



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

NETWORKER

Summer/Fall 1996
Volume 10 • Number 2

SPECIAL COMMEMORATIVE ISSUE



NCCS 10th Anniversary

1986 – 1996

“From the *time* of discovery
and for the balance of *life*,
an individual *diagnosed* with
cancer is a **S U R V I V O R .**”

—from the NCCS charter (see page 8)

INSIDE

NCCS then and now

This special issue features articles from the first issue of the newsletter (March 1987) paired with new stories offering fresh perspectives.

Letters from the
presidents

3

The importance
of a national
coordinating effort

4

The birth
of NCCS

5

Confronting cancer
through art

6

The NCCS charter

The original mission,
and what NCCS has
done to fulfill it

7

Workplace bias:
much progress,
much to do

9

The horizon
of hope

10

Hooked on survivorship

Natalie Davis Spingarn recalls
the first NCCS Assem-
bly, where she met a
new breed of survivors

11

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.

FOR MORE INFORMATION



The National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 505
Silver Spring, Maryland 20910
Phone: 301/650-8868

THANK YOU

Sustaining Sponsors

Bristol-Myers Squibb Oncology, Princeton, NJ
CaP CURE, Santa Monica, CA
Robert Wood Johnson Foundation, Princeton, NJ

Leadership Circle

Amgen Inc., Thousand Oaks, CA
Fox, Bennett & Turner, Washington, DC
National Cancer Institute, Bethesda, MD
Ortho Biotech Inc., Raritan, NJ

Chair's Circle

GlaxoWellcome, Research Triangle Park, NC
Potomac Chapter-Meeting Professionals International, Annapolis, MD

President's Circle

David Katz Foundation, Honesdale, PA
PaineWebber, New York, NY
Pfizer Inc., New York, NY
Physician Reliance Network, Dallas, TX
Schering Corporation, Kenilworth, NJ
Upjohn Company, Kalamazoo, MI
U.S. Bioscience, West Conshohocken, PA

Platinum

American Cancer Society, Atlanta, GA
International Bottled Water Association, Washington, DC
Moore & Associates, Inc., Silver Spring, MD
SmithKline Beecham, Philadelphia, PA

Gold

The Marti Bernstein Fund (GWCCS), Washington, DC
Zeneca, Wilmington, DE

Silver

Brooklyn Academy of Music, Brooklyn, NY
Franklin National Bank, Washington, DC
Genetics Institute, Inc., Cambridge, MA
Leslie Scherr, PC, Washington, DC
Technical Resources International, Inc., Rockville, MD
Tumor Institute, Seattle, WA

We also wish to acknowledge generous in-kind donations by the following:

A.E.R., Inc., Laurel, MD
Foundation for Hospital Art, Atlanta, GA
Fox, Bennett & Turner, Washington, DC
Franklin National Bank, Washington, DC
Matthew Goode
Marshall Kragen
Lombardi Cancer Center at Georgetown University Medical Center, Washington, DC
MPI Business Systems, Inc., Fort Washington, MD
National Office Systems, Inc., Gaithersburg, MD
Office Movers, Inc., Rockville, MD

NETWORKER

Board of Directors

Chair *Vice Chair*
Fitzhugh Mullan, MD *Natalie Davis Spingarn*
Garrett Park, MD *Washington, DC*

President *Immediate Past President*
Elizabeth Clark, PhD *Susan Leigh, RN*
Albany, NY *Tucson, AZ*

Vice President, Development *Vice President, Interoorganizational Relations*
Diane S. Blum, ACSW *Dean H. Gesme, Jr, MD*
New York, NY *Cedar Rapids, IA*

Vice President, Strategic Planning
Samuel D. Turner
Washington, DC

Secretary/Treasurer
Linda B. Johnson
Washington, DC

Directors

Gail S. Broder, JD
 Ft. Lauderdale, FL

Daniel Fiduccia
Cupertino, CA

Pat Fobair, LCSW, MPH
Stanford, CA

Kathy LaTour
Dallas, TX

Jane Rodney
Princeton, NJ

Debra K. Thaler-DeMers, RN
San Jose, CA

Sandra Millon Underwood, RN, PhD
Milwaukee, WI

Karrie Zampini, CSW
New York, NY

Brad Zebrack, MSW, MPH
Ann Arbor, MI

Staff

Executive Director
Ellen L. Stovall

Director of Operations
Judith S. Blanchard

Deputy Executive Director
Susan L. Scherr

Director of Development
Sally C. McElroy

Director, Programs and Planning
Deborah K. Ash

Assistant to the Director
Donna Doneski

Administrative Assistant
Sonja Tyler

General Counsel
Barbara Hoffman, JD
Princeton, NJ

Editor
Terrence Campbell

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.

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.

Copyright © 1996. All rights reserved.

Letter from the president: A new idea, a new movement

BY FITZHUGH MULLAN, MD

I want to welcome you to the National Coalition for Cancer Survivorship—a new organization, a new idea, a new movement.

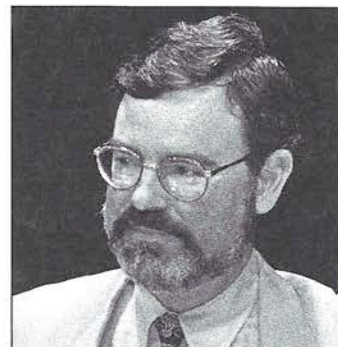
In October of 1986, 25 people met in Albuquerque for an intensive weekend of exchange and debate. The subject was cancer survivorship, the art and science of living after the diagnosis of cancer. All of the participants were involved in the issue as patients, as family, or as healthcare professionals, and all were concerned about the absence of coordination and collaboration among groups and individuals interested in survivorship.

And, indeed, we left Albuquerque with resolve—the resolve to pool a portion of our energies to build a network, an alliance of people and groups from around the United States who work to improve the quality of life, mutu-

al support, and opportunities for cancer survivors. This is the National Coalition for Cancer Survivorship, the NCCS.

The first edition of the NCCS newsletter is an important step in the development of NCCS activities. In it you will find the NCCS Charter, as well as more information about the plans of the organization and the writing of others concerned with survivorship. Most importantly, it is an invitation for you to join the NCCS. Without your support, both in interest and in finances, the NCCS will not succeed. We are counting on the dues of organizations and individuals to get the NCCS off the ground and on the ideas and activities you share with us to give substance to the network we intend to build.

So do get on the grapevine! We look forward to working with you. ♦



Mullan

TODAY ▶ Letter from the president

It's been 10 years since Fitzhugh Mullan wrote his introductory letter as the first president of the National Coalition for Cancer Survivorship. As the fourth president, I'm honored to have the opportunity to lead NCCS into its second decade of activities on behalf of this nation's 10 million survivors.

This issue of the *Networker* juxtaposes the past with the present, and highlights the outstanding achievements and milestones of the survivorship movement. For example, that first assembly of 25 people opened the way for events such as the First National Congress on Cancer Survivorship, held last November, and NCCS Town Halls™, which have been convened throughout the country.

Our founders called for more research on survivorship issues; the National Cancer Institute responded by establishing an Office of Cancer Survivorship last summer. A decade of vigorous advocacy in the policy arena has helped secure portability of insurance, the Family Medical Leave Act, the Americans with Disabilities Act, and FDA reform. Our report, *Imperatives for Quality Cancer Care*, has gained respect throughout the cancer community as a blueprint for future policy and program agendas. And, just recently, President Clinton appointed Ellen Stovall, our executive director, to the National Cancer Advisory Board.

You'll note dozens of such accomplishments as you read this issue. They bear tribute to the dream and the vision of the founders of NCCS. I proudly invite each of you to continue to work with us as we build on these past achievements and move our expanded survivorship agenda into the next century.—Betsy Clark



Clark

The importance of a national coordinating effort

Throughout the country, more organizations are working in the area of cancer survivorship. Most of them are small local units; many

each individual and organization has something valuable to offer

are neighborhood support groups—perhaps the heart of this movement. Others are larger, addressing the needs of specific segments of the cancer population, such as survivors of

TODAY ▶ Real progress, real hope

The visionary pioneers who founded the National Coalition for Cancer Survivorship probably did not foresee the decade's sea change in consumer and patient advocacy on behalf of people with cancer. In fact, it now seems that the founders were not only visionary, but prophetic.

A call for a national coordinating effort did not go unheeded by breast-cancer survivors. They took up that gauntlet in 1991 and, with NCCS as one of the founding organizations, began a grassroots effort that grew into the largest cancer advocacy phenomenon in the country—the National Breast Cancer Coalition. Similarly, men with prostate cancer, once organized around peer support, are now engaging political advocacy issues. NCCS continues to play a leading role in bringing segments of the cancer community together. Through our more than 350 member organizations and institutions, the individual and collective voices of survivors of all types of cancer and their supporters are heard whenever their concerns are debated in local, regional, and national forums. And with our establishment of the Cancer Leadership Council in 1993, seven of the nation's leading cancer patient advocacy and support organizations now come together on a regular basis to discuss and take action on policy issues affecting people living with cancer.

When Dr. Richard Klausner, director of the National Cancer Institute, established the Office of Cancer Survivorship in July, he sent a strong message of recognition and support for NCCS' advocacy efforts on behalf of this country's 10 million cancer survivors. Marking this historic milestone, we can move toward the future with real hope for more progress.—*Ellen Stovall*

breast cancer or persons dealing with childhood cancers. Still others address specific concerns, such as the emotional needs of cancer survivors in treatment, employment rights, or insurance issues.

Each individual and organization has something valuable to offer; together they could be a tremendous resource to each other. But that resource has never been utilized because, in the past, most groups and individuals have worked alone, in separate communities, or with separate segments of the cancer population.

The strength of the movement can be multiplied through a national coordinating effort; individuals and organizations, working together, can increase their productivity through the exchange of ideas, information, materials, programs, and personnel. In addition, groups that serve specific segments of the cancer population can be made accessible to members of support groups across the country, while other groups—those that address specific issues—can tie into a network of thousands of survivor groups.

Despite the impressive work already accomplished, large segments of the cancer population remain unreached. Many communities do not yet have any resources for the survivor population. This is especially true of small and rural areas and inner city neighborhoods where poor and minority groups live. In communities that do have resources, few programs address the needs of long-term survivors; programs are usually designed for survivors in treatment.

Thus NCCS seeks to strengthen and broaden an already viable movement by creating a comprehensive clearinghouse on survivorship. It will build on the already impressive achievements of its members, facilitating the sharing of the existing resources with the potential to multiply their productivity. NCCS will also encourage the movement to reach out to those who are currently underserved, the poor and minority survivors, those in communities with no survivors' activities, and long-term survivors. ♦

The birth of NCCS

NCCS was founded at a first-of-its-kind national meeting in October, 1986. The three-day meeting held in Albuquerque, NM, assembled individuals from across the country who have taken leadership roles in the cancer survivorship movement. Participants were chosen from respondents to a national survey taken in the summer of 1986.

That survey gathered basic information on organizations and individuals filling two criteria: first, they were addressing the concerns of cancer survivors, and second, they focused on peer support as a fundamental part of addressing those concerns. The survey's respondents

an organization founded of, by, and for cancer survivors

expressed a desire to join a national networking organization. To explore the possibility of establishing such an organization, the October national planning meeting was convened. The survey and the planning meeting were developed by New Mexico cancer survivors working out of the office of Living Through Cancer, Inc.

The meeting provided an opportunity for leaders from across the country to meet, to look at the growing national movement, and to define its needs and potentials.

The meeting began with a sharing of information and an assessment of the then current state of the movement. That was followed by a lengthy discussion of the needs of individuals and organizations involved with survivorship, and of the potential of the survivorship movement. The participants then formulated a statement of the goals and objectives of the yet unborn organization. The primary goal would be to generate a national awareness of cancer survivorship. Specific objectives would include developing a communication network and a

comprehensive clearinghouse for survivorship materials, advocating the rights of survivors, and promoting the study of survivorship.

TODAY ▶ Growing into leadership

The National Coalition for Cancer Survivorship (NCCS) was the vision of 25 individuals who, in 1986, met for three days in Albuquerque, NM. They represented leadership and expertise in community-based cancer support programs, cancer research, cancer information services, and cancer advocacy.

NCCS devoted most of the last decade to fulfilling the objectives of its founders—facilitating communication among people involved with cancer survivorship, promoting peer support, serving as an information clearinghouse, advocating for the interests of cancer survivors, and encouraging the study of cancer survivorship.

Most importantly, NCCS has succeeded as an organization founded *of, by, and for cancer survivors*, and, through thoughtful and responsible advocacy, has assumed a leadership role in the survivorship movement and the cancer community.

Central to NCCS's mission has been generating a nationwide awareness of cancer survivorship. This has been accomplished through publications, education to eliminate the stigma of cancer, advocacy for insurance and employment rights for cancer survivors, and by networking and promoting the many organizations and institutions that strive to inform, serve, and empower persons with cancer in the communities where they live and work.

Illustrative of this success is the increasing responsibility that cancer survivors are taking to ensure that their views are heard when issues which will affect their care and the quality of their lives are debated. As informed and responsible advocates, cancer survivors must represent a collective voice in shaping healthcare policy and standards of quality cancer care.

On behalf of our country's 10 million cancer survivors, and for the millions more who will be diagnosed with cancer, NCCS will continue to provide public policy leadership and to promote responsible advocacy among cancer organizations. We invite you to join with NCCS in this important effort.

—From *Imperatives for Quality Cancer Care, an NCCS report*

During the final day of the meeting, a carefully crafted charter was approved [see page 7] and the structure of the infant organization was established. The founding members contributed funds to support the organization for its first six months. Thus on October 26, 1986, the new organization was born. ♦

Confronting cancer through art

The first national exhibition featuring artwork by individuals with histories of cancer will run May 9 – June 2, 1987, at the

“the exhibition is designed to celebrate the creativity of those who, through art, have found a special avenue for coping with a life-threatening disease”

TODAY ▶ The confrontation continues

The “Confronting Cancer Through Art” exhibit culminated in a catalog commemorating the event. Its 60 full-color pages glowed with a generous selection of the colorful and dramatic artworks.

NCCS made the book, now out of print, available to survivors by mail.

NCCS held a paint-in at the 9th Assembly in Washington, DC. Led by John Feight of the Foundation for Hospital Art, participants painted images of butterflies and toucans on ceiling tiles later donated to area cancer treatment facilities. These bright images, painted by survivors for survivors, offer people undergoing treatment a visual oasis in otherwise austere treatment rooms.

This past year, NCCS made available a set of posters by Margaret Roberts. Roberts, whose story was featured in the Winter 1995 *Networker*, created images to accompany poetry written by her sister Susan, who died in 1988 from lung cancer. The artist created one poster, “To Care,” especially for NCCS. That poster took its inspiration from remarks made by NCCS Executive Director Ellen Stovall at the Albany Town Hall in June, 1995.

The 1996 conference in Albuquerque will offer another paintfest, again facilitated by Feight. In addition, we will display the Ribbon of Hope™, a travelling work in progress.

The Ribbon has toured the country—and the world—picking up signatures from cancer survivors, friends and families, and care providers. Hillary Clinton was the first to sign. The Ribbon made an appearance at the Olympic Games in Atlanta this past summer, where world-class athletes took part in signing.

—Terrence Campbell

municipal galleries of the Brand Library in Glendale, California. The Show is sponsored by the Jonsson Comprehensive Cancer Center (JCCC) of the University of California/Los Angeles.

Devra Breslow, Director of Special Programs at JCCC, explains, “The exhibition is designed to celebrate the creativity of those who, through art, have found a special avenue for coping with a life-threatening disease.” She also says that the art of cancer patients reveals a vast range of emotions including rage, anxiety, grief, and denial, as well as relief, joy, inner harmony, and peace. The show is designed “to celebrate the breadth and depth of the creativity of artists and craftspersons who have confronted the life-threatening condition of cancer.”

Expressing emotion through art is increasingly used as therapy for persons who are facing serious illness.

For genuine artists, this form of expression can be especially powerful. Many artist-survivors feel that their art played an essential role in coping with cancer. A typical statement made by artists: “If it hadn’t been for my art, I would not have survived.”

Even for those who do not consider themselves artists, such therapy can help in the expression and acceptance of feelings, which is an important part of living through an illness. Art can also inspire imagination, hope, and self-esteem.

The Confronting Cancer exhibition offers a unique opportunity for cancer survivors to see work by well-known artist-survivors that reflects the artists’ lives after diagnosis. The exhibition will allow survivors to experience the feelings others have about cancer and to gain insight into those feelings through the artistic medium. It will also serve to educate the public about the emotional impact of living with cancer. Additionally, the show will reinforce the important message that many individuals live productive, creative lives after the diagnosis of cancer. ♦

Seeking equitable healthcare through collaboration

BY DEAN H. GESME, JR, MD
AND SAM TURNER

Nearly five years after its move to Washington, DC, NCCS can take genuine pride in its accomplishments in public policy. Under the leadership of Executive Director Ellen Stovall, NCCS has voiced the cancer community's perspective in every major policy debate.

NCCS emerged as a major healthcare player in the 1993 healthcare-reform debate. The coalition asserted its support for universal health insurance coverage and focused policy-makers' attention on the vital concerns of people with cancer.

Working closely with the American Society of Clinical Oncology (ASCO), NCCS participated in the legislative effort to ensure coverage

of clinical trials for people with cancer and other life-threatening diseases.

Because of this collaboration, almost every major healthcare reform proposal included

NCCS has voiced the cancer community's perspective in every major policy debate

clinical trial coverage based on ASCO-NCCS criteria. Despite the collapse of comprehensive reform, coverage of clinical trials remains an important aim, with several bills supporting it

Continued on next page

1986 ▶ The NCCS Charter

Preamble

Cancer is an unwelcome intruder in life. Yet cancer is also an inescapable part of many lives. From the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor. Surviving is an enormously important, often difficult, always challenging human enterprise that involves the individual, the family, and the givers of care.

Mission Statement

The mission of the National Coalition for Cancer Survivorship (NCCS) is to communicate that there can be vibrant, productive life following the diagnosis of cancer; that millions of cancer survivors share a common, transforming experience that has impacted their lives with new challenges and enhanced potentials; and that these survivors, their families and supporters represent a burgeoning constituency and a powerful, positive force in society.

Objectives

1. To serve as a clearinghouse for information, publications, and programs for the many organizations working on the issues of survivorship
2. To provide a voice for the many common and recurring issues of those organizations reflecting the spirit, skills, and needs of the survivorship community
3. To advocate the interests of cancer survivors to secure their rights and combat prejudice
4. To promote the study of the problems and potentials of survivorship.

proposed in this Congress. During the health-care-reform debate, NCCS convened the Cancer Leadership Council, an informal coalition of diverse cancer advocacy groups. CLC members developed a position paper outlining essential elements of healthcare reform for cancer survivors. Representing NCCS and the CLC, Stovall presented the positions in testimony to a Congressional committee.

NCCS will play a key role in establishing quality care standards that include the consumers' viewpoint

The council provides a forum for exchanging ideas and information among groups with dissimilar priorities, ranging from breast to prostate cancer, from biomedical research to psychosocial support.

Through the council, NCCS has helped these disparate groups forge a common approach to many policy controversies affecting cancer treatment and research. During this Congress, the CLC has called for reforms in private health insurance practices and in the Food and Drug Administration (FDA).

Recently, the council expanded its membership to include, in addition to advocacy groups, organizations such as ASCO (the largest medical professional society for cancer specialists), the American Cancer Society, and the Leukemia Society of America.

Apart from the legislative activity, NCCS compiled and published a landmark report, *Imperatives for Quality Cancer Care*. The report sets standards for quality cancer care in the face of a rapidly changing healthcare delivery system.

To devise the standards, NCCS drew on a diverse cross section of cancer experts, including survivors, physicians, nurses, and researchers. NCCS continues to work with the Cancer Leadership Council and others in the cancer community to gain wide acceptance of these quality measures.

In the private sector, NCCS joined forces with the Foundation for Accountability

(FACCT). Formed by noted health service researchers and large self-funded insurance plans of Fortune 100 employers, FACCT seeks to develop guidelines for treatment that include quality as well as cost considerations. NCCS serves on the FACCT board as the only representative of cancer interests. Thus NCCS will play a key role in establishing quality care standards that include the consumers' viewpoint.

At the National Cancer Institute, NCCS served on the prestigious Subcommittee to Evaluate the National Cancer Program under the auspices of the National Cancer Advisory Board (NCAB). More recently, President Clinton appointed Ellen Stovall to the NCAB itself. Thus, Stovall can better ensure that survivors' interests receive full consideration in formulating cancer policy in the US. And NCCS' role in the recent establishment of the Office of Cancer Survivorship at NCI highlights the coalition's growing influence in the policy arena.

NCCS will carry its public policy message across the nation through grassroots ventures with groups such as ASCO, the Oncology Nursing Society, and the American Cancer Society. By building bridges among cancer groups, NCCS is working to help create an equitable healthcare system for all Americans.

Dean Gesme, an oncologist practicing in Cedar Rapids, IA, and Sam Turner, a partner in the law firm Fox, Bennett & Turner, serve on the NCCS board of directors. ♦

NEXT ISSUE

The next *Networker* will feature reports from the Albuquerque meeting, plus:

- a look at NCI's new Office of Cancer Survivorship
- profiles of NCCS awardees Arthur Frank, author of *At the Will of the Body*, and Susan Stewart, editor of *BMT Newsletter*

Workplace bias: much progress, much to do

BY BARBARA HOFFMAN, JD

From the very beginning, NCCS recognized that people with cancer suffered discrimination in various forms. Workplace bias was common (and remains too common today).

In the first issue of the NCCS newsletter, an article appeared that summarized the employment rights of cancer survivors at that time. The article was brief, because few laws, and accordingly few lawsuits, addressed whether cancer survivors had the right to be free from employment discrimination.

In 1986, only two federal laws—the Rehabilitation Act of 1973 and the Employment Retirement and Income Security Act (ERISA)—provided some relief. These laws, however, protected very few survivors because the Rehabilitation Act was limited to employers that received federal funding, and ERISA only prohibited employers from denying employees full participation in employee benefit plans. Although most states had laws that prohibited discrimination based on disability, these laws varied widely in whether and how they applied to cancer-based discrimination.

But in the past 10 years, the legal rights of cancer survivors have expanded significantly.

In 1992, the Americans with Disabilities Act (ADA) took effect. The law prohibits private and public employers from discriminating against people with disabilities, including (for purposes of the law) cancer survivors. The ADA requires employers to provide cancer survivors with reasonable accommodations, such as flex-time, to accommodate medical treatment. It prohibits prospective employers from asking detailed questions about your health until after they have offered you a job.

A brain-tumor survivor won the first case to go to a jury under the ADA. Many states have amended their laws to provide similar or stronger protection.

In 1993, Congress passed the Family and Medical Leave Act (FMLA). The FMLA requires employers with 50 or more employees

to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to address their own serious illness or in order to care for a seriously ill child, parent, or spouse.

What will the next 10 years hold for cancer survivors in the workplace? That's difficult to predict, because the ADA and the FMLA are relatively new laws. Court decisions rendered so far show no clear pattern as the courts struggle to apply the laws to people with a variety of medical conditions.

In the past decade, NCCS focused on expanding the legal rights of cancer survivors. Now that we have worked for and won passage of the ADA and FMLA, NCCS must focus on educating survivors, employers and the courts about how new federal and state laws apply to cancer-based employment decisions.

To that end, NCCS produces publications such as "Working It Out: Your Employment Rights As a Cancer Survivor" (a free booklet) and *A Cancer Survivor's Almanac: Charting Your Journey* (a book with an extensive chapter



Hoffman

in the past 10 years, the legal rights of cancer survivors have expanded significantly

on employment rights). NCCS also provides information and referrals to survivors who call with employment questions, and legal research assistance to attorneys who represent cancer survivors.

Overcoming obstacles to job security stands as a major challenge facing persons with cancer. In the years ahead, NCCS will continue the fight to end discrimination based on cancer, and to empower survivors with the information they need to protect their rights.

Barbara Hoffman, general counsel for NCCS, helped craft the language of the Americans with Disabilities Act. ♦

The horizon of hope

BY BETSY CLARK

Hope is the cornerstone of the survivorship movement. Symbolizing cancer survivorship, the Ribbon of Hope™ is a traveling “work in progress” and part of NCCS’ Celebration of Survivorship Through the Arts project whereby NCCS works with artists to inspire, build community, and raise awareness about cancer survivorship.

The Ribbon, created for NCCS by John Feight, director of the Foundation for Hospital Art (FHA) in Atlanta, has become an important component of NCCS’ outreach and public awareness campaign.

At the First National Congress on Cancer Survivorship last November, NCCS introduced the Ribbon of Hope as a symbol of the cancer survivorship movement’s hope and life force.

Congress attendees, including Harold Freeman, MD, chair of the President’s Cancer Panel and director of surgery at Harlem Hospital, and Richard Klausner, MD, director

of the Congress, yards and yards of bright yellow ribbon have been signed in gold ink by thousands of cancer survivors, their family members, friends, and healthcare providers at locales and events throughout the United States and in numerous other countries.

Ribbon signings have transpired at the centennial Olympics, at Survivors’ Day celebrations, at cancer awareness events like Race for the Cure and Relay for Life, and at hospitals and treatment centers.

Event coordinators have sent warm and heartfelt reports describing how much it meant to participants to sign the Ribbon of Hope™. The Ribbon has become a bright symbol of progress and it has helped the public to recognize that cancer no longer automatically equates with a death sentence. Half of all persons diagnosed with cancer survive, living full and productive lives after their diagnosis.

FHA’s Feight will configure all of the signed rays of the Ribbon into a giant sunburst for display October 4-6 during NCCS’ 10th anniversary celebration in Albuquerque.

The sunburst represents not only the progress made against the ravages of cancer, but also the progress made by NCCS in advocating for the rights and needs of cancer survivors.

At the conclusion of the Albuquerque meeting, NCCS will make available signed rays of the sunburst for local display. Later, wall-sized sunburst kits—Ribbons of Hope™—will be available to organizations and institutions to create their own local symbol to help to raise awareness about cancer survivorship issues and to create a community of hope in support of persons with cancer. To order the kits, contact NCCS.

NCCS President Betsy Clark is author of “You Have the Right to Be Hopeful,” available from NCCS. ♦

Share your “silver linings”

Do you have a story to tell? Share it with the world in Silver Linings: The Other Side of Cancer, a collection of stories of people’s positive outcome experiences with cancer. Oncology Nursing Press, Inc., will publish the book in early 1997. Share your experience as a patient, family member, friend, or healthcare provider. Contributors will receive a free copy of the book. You can send your story (250 words or less) or request for details to:

Shirley M. Gullo, RN, MSN, OCN
11967 Sandgate Drive
Chesterland, OH 44026
216/444-9825

of the National Cancer Institute, were among the first to sign the Ribbon of Hope’s™ rays. First Lady Hillary Rodham Clinton, whose mother-in-law died from cancer, boosted the project with a signing at the White House.

Hooked on survivorship

BY NATALIE DAVIS SPINGARN

Hooked. Hooked on survivorship. That's what happened to me when I first went to Albuquerque to keynote NCCS' first national Assembly nine years ago as a 13- (now 22-) year survivor.

I had not expected anything of the kind. I had expected another meeting, another speech like most I had given promoting my book *Hanging in There: Living Well on Borrowed Time*. I had expected the usual audience, full of questions about how I "felt" when I was first diagnosed with cancer, or asking why, if I had survived so many years with breast cancer, I was not "cured."

Instead I found a gathering of extraordinary people who had been through the trials of the cancer experience and come out punching. I found them the teachers, and myself the learner. Bowled over by the guts and optimism of the Cathy Logans and Susie Leighs I met in Albuquerque—people who hoped for the best but pragmatically prepared for the worst—I hopped aboard the NCCS bandwagon and onto its board of directors.

Back home I tried to define the pull I felt in a *Washington Post* article entitled "The New Breed of Cancer Survivors." Most of these new survivors, I reported, now expect to survive. Instead of resigning themselves to the fates, many, after an initial rough shocked period, set about fighting for their lives, searching for new treatments, investigating new ways, working hard for the right to enjoy "quality time." Seldom do they hide any more, even if they have suffered disfigurement or disability.

This attitude has not changed during NCCS' first decade. If anything, it has intensified as treatment opportunities and options have expanded. Now we find more men swelling our numbers, talking about their illness, whether it be out on the golf course, in a China-bound plane, or in the executive suite. After all, have not a major presidential candidate, a swashbuckling general, and others

joined us "to talk about it...slug it out in the open," as the inimitable late Sally Henderson once put it?

What has changed is the way other people regard us, and our sense of ourselves and our possibilities. As we have organized our forces

I found a gathering of extraordinary people who had been through the trials of the cancer experience and come out punching

and become more sure of our ability to speak up to national audiences as well as intimate groups, others begin not just to tolerate our participation, but to encourage (even court) it, not just to listen to our views, but to adopt and act on them.

So we see breast cancer survivors leading the way to a massive increase in government funding for breast cancer research. Or the National Cancer Institute responding to our concern about such issues as fear of recurrence or late effects of treatment with the creation of a special office to explore the physical, psychological and economic well-being of individuals following cancer treatment.

To say we have come a long way is an understatement. We need to increase our participation wherever survivorship decisions are made. The fact that we have been included on a few such bodies does not mean we have not been excluded from many—whether they be local hospital boards or national corporate-oriented managed care meetings (where, though we are the subject of marketing efforts, we are usually not invited to the podium).

Continued on next page

Hooked on survivorship

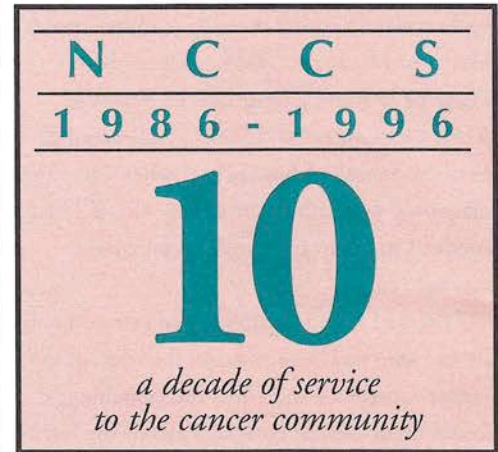
Continued from page 11

We should be able to spread the word about our concerns worldwide—about the kind of physicians we need and the crucial nature of patient-doctor communications, about the confidentiality of our medical records, about our need for adequate, universal health insurance, about the way we are treated in hospitals and clinics, and outside of them, in the workplace and our homes. Joining with other groups, in our own and in other countries, we need to articulate our suggestions, complaints, and expectations about patient centered care.

But as we work with others, we must be careful not to be exploited to advance agendas which are not our own. This is easier said than done, and often requires a considerable amount of sophistication. But with the medical marketplace growing increasingly competi-

tive, and our presence and patronage in demand, we must keep the power of our experience up front and center, and use it to speak with passion on behalf of our own rights, and those of our fellow survivors.

Natalie Davis Spingarn, vice chair of the NCCS board, frequently writes for the Washington Post Health Magazine. ♦



1010 Wayne Avenue, Suite 505
Silver Spring, Maryland 20910

Non-Profit Organization
U.S. Postage
P A I D
Silver Spring, MD
Permit No. 3268