immediate Past President and three-time cancer survivor Susan Leigh, RN, presented the outcomes of the long term and late effects working group, which asserted the right of every cancer survivor to have continued medical followup and access to specialized survivor clinics.

WATCH FOR THE NEW NETWORKER

The *Networker* is dressing up to celebrate NCCS' 10th anniversary! Starting next issue, we will sport a fresh, smart appearance to honor NCCS' decade of service to the cancer community and to mark a new beginning to that commitment. Next issue also features more stories on the NCCS Congress. Don't miss it!

IMPORTANT NOTICE

The National Cancer Institute seeks breast cancer survivors to participate in several high-priority clinical trials. Minority women are especially encouraged to participate. For information, call NCI at 800/4-CANCER (422-6237).

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