



**National Coalition
for
Cancer Survivorship**

NCCS NEWSLETTER

A National Networking Publication

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THE IMPORTANCE OF A NATIONAL COORDINATING EFFORT

In response to the significant special needs of a burgeoning cancer survivor population, independent and unrelated support organizations have arisen in various communities across the country. Although most of those organizations have been in existence less than ten years, many of their members are already developing high levels of expertise in working with support groups and various aspects of survivorship. Many groups are led by individuals who are themselves cancer survivors. On a different level, a number of survivors are publishing books and articles that define the issues and concerns of survivorship and offer guidance. Some are starting private practices in counseling and related areas to help others living with cancer. A few national organizations, such as Cancer Care and The American Cancer Society, and a number of local health care facilities are further expanding their programs to address issues of survivorship — and there is even a national news magazine for cancer survivors, COPE, now in its first year of publication.

Throughout the country, more and more organizations are working in the area of survivorship. Most of them are small local units; many are merely neighborhood support groups, which are perhaps the heart of this movement. Others are larger, addressing the needs of specific segments of the cancer populations, such as survivors of 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.

There is plenty of evidence that the movement has already been very productive. In the area of publishing alone, a number fine newsletters and other small publications have been produced, as well as books, periodical articles, and other educational materials. Each individual, agency, and organization working in survivorship has something valuable to offer; all of them together 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.

Ironically, the strength of the survivorship movement can be measured, in part, by the fact that these activities have developed independently, without coordination. That, in itself, is a sign that they are in response to real needs and that the needs exist in communities across the country. This is a real grassroots movement.

Now the strength of the movement can be multiplied many times 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 be enabled to tie into a network of thousands of survivor groups.

In spite of the tremendous amount of impressive work already being done, there are large segments of the cancer population not yet being reached. 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.

The mission, then, of NCCS is to strengthen and broaden an already viable cancer survivorship movement by creating a networking system, opening and maintaining channels of communication, and 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 survivor activities, and the long-term survivors.

Those involved in this movement can be proud of their achievements. Working together through NCCS they now have an opportunity to enhance those achievement and to reach a larger portion of the survivor population. NCCS is an important investment in the future of survivors and in the future of all who are involved in survivorship.

Needed: An Agenda for Survivors

By Fitzhugh Mullan

Reprinted with permission from COPE magazine, November 1986.

Surviving. Nine letters that comprise a short word but a powerful concept.

Surviving is "to remain alive or existent," Webster's tells us, and also "to outlive" — to live beyond, to keep on living, to outlive ourselves, to outlive our diagnosis, to outlive, day by day, what might have been. Surviving is a potent idea, but one that has been paid little heed in the field of cancer treatment.

When I was diagnosed as having a cancer deep in the chest cavity, my mind riveted on two possibilities: cure and death. They seemed to be the options for my future, and I spent much of my waking life ruminating on them. It did not occur to me then, or for some time, that these two notions were insufficient to describe what was happening to me. I was not cured and I was not dead. Rather I was surviving — living on, existing and battling.

Survival was desperate days of nausea and depression and buoyant days of improved strength. It was the anxiety of waiting for my monthly chest X-ray and the joy of eating Chinese food for the first time after struggling with radiation burns of the esophagus.

These reflections and many others are a jumble of memories of a purgatory that was touched by sickness in all its aspects but was neither death nor cure. It was survival — an absolutely predictable but ill-defined condition that all cancer patients engage as they struggle with their illnesses.

There are what I call "seasons of survival" — distinct stages that all cancer patients go through as they cope with their illnesses. The acute stage starts at the moment of diagnosis and continues through the initial rigorous surgical, medical and radiological treatments. This "season," more than the others, is recognized for the support shown the newly diagnosed patient.

The period of extended survival that follows the acute stage is less well recognized. Out from under the initial treatments, the person with cancer now sets about trying to resume some semblance of normal activity. Yet this is a time of diminished physical strength and exercise capacity. Problems such as a lost body part, missing hair and lost weight now have to be dealt with in public and are set against the challenges of the home and the work place. Since this second phase is not predominantly a medical one, doctors and nurses tend to play a much smaller support role. The result often leaves many patients and their families fending awkwardly for themselves in the "healthy" world.

The third phase is not cure but permanent survival, an evolution to a period when the activity of the disease or the likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested. The Humpty Dumpty idea of "as good as new" — a powerfully appealing notion for all cancer patients — simply does not happen. For better and for worse, physically and emotionally, the illness leaves a mark, a permanent and important legacy. Problems with employment and insurance are common; survivors remain at risk for complications from original treatments; and long-term health programs are not well worked out.

There are five million survivors in the United States today. Five million. That is 2 percent of our citizenry; a population larger than that in 39 of our states. Survivors need to recognize their common ground, map it and cultivate it. We need to stimulate the development and use of mutual support groups and communication networks. We need to be able to participate in discussions about national research priorities. We need to be active politically to see that laws are written to assure cancer survivors a full and participatory life.

A LETTER FROM THE PRESIDENT OF NCCS

Dear Friends,

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 twenty-five 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 health care professionals, and all were concerned about the absence of coordination and collaboration among groups and individuals interested in survivorship. The spirit that brought many of us to Albuquerque is, in fact, captured by the accompanying article "Needed: An Agenda for Survivors" reprinted from COPE magazine.

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, mutual 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.

Sincerely,

Fitzhugh Mullan, M.D.
President of the Board of Directors

Fitzhugh Mullan is a pediatrician and a member of the faculty of the Johns Hopkins University School of Public Health. He is the author of the autobiographical book Vital Signs: A Young Doctor's Struggle with Cancer.

NCCS Newsletter
Published by

The National Coalition for Cancer Survivorship
323 Eighth Street SW
Albuquerque, NM 87102
(505) 764-9956

The National Coalition for Cancer Survivorship is a network of independent organizations and individuals working in the area of cancer support and survivorship. The primary goal of NCCS is to generate a nationwide awareness of survivorship, communicating that there can be a vibrant, productive life after the diagnosis of cancer. NCCS facilitates communication between those involved with cancer survivorship, serves as a clearinghouse for information and materials on survivorship, advocates the interests of cancer survivors, and promotes the study of survivorship.

There is a richness to surviving, a richness of having something that might never have been — whether it is two weeks of life or 50 years. We need to celebrate that richness by proclaiming ourselves survivors and building organizations to reflect our concerns on the local, regional and, ultimately, national level. That is an agenda for the immediate future.

THE BIRTH OF NCCS

The NCCS was founded at a first-of-its-kind national meeting in October, 1986. The three-day meeting held in Albuquerque, New Mexico assembled individuals from across the country who have taken leadership roles in the cancer survivorship movement. Twenty-one 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 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., New Mexico's cancer survivor organization. Funding was provided by St. Joseph Cancer Center of Albuquerque and St. Vincent Hospital of Santa Fe.

The October meeting, which has been called the "Constitutional Convention" of the cancer survivor movement, 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 focus of attention was the strengthening of the national movement.

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 were then ready to formulate 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.

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. From among the participants, the founding members pictured below, funds were raised to support the organization for its first six months.

The meeting was enormously successful. On October 26, 1986 the new organization was born. NCCS's work had just begun.



Founding members of the National Coalition for Cancer Survivorship take time for a group photo after the October 24-26 meeting in Albuquerque. They are left to right, bottom to top: Michael Lerner, Commonweal, Bolinas, CA; Fitzhugh Mullan, Garrett Park, MD; Neil Fiore, Albany, CA; Harold Benjamin, The Wellness Community, Santa Monica, CA; Pamela La Fayette, Cancer Lifeline, Seattle, WA; Helen Crothers, American Cancer Society, Oakland, CA; Barbara Waligora-Serafin, Harrington Cancer Center, Amarillo, TX; Estelle Weissburg, Cancer Guidance Institute, Pittsburgh, PA; Alice Hiat, Albuquerque, NM; Shannon McGowan, Cancer Support Community, Point Richmond, CA; Peggie Carey, Life After Cancer, Asheville, NC; Al Hiat, Albuquerque, NM; Julie Becker, Cancer Share, Cincinnati, OH; Yvonne Soghamonian, Candlelighters Childhood Cancer Foundation, Washington, DC; Shirley Miller, Cancer Hot Line, Plantation, FL; Patricia Ganz, UCLA Cancer Rehabilitation Project, Los Angeles, CA; Susan Leigh, University of Arizona Cancer Center, Tucson, AZ; Catherine Logan, Living Through Cancer, Albuquerque, NM; Barbara Hoffman, Cancer Patients' Employment Rights Project, Philadelphia, PA; Wendy Traber, "Surviving," Stanford, CA; Jan Kinzler, Oncology Nursing Society, Pittsburgh, PA.

SAMPLINGS

A wealth of printed material is currently being produced throughout the country by people who are involved in some way with cancer survivorship. To provide a sampling of that material and to demonstrate the potential of networking, each issue of this newsletter will carry one or more selected items from the publications of our member organizations.

If you have items, long or short, that seem appropriate to share through this feature, please mail them to The National Coalition for Cancer Survivorship, 323 Eighth Street SW, Albuquerque, NM 87102.

From

Surviving!

Surviving is published by a Hodgkin's disease support group in Stanford, California. It is written by survivors and focuses on personal stories. The publication is free to donors of \$10 or more. For more information, write: Pat Fobair, Department of Radiation Therapy, Room C050, c/o Stanford University Medical Center, 300 Pasteur Drive, Stanford, CA 94305.

The following is an excerpt from "Shadow Journey," a series of journal entries by Lyn Kahall reflecting her experiences as she lived through cancer treatment. "Shadow Journey" has been published in a series of issues of *Surviving* beginning with the August, 1986, issue. The excerpt is from the most recent issue, January/February, 1987.

Coping — The Person Within

I've had a glimpse of what it is like to grow old. Bodies hurt, energy lags, and looks fade. And yet the Spirit can remain untouched by all of those. What a pity happy, vibrant, hopeful, laughing, joking, moving Spirit should be locked into a frail, wrinkled, unmoving prison of a body. The mind is ever active and how often, I've looked in to an old one's face and seen the lively twinkle in the eye even through the hand palsied and body moved only in a wheelchair.

My momentary experience with aging will pass. My energy will return, my skin will become supple again and my hair will be glossy, thick and long. I will have metamorphosized after touching age and death. My Spirit will be every joyous but after the years have passed I hope someone will recognize the twinkle in my eye.

At this new beginning I feel better able to face the future and am more open to many choices for what life can be and what I can do. I feel free. I've often had the image of a line in which everyone must stand waiting for something bad to happen when it's your turn to be up front. I don't feel I'm in that line anymore although I know I'm just as vulnerable as the next person to life's risks. I'm not worried about the line anymore, I don't feel in it. I look forward to the future with all its opportunities for a full life.

It's my anniversary week — a time to remember the most horrible week in my life and be happy. Sometimes it doesn't even seem possible it could have happened and I speak lightly of it now. And then I remember those who can't write their journals any more and know that living can demand too much.

Lyn Kahall

From: *Living Through Cancer*, September/October 1985, Volume III, No. 5

Living Through Cancer, A Journal of Quality Living is published by Living Through Cancer, Inc., a cancer survivor organization based in Albuquerque, New Mexico. The bimonthly journal, usually twelve pages long, is available through an \$18 membership or a \$12 subscription. Write to LTC, 323 Eighth Street SE, Albuquerque, NM 87102.

LIVING THROUGH... A NEW AWAKENING...

Original Poetry by
BRENDA NEAL

Brenda is a 35-year-old cancer survivor. Born in Texas, she has lived the last 29 years in Albuquerque, New Mexico. In May of 1984, she received a diagnosis of non-Hodgkins lymphoma, and was treated with chemotherapy from August 1984 to January 1985.

Since Ms. Neal finished her treatment, she has experienced what she describes as "a whole new awakening." Much of her poetry reflects her own personal growth process, which has been greatly influenced by her cancer experience. Because most of us who have been diagnosed with cancer have also looked within ourselves in a new way and experienced a great deal of personal change, her poetry speaks to us in a very special way.

BRAND NEW

it's nice to see the world
with new eyes
renewal, rebirth
it's everywhere
— or is it in me?
Second chances can do that.

LIVING THROUGH

This kind of survival
is enough for me now.
Each day of living through
is another day made
another day mine.
I made it.
Come over the finish line
First, second, third
— it doesn't matter —
Just coming across
is winner enough.
Take each as it comes
and savor the victory
of living
and living through.

PERSPECTIVE

In a fragment of eternity
I went from
victim to visionary.
No longer content
to wallow in the past,
I live on the edge of tomorrow
with my feet squarely planted
in the timeless NOW.

PRIORITIES

I'd rather live
with uncertainty
than a deferred pension plan.
I'd rather embrace the unknown,
dancing on the edge
of tomorrow
than worry about a future
that may never come.
I can plan my life away
saving for the proverbial
RAINY DAY,
but what do I do
in the meantime —
when the sun's shining?

SHARING THE JOURNEY

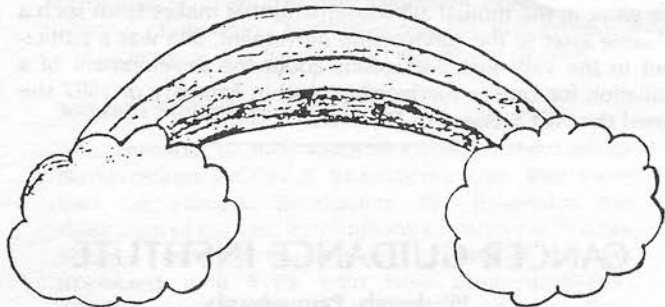
Interdependence
not independence
is the reality of this world.
I have a shared destiny
touching the lives
of countless others
as ripples in a pond
fan out in ever widening circles.
We live in
one another's company.
together we can diffuse the pain
and multiply the
joy
of being.

From: The Candlelighters Childhood Cancer Foundation Youth Newsletter, Volume VIII, No. 2; reprinted here with permission.

MY BROTHER

by Amy Ferguson

Amy Ferguson of Cincinnati, Ohio, who is eleven years old, wrote and illustrated this story when she was eight as a present for her mother after her sixteen-year-old brother's death.



My brother had Leukemia. It was a little hard to look at him sometimes because he lost his hair. I love my brother and my family and everything. And I wish they would take a little more time on the cure for Leukemia.

The day he died I couldn't go to sleep and my dad called my relatives. And they all came over and my dad called my neighbors and told them too.

I miss my brother.

The youth newsletter provides information for young cancer patients, their families, and care takers; reports news for young cancer patients and their siblings about how their peers are surviving and coping; and is an outlet for positive expression for young people with cancer.

To receive the free newsletter, you may write to the Candlelighters, 2025 Eye Street NW, Washington, D.C. 20006. Be sure to include the name of the publication in your request.

NOTEWORTHY CALENDAR ITEMS

March 19-21, 1987

ACS Fifth National Conference on Human Values and Cancer. "The Dynamics of Surviving Cancer: Clinical and Research Challenges and Opportunities." To be held in San Francisco, CA. For more information: ACS, 13 Elm Street, Manchester, MA 01944.

March 27-28, 1987

Make Today Count National Convention in Dayton, Ohio. Featuring Wayne Dyer, author of *Your Erroneous Zones*. For more information: Make Today Count, P.O. Box 222, Osage Beach, MO 65065.

CONFRONTING CANCER THROUGH ART

National Exhibition of Art Work by Cancer Survivors

The first national exhibition featuring art work by individuals with histories of cancer will be held May 9-June 2 at the municipal galleries of the Brand Library in Glendale, California. The show is being 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 goes on to say 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 craftspeople who have confronted the life-threatening condition of cancer."

Expressing emotion through some kind of art form 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 has played an essential role in coping with cancer; a typical statement made by artists is "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 will be a unique opportunity for other cancer survivors to see the work of well-known artist-survivors, work which is a reflection of the artists' lives after a diagnosis of cancer. The exhibition will allow survivors to experience the feelings others have about cancer and to gain insight into those feelings through the artistic medium. This will be an unusual opportunity for networking, a kind of peer support from a different perspective. It will also serve to educate the public at large 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.

For more information contact:

Devra Breslow

Director of Special Programs

Jonsson Comprehensive Cancer Center, UCLA

924 Westwood Blvd., Suite 630

Los Angeles, CA 90024

(213) 825-4066

AN INVITATION FROM RICHARD BLOCH

Last year's Fighting Cancer rally in Kansas City was so successful that a decision has been made to repeat the event this year. The date will be May 31 and the coordinator, Rose Mary Padberg.

Richard Bloch, founder of Kansas City's Cancer Hot Line, is inviting organizations in other communities to plan similar celebrations. It is hoped that, eventually, such events will be held in every major city in the United States. To make that hope a reality, Richard is offering the assistance of volunteers from the Kansas City group to work with groups in other communities. Extensive preparation is required, he says, but the results are well worth the effort. For more information, feel free to call

The Cancer Hot Line

4410 Main Street

Kansas City, MO 64111

(816) 932-8443



Edith Lenneberg — A Proponent of Mutual Aid

In the earliest stages of the development of our thinking about a national coalition, Edith Lenneberg was the one to point out that the very foundation of the survivorship movement in which we were involved is mutual aid. Edith is a person who abounds with wisdom and insight, gained through years of leadership and organizational work in the mutual aid movement.

Edith has been involved in mutual aid since it first became a part of health care. In 1952, following her own surgery for ulcerative colitis, she founded the Ostomy Association in Boston. At that time Alcoholics Anonymous was the only mutual aid organization that had received public recognition. Ostomy associations throughout the country were being formed by ostomates themselves — a grass roots movement in direct response to unmet needs. When the national organization was founded in 1962, the Boston group's publication, which Edith had initiated, became the national newsletter.

Edith went on to take an active role in the development of the Enterostomal Therapy profession, another development in direct response to unmet needs. It was the ostomates who understood the need for the development of this kind of expertise, and in the early years of the profession, most of the Enterostomal Therapists (E.T.'s) had ostomies or were relatives of ostomates. Edith was one of the first E.T.'s in the country. She believes that this kind of grass roots response to unmet needs can readily pave the way to appropriate response by professionals.

Edith also believes that the development of different levels of expertise to meet different kinds of needs is of prime importance. Today's ostomates in the acute stage are served by a highly skilled team — doctor, nurse, and enterostomal therapist — in a hospital setting. Registered nurses on the team must have special training to work in this field. Ambulatory patients are served by enterostomal clinics on an outpatient basis. And for the ostomate living in the community, the Ostomy Association functions as a support system. Of all of her achievements, Edith finds the most satisfaction in having been active in the development of this full continuum of services.

From 1967 to 1977, Edith worked at the New England Deaconess Hospital, where she developed a multidisciplinary clinic for ostomates that was years ahead of its time. With an emphasis on *living* with an ostomy, the clinic helped individuals make their way back into normal, everyday activities. This was one of the first programs to deal with the broad ramifications of recovery in relationship to patient and family life. In 1975 the clinic was used as a model for the development of a comprehensive life support clinic for cancer patients who were receiving treatment on an outpatient basis at Deaconess Hospital.

PROFILES

Edith brings all of this experience with her as she continues her work in the cancer survivorship movement. Her particular interest in the NCCS is, in part, a result of her own history of cancer. She underwent surgery for ovarian cancer in 1965 and again in 1975. In 1977 she had both chemotherapy and radiation therapy as further treatment for the cancer.

It is this personal experience with cancer, along with her extensive work in the mutual aid movement, that makes Edith such a valuable asset to the survivorship movement. She was a participant in the very first discussions about the development of a coalition for cancer survivorship, and in February of 1987 she joined the NCCS Board of Directors.

CANCER GUIDANCE INSTITUTE

...Pittsburgh, Pennsylvania

"A positive attitude is crucial. Think of cancer as a chronic, rather than a fatal, disease. In spite of the problems it causes, in many cases it can be controlled, allowing for years of productive and satisfying life."

In 1981 Lynn Gray, a cancer survivor, founded the Cancer Guidance Institute for the following purposes:

- To enable patients, families and medical/helping professionals to understand the vital role the patient plays in health recovery and health maintenance.
- To expand patient education materials.
- To facilitate effective communication between the medical/helping professions, the patient and the family."

The Institute's mission is "to promote a positive and realistic attitude to cancer patients, their relatives and friends through providing support from a person who has had a similar experience."

The Institute provides information on all types of cancer, on currently available methods of treatment, and resource materials. It also offers emotional support and guidance for immediate problems, from diagnosis through the course of the illness, as well as referral to other community resources.

In 1983 the Institute established a Cancer Hotline. The Hotline is a twenty-four-hour telephone service matching callers with trained volunteers who, themselves, have experienced cancer. The Hotline, which already has serviced over eighteen hundred calls, not only gives callers emotional support, but also gives volunteers a sense of fulfillment. Callers are urged to maintain open communication with family, friends, and care givers while learning about cancer, its prevention, and treatment, using all available resources — professional persons and health care agencies, printed material, and sources of emotional support.

To promote insight into the special needs of cancer patients, the Institute also sponsors workshops and conferences for the public and for health care professionals.

The Cancer Guidance Institute has several noteworthy publications. *The Cancer Challenge* is a quarterly newsletter containing current information on cancer topics. It is free to members; membership fees start at \$15. *Living with Cancer*, a booklet by Lynn Gray, and *Mind Over Cancer*, a cassette by Lynn Gray, are also available from the Institute.

For more information contact:

Estelle Weissburg, Executive Director
Cancer Guidance Institute
5604 Solway Street
Pittsburgh, PA 15217

National Coalition for Cancer Survivorship

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

The objectives of NCCS are:

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.

DID YOU KNOW?

The Wellness Community in Santa Monica, California has over 280 cancer patients involved in its programs each week and more than 3,500 since the organization was founded in 1982.

Life After Cancer-Pathways, in Asheville, North Carolina, has over thirty volunteers helping patients participate more fully in their treatment.

Commonweal, in Bolinas, California, offers seven, week-long retreats each year for exceptional cancer patients and family members interested in an intensive experience of stress reduction and group support, as well as in surveying the possible choices in established and complimentary cancer therapies.

Plantation, Florida, along with a number of other communities, has an active cancer hot line with trained cancer survivor/volunteers helping others who have questions or are in need of support.

The Cancer Counseling Institute in Bethesda, Maryland, was founded by cancer survivor Caroline Sperling.

NCCS has invited a number of prominent individuals to serve on the advisory board. The following have already accepted the invitation.

Rose Kushner, Author, President of The Breast Cancer Advisory Center, Kensington, MD.

Patricia Ganz, M.D., oncologist, Sepulveda, CA.

Michael Lerner, Ph.D., President of Commonweal, MacArthur Prize Fellow, Bolinas, CA.

John Durant, Director, Fox Chase Cancer Center, Philadelphia, PA.

NCCS would like to thank Margaret Kutcher for her help on this newsletter.

NCCS needs your support

Membership Information

NCCS membership is available to organizations and individuals. Membership fees will be used to develop a national network of cancer support and survivorship organizations and will entitle members to receive this newsletter, as well as future publications, and to participate in NCCS networking activities.

Membership fees are critical to launching NCCS, for it starts with no endowment and no assets other than the enthusiasm of its members and potential members.

☐ Charter Membership

NCCS is inviting individuals and organizations to become Charter Members by making an initial contribution of \$50 or more. Charter Members will be recognized as such in NCCS literature in the future.

☐ Organizational Membership

1 percent of the member organization's budget is suggested, or a minimum of \$25 (annual).

☐ Individual Membership

\$10 (annual).

Donations

☐ \$500 ☐ \$250 ☐ \$100 ☐ \$50 ☐ Other _____

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Make checks payable to the National Coalition for Cancer Survivorship, a project of LTC. (Until NCCS incorporation is completed, it is operating as a project of Living Through Cancer, Inc., a New Mexico 501(c)3 corporation.) Mail to:

The National Coalition for Cancer Survivorship

323 Eighth Street, SW

Albuquerque, NM 87102

EMPLOYMENT DISCRIMINATION AGAINST CANCER SURVIVORS:

The Current State of the Law

by Barbara Hoffman

Barbara Hoffman is a practicing civil rights attorney in Philadelphia who specializes in the rights of individuals with disabilities. She also serves as the Director of the Cancer Patients Employment Rights Project of the Foundation for Dignity, providing counseling to individuals and agencies, public and professional education, and consultations to federal and state legislators regarding pending legislation concerning the rights of individuals with a cancer history. Ms. Hoffman is a founding member of NCCS and Secretary of the Board of Directors.

Current studies estimate that more than one million of the five million cancer survivors in the United States experience some form of employment discrimination solely because of their cancer history. Types of discrimination include denial of a new job, demotions, undesirable transfers, loss of benefits, and outright dismissal. In many instances, cancer survivors are able to perform a job, yet are denied the opportunity to do so because employers and fellow workers erroneously believe that cancer is always fatal, is contagious, or renders the survivor disabled.

What are the legal rights of cancer survivors who are qualified to perform the job they seek of hold, yet are discriminated against solely because of their cancer history? Although the scope of anti-discrimination laws frequently changes, cancer survivors have some legal remedies in current federal and state laws.

Federal Laws:

1. The Rehabilitation Act of 1973 prohibits discrimination based on handicap in programs receiving federal financial assistance. Because federal courts have not reached the issue of whether the Act applies to cancer-based discrimination, its impact on cancer survivors is unclear. Some cancer survivors may fit under the Act's definition of handicap. Additionally, because the Act prohibits discrimination against an individual who is "perceived" to be handicapped, regardless of whether he or she is actually handicapped, the Act may apply to cancer survivors who face job problems because their employer erroneously "perceives" them to be impaired. The Act provides remedies such as back pay and reinstatement.

2. The Employee Retirement and Income Security Act (ERISA)

prohibits discrimination against an employee when the purpose is to keep that employee from collecting benefits under a benefit plan. ERISA may provide a remedy to an employee who has been denied full participation in an employee benefit plan. ERISA may also be implicated if an employer encourages an employee with a cancer history to retire as "disabled" when, in fact, the employee is able to continue working.

State Laws:

Most states have laws which prohibit discrimination based on handicap. Only Arizona, Delaware, North Dakota, South Dakota, and Wyoming do not prohibit employment discrimination based on real or perceived disabilities. Many state laws borrow language from the federal Rehabilitation Act. Some expressly prohibit cancer-based discrimination, while others provide protection only to individuals with real, as opposed to "perceived," disabilities.

Because few cancer survivors have brought lawsuits to enforce their rights to equal job opportunities, the handicap laws in many states remain untested as to cancer survivors. In a few states the law is clear.

In California, Vermont, and Illinois, state law expressly prohibits employment discrimination against a cancer survivor who is able to perform the job. In New York and Wisconsin, state courts have held that cancer survivors are covered under the state's handicap law.

What should you do if you are considering a legal remedy because you have been treated unfairly in the workplace because of your cancer history? You should not assume that you are included or excluded by any specific law. Employment discrimination laws undergo frequent modification, and groups such as the National Coalition for Cancer Survivorship are currently working with federal and state legislators to introduce new laws designed to address the specific needs of cancer survivors. If you are unable to work out a satisfactory agreement with your employer, you should contact a local attorney to determine how your specific case fits under current federal laws and the laws in your state.

Publication of this newsletter is made possible by a generous gift from Patricia MacManus of New York.

The NCCS Newsletter wants your participation. NCCS invites letters, poetry, comments, photos, and unsolicited articles on cancer survivorship. Articles should be written in nontechnical language and range in length from 350 words to 1000 words. Unused items will not be returned unless a stamped, self-addressed envelope is provided for that purpose.

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