National Coalition
for
Cancer Survivorship

NCCS NEWSLETTER

A National Networking Publication

Summer 1987 • Vol. I • Number 2 • 323 Eighth Street SW • Albuquerque, NM 87102 • 505-764-9956

LOBBYING EFFORTS FOR H.R. 1546

In May, NCCS initiated lobbying efforts to support passage of H.R. 1546, The Cancer Patients' Employment Rights Act. A letter addressed to members and friends of NCCS went out across the country. Many supporters responded by contacting their representatives and by publicizing the issues in their communities. The article in this issue, entitled "NCCS and Harrington Cancer Center Mutual Benefactors," details how Harrington Cancer Center in Amarillo, Texas campaigned vigorously for H.R. 1546 and how the relationship between NCCS and the cancer center has worked for mutual benefit of each organization.

Other NCCS members have responded to the publicity about H.R. 1546 in other ways.

In the spring 1987 issue of *The Cancer Challenge*, newsletter of the Cancer Guidance Institute in Pittsburgh, Pennsylvania, a full page was dedicated to the passage of H.R. 1546 and a reminder note was printed next to the address lable. The newsletter reaches seventeen hundred supporters.

The Candlelighters National Childhood Cancer Foundation sent the NCCS mailing to friends and supporters, along with information on the "Patients' Viewing Rights Act." (See information below.)

In New Mexico, the NCCS mailing was copied and forwarded to the members of Living Through Cancer. In one support group, a survivor who has her own computer offered to write letters for other group members. That's really getting down to the grass roots!

Many others, including Cancer Care in New York and the American Cancer Society, participated in the national lobbying effort. As a result of that effort, the number of legislative supporters of H.R. 1546 has already been increased from thirty-seven to ninety-four.

Please let the NCCS office know of your lobbying efforts. That information will be helpful in future lobbying efforts.

Other Lobbying Needs From Candlelighters

Current copyright laws prohibit the showing of VCR movies to patients in hospitals without the payment of thousands of dollars in fees. Candlelighters is requesting your support of H.R. 2429, which would change those laws by allowing the movies to be shown in hospitals, nursing homes, and hospice facilities for the same fee as a showing in a private home. Please contact your congressional representatives about this matter and alert your local news media to the issue.

Barbara Hoffman, J.D., secretary of the Board of Directors of NCCS. On June 17, Ms. Hoffman testified in support of H.R. 1546 before the House Committee on Labor and Education, Subcommittee on Employment Opportunities.

JOB DISCRIMINATION: HOW YOU CAN FIGHT BACK

By Barbara Hoffman, J.D.

• • • • •

Today, for the first time, you have a direct role in outlawing employment discrimination against cancer survivors. In March 1987, Congressman Mario Miaggi (D-NY) introduced H.R. 1546, the Cancer Patients' Employment Rights Act, a law that would make it illegal for public and private employers to discriminate against an individual because of his or her medical history. This article describes the bill and how you can support it.

The Cancer Patients' Employment Righs Act is necessary because there currently exists no uniform prohibition against cancer-based discrimination. The Federal Rehabilitation Act of 1973 applies only to certain recipients of federal funds and prohibits discrimination based on "handicap," a term that does not pertain to many cancer survivors. Coverage of state discrimination laws varies widely, with only a few states expressly prohibiting cancer-based discrimination. Because discrimination against qualified cancer survivors is a national problem, it requires a solution at the federal level.

continued on page 2

IN THIS ISSUE: Delayed Side Effects of Cancer Treatment; NCCS and Harrington Cancer Center, Mutual Benefactors: Samplings from *Make Today Count Newsletter;* Follow-up On Art Show; Bike America Tour.

NCCS Newsletter
Published by
The National Coalition for Cancer Survivorship
323 Eigth 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 persons 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.

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 individuals 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.

Job Discrimination, continued from page 1

H.R. 1546 is the most appropriate solution. It will explicitly prohibit discrimination based on medical history, thereby requiring that all qualified workers be afforded equal job opportunities. It will also require employers to evaluate employees according to their individual qualifications instead of their often irrelevant medical histories; thereby, it will eliminate medical examinations that are unrelated to job performance.

Many personnel policies prohibit employment of individuals who have had cancer or have received cancer treatment within five years. H.R. 1546 will prohibit policies such as these, which ignore actual abilities and treat cancer survivors as criminals, forced to serve a five-or-more-year sentence of unemployment and social ostracism. H.R. 1546 fairly and appropriately balances the right of employers to hire only qualified workers with the right of cancer survivors to be considered according to individual qualifications, rather than destructive mythology.

By increasing employment opportunities for all qualified individuals, H.R. 1546 will increase the number of wage earning taxpayers and decrease the number of persons receiving disability and unemployment benefits. It will also dispel inaccurate information about the survivability of persons with cancer and will promote full rehabilitation and integration into society of the more than five million individuals with histories of the disease.

Nearly one hundred years ago, President Grover Cleveland attempted to conceal his mouth cancer by telling the public that he needed a little dental work. Today, the President of the United States can disclose his medical history without causing public outcry or national panic, but the average worker with cancer must remain in the closet for fear of discrimination that will be financially and emotionally draining. Despite dramatic gains in cancer survivorship, an irrational attitude toward survivors is still commonplace.

One year ago, both the 99th Congress and the National Conference of Mayors passed resolutions recognizing the scope of cancer-based discrimination and expressing the need for a legislative solution. H.R. 1546, the Cancer Patients' Employment Rights Act, is that solution. There are not powerful PAC's behind the bill. It will pass only with grassroots support. This is a rare case in which action on your part will make a difference.

How You Can Make a Difference

1. Write to your congressman/congresswoman. Consult your telephone directory (under *Government Offices, United States Government — Congressman),* your library, or your local Democratic or Republican headquarters for the name of the person and his or her Washington address.

2. Include in your letter your name and address and the number and name of the bill (H.R. 1546, The Cancer Patients' Employment Rights Act).

3. Send a copy of your letter to:

The Honorable Mario Biaggi
U.S. House of Representatives
2428 Rayburn House Office Building
Washington, DC 20515

Representative Biaggi will follow through by calling your congressman/congresswoman and asking him or her to support the bill, as you have requested.

4. If you are a group, write to the congressman/congresswoman for each district in which you operate. Include a brochure or a *very* brief description of your activities.

5. Call your congressman/congresswoman's local office to schedule an appointment during the next Congressional recess to discuss the need for H.R. 1546, or take advantage of "open office" arrangements through which some representatives make themselves available on a first come, first served basis. They do listen to constituents who voice concerns in person.

A LETTER FROM THE PRESIDENT OF NCCS

The National Coalition for Cancer Survivorship is now more than six months old and, happily, we are passing from infancy to toddlerhood. We have a Board of Directors and a Board of Advisors. We also have a well-established office in Albuquerque, New Mexico, staffed by a skilled and experienced Executive Director, Catherine Logan.

New individual memberships arrive in the mail each day, as do new charter and organizational memberships. Fund raising goes slowly — nobody puts money on a stump and lets you carry it off — but important contacts have been established and some significant donations have been received. All in all, I think it is safe to conclude that the NCCS has established itself as an important and durable presence in the team of people and organizations in this country who are struggling against cancer.

One question may fairly be asked: Whither the NCCS? What are the plans, expectations, and goals of this new organization?

So far, the Board of Directors which meets monthly by conference call, has dedicated most of its energies to the issues of fund raising and organizational stability; it has not spent much time on long-range planning. Nonetheless, from our discussions a number of ideas have emerged that should be shared with members and friends of the NCCS.

Our immediate goals are to build membership and establish a firm financial base. In the longer term we have plans for publications beyond the newsletter including a book tentatively titled *An Almanac for Cancer Survivorship.* We would like to hold a national survivors' assembly and a conference on research issues related to survivorship, as well as establish a number of working groups in areas such as employment and insurance, professional education, and the promotion of mutual support groups. We see ourselves developing as a consumer alliance in cancer care.

We are interested in your reaction to these ideas and in your own ideas about NCCS and its future directions. Please do let us hear from you.

Fitzhugh Mullan, M.D.

The NCCS Newsletter wants your participation. NCCS invites letters, poetry, comments, photos, and unsolicited articles on cancer survivorship. Articles should be, double spaced, written in nontechnical language, and limited 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.

NCCS Advisory Board

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

Harold Benjamin, Esq.
President
The Wellness Community
Santa Monica, CA
Richard Bloch
Executive Director
Cancer Hot Line
Kansas City, MO
John Durant, M.D.
Director
Fox Chase Cancer Center
Philadelphia, PA
Neil Fiore, Ph.D.
Psychologist and Author
Albany, CA
Patricia Ganz, M.D.
Oncologist
UCLA Cancer
Rehabilitation Project
Los Angeles, CA
Stephen Jay Gould, Ph.D.
Professor of Geology
Harvard University
Cambridge, MA
Jimmie Holland, M.D.
Chief, Psychiatry Service
Memorial Sloan Kettering Inst.
New York, NY

Judie Johnson, R.N, Ph.D.
Nursing Director, Oncology
North Memorial Medical Center
Robbinsdale, MN
Rose Kushner
Executive Director
Breast Cancer Advisory Center
Kensington, MD
Michael Lerner, Ph.D.
MacArthur Prize Fellow
President, Commonweal
Bolinas, CA
Frederick P. Li, M.D.
Head, Clinical Studies Section
Clinic Epidemiology Branch
National Cancer Institute
Boston, MA
Grace Monaco, Esq.
Chairman of the Board
Candlelighters Childhood
Cancer Foundation
Washington, DC
Brandon Tartikoff
President
NBC Entertainment
New York, NY

CancerShare
Sharing Hope and Recovery
"We've Been There"

CancerShare, Cincinnati, Ohio

NCCS Member

BIKE AMERICA TOUR TO BENEFIT NCCS

A new organization called Bike America has been founded to raise public awareness and funds for charity. Each year the group will concentrate on a different charity, beginning with the National Coalition for Cancer Survivorshp in 1987.

This year's cyclists are Nina Cooper, Ginni Fleck, and the group's founder, Eric Rock. The three left Portland, Oregon, on June 10 and are planning to pass through thirteen states, finishing at Fox Chase Cancer Center in Philadelphia on September 2. During the tour, they will seek funds by soliciting direct donations and per-mile sponsorships. They intend to contact media personalities, hospital staffs, civic organizations, and individuals along the way, asking them to sponsor the team for a day. The cyclists will also be filling speaking engagements arranged by local hosts in each major area of their itinerary.

The proposed schedule for this year is listed below. Actual arrival dates may vary by two or three days. For more information on the Bike America tour, contact Mary Keck at (215) 947-9956.

1987 BIKE AMERICA TOUR ITINERARY

June 8	Portland, Oregon
June 17	Eugene, Oregon
July 3	Missoula, Montana
July 9	Yellowstone, Wyoming
July 18	Breckenridge, Colorado
July 29	Wichita, Kansas
August 2	Springfield, Missouri
August 8	Carbondale, Illinois
August 14	Lexingontin, Kentucky
August 23	Roanoke, Virginia
August 27	Richmond, Virginia
August 29	Washington, D.C.
August 31	Baltimore, Maryland
September 2	Philadelpia, Pennsylvania

FROM NCCS NEWSLETTER SUMMER 1987

DELAYED SIDE EFFECTS OF CANCER TREATMENT

The information in this article was obtained in an interview with Patricia Ganz, M.D., a medical oncologist and Adjunct Associate Professor of Medicine at the University of California, Los Angeles-San Fernando Valley Program in Sepulveda, California. Dr. Ganz has written and spoken widely on the rehabilitation of cancer patients. She is a founding member of the National Coalition for Cancer Survivorship.

• • • • •

For persons who have lived through chemotherapy and radiation, the immediate side effects of cancer treatment, such as nausea, loss of hair, and lowered blood count, are quite evident. There are also other side effects that are not immediately evident. To discuss these delayed side effects may be somewhat disturbing for some survivors, yet the matter needs to be explored; it may have a significant impact on the lives of many, particularly if they are caught unaware and unprepared.

Living with the side effects of cancer treatment is only one side of a vital trade-off. For the survivor, the other side is life itself. This fact must be kept in mind when considering the down side of the trade-off. The delayed side effects of treatment may be a threat to one's health and well-being, but were it not for the treatment, most survivors would not live to experience the threat.

Almost all of the drugs used in chemotherapy have both immediate and delayed side effects. Of the immediate effects, most are the result of treatments designed to act on rapidly growing and dividing cells — most importantly, cancer cells. Unfortunately, there is as yet no way to prevent those treatments from acting as well upon fast growing and dividing normal cells, such as those that line the intestinal tract; form the hair follicles; and fill the bone cavities, where red blood cells, white blood cells, and platelets are produced. Thus, unwanted side effect are inevitably produced.

In addition to the obvious and immediate side effects, there are less obvious cumulative effects caused by the build-up of the drugs in normal tissues. Cumulative effects can occur in almost any organ in the body, but most commonly affected are the lungs; the kidneys and other organs that metabolize the drugs; and the heart, where some drugs tend to "bind" to the tissue of the organ.

At the time of treatment, and even for a number of years thereafter, damage to the internal organs may be described as "subclinical," that is, not apparent to the patient. Eventually, such damage may become apparent. For instance, there may be some scarring of the lung tissue in a young survivor who has been treated recently with bleomycin, a drug that is used quite effectively against testicular cancer. For the present, the survivor may be symptom free, but, after many years, the scarring may lead to diminished lung capacity, which may become more noticeable with advancing age.

A physician may be aware of the possible side effects of each of several drugs when they are used separately. However, because some of the drugs have overlapping toxicities, the situation becomes complicated when the individual in treatment receives more than one drug. Using drugs together — although often very effective against the cancer — may create significant and unexpected problems. Combining radiation therapy with cheomotherapy complicates the matter even further, because radiation may sensitize tissues to drug effects. Although such complex treatment is quite common today, it is still relatively new in practice; consequently, experience with delayed side effects is limited.

Because there have not yet been significant numbers of survivors who have lived ten, twenty, or thirty years beyond treatment, many questions about delayed secondary effects remain unanswered. For instance, there are questions about what will happen to survivors as they age. Even in a normal, healthy person who has had no exposure to cancer treatment, aging causes a decline in the function of such organs as the heart, lungs, and kidneys. It is not yet known if those functions will deteriorate at a faster rate in cancer survivors who have received drugs with long-term, cumulative effects. Will those individuals experience a normal aging process? That is an unanswered question.

Even though damage to normal tissue, as described above, can be significant, it is usually not life-threatening. What is more serious is the possible development of second malignancies, both leukemias and solid tumors, that may result from exposure to certain chemotherapy drugs and to radiation. Although the occurrence of second malignancies probably will not affect a large percentage of survivors, there is some increased risk. As yet, the risk beyond ten years has not been well studied.

In survivors of Hodgkin's disease and some survivors of ovarian cancer, studies do indicate that leukemias which develop as a result of treatment usually occur five to seven years after the treatment. Solid tumors may develop ten to twenty years after treatment. That aspect of the problem has not yet been thoroughly studied. Only recently have there been sufficient numbers of survivors to provide adequate data on the occurrence of secondary malignancies. Until now, leukemia has been the most prevalent second malignancy in the first decade after treatment. But now, at the beginning of the second decade with large numbers of survivors who have received chemotherapy and/or radiation therapy, there may be some increase in the number of solid tumors or nonhematological malignancies. This area will undoubtedly be studied quite intensively in the next few years.

Much of the research that has been done on the long-term consequences of treatment has been concerned with the survivors of childhood cancers. Because most of those survivors have been treated at specialized cancer centers, and because a number of childhood cancers have been treated very successfully, there is a fairly large pool of survivors available for study. What is learned from tracking those survivors of childhood cancer for ten or twenty years after treatment is giving some indication of the problems that survivors of adult cancers may face.

However, because children are not yet fully developed, they are more vulnerable to damage than are adults. Therefore, delayed effects are usually more severe in children. For example, children who have received both chemotherapy and radiation therapy sometimes experience serious learning disabilities and growth retardation. While studies on older adults who have received whole-brain radiation also show cognitive problems, the problems in children are more pronounced. A child may not be able to function normally, yet an adult, even with cognitive processes that may be somewhat dulled, is likely to be functionally less affected by the therapy.

A number of pediatric studies are now concentrating on the problem of minimizing the dysfunction caused by secondary medical problems, yet maintaining high cure rates. Such studies can be done because the cure rate for many childhood cancers is very high, as high as seventy-five to one hundred percent. Until the cure rates for other cancers reach equally high levels, treatment will be geared toward attacking the cancer with everything available. No attempt will be made to back off in order to avoid or modify toxicity.

Some institutions such as the St. Jude Children's Research Hospital in Memphis, Tennessee, are now beginning systematic follow-up of long-term survivors. Much more research of that sort needs to be done, but again, until we have a highly significant number of survivors in their second decade after treatment, there will be no opportunity for the kind of follow-up needed, and many crucial questions will remain unanswered.

In the meantime, there are ways for oncologists to manage some of the delayed secondary medical problems. In cases where several standard treatment methods are available, choices can be made with possible delayed effects in mind. For example, several equally effective treatments are available for Hodgkin's disease. The older one, commonly referred to as MOPP, often causes infertility and increases the risk of leukemia. A newer treatment, ABVD, also has some delayed consequences (toxicity in the heart and lungs), but, as yet, it has not been associated with infertility or increased risk of leukemia. Therefore, in the case of a young person who wants to have children, ABVD may be chosen over MOPP. Possible infertility can also be addressed by the use of sperm banking prior to treatment.

It is possible, as well, for survivors who are at risk for secondary problems to take steps to protect themselves — at least from being caught unaware. The following are some suggestions for those survivors.

1. Familiarize yourself with the specifics of the treatment you received. It is not enough just to know that you had radiation; you should know how much radiation you had. It is also important to know precisely which drugs you took and for how long.

2. Keep a written record of your treatment. Perhaps the simplest way to do this would be to ask your oncologist for a summary letter describing your treatment in specific terms as to the drugs that were taken and how much radiation was given to what parts of your body. This could be used as an introduction to a new physician, especially ten or twenty years after treatment, when it might be difficult to track down old medical records.

3. Remain alert to the possibility of secondary medical effects, however remote that possibility might seem to be. Do not dwell on it, but remain cognizant of it. If an unexplained problem arises do not hesitate to remind your physician of the cancer treatment and ask if the problem might be related to that treatment.

4. Plan to have regular follow-up visits for the rest of your life. Even if you are one hundred percent sure you are cured, you will need more than just ordinary periodic health check-ups. The farther you get from the treatment, the more casual you are likely to become about ever having had the disease, so it is important to remember that late effects may not show up for ten or twenty years.

5. Stay abreast of the growth of knowledge and information about secondary medical effects. Remember that more information will become available as time goes on. Support organizations, such as the NCCS, which encourage the study of late effects and disseminate new information as it becomes available.

When we speak of surviving cancer, we are speaking of many different kinds of disease, with many different treatments. Even for one particular kind of cancer, different treatments may be used with different persons. Thus, it is virtually impossible to generalize about or predict what the side effects on the individual survivor will be. But, no matter what the type of cancer or the kind of treatment, survivors who want to do as much as possible to protect their health will be alert to the possibility of the delayed effects of their treatment.

Editor's note: *In connection with the article above, Dr. Ganz has requested that we inform our readers of a recent report in the* New England Journal of Medicine *(Vol. 316, March 1987, page 710), which describes the most recent studies in the area of secondary malignancies in individuals who have received earlier treatment for Hodgkin's disease.*

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

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: *Make Today Count*, a bimonthly newsletter

Make Today Count, Inc., is an organization offering emotional support to persons with cancer and other life-threatening illnesses, their family members and friends, as well as to professionals who work with them. You may subscribe to the newsletter for $10. Write: Make Today Count, Inc., P.O. Box 222, Osage Beach, MO 65065.

The following exerpt is from the September/October, 1986 issue of the newsletter. It is taken from *Until Tomorrow Comes* by Orville E. Kelley, Everest House, 1979, and reprinted here with permission from Make Today Count's administrator Mary Lou Alsin.

—

Many patients and families of patients have sent me poetry and articles they have written, mostly about their experiences in living with a serious illness, or how it feels to watch someone you love die of an illness. Through these poems and articles, I learned that from the deepest tragedies can come a new and greater awareness of life, and a determination to help others. It soon became apparent that people from all over the world were having to adjust to their own new worlds after the diagnosis of a life-threatening illness. Some faced it bravely; others were terrified. I couldn't find any common thread linking responses to a terminal illness, but it was apparent we all must choose our own life-style.

I wanted my own life, no matter how short, not to be a wasted one. I knew that a person could live for seventy years and waste much of the time, or live only twenty years, with a full life involved.

No matter how you decide to spend the rest of your life, time keeps moving along. For those of you who feel cheated because of an unexpected illness or tragedy, I suggest you quit asking, "Why me?" and discover how important life is. If you have recently been diagnosed as having a life-threatening illness, you might find it difficult, if not impossible, to believe that some of your most memorable days might be ahead of you. But my files are full of letters from patients who have told me this is true. And it certainly has been true for me.

EDUCATION INFORMATION SUPPORT

A positive approach
to breast disease

OPERATION
UPLIFT

1703 W. 14th
Port Angeles, WA 98362

NCCS Member

NCCS & Harrington Cancer Center, Mutual Benefactors

by Kathy Watson

Kathy Watson is Communications Coordinator for The Don and Sybil Harrington Cancer Center in Amarillo, Texas. She has a background in print and broadcast journalism and specializes in program production. This article is the first of what she hopes will be many of national interest on cancer survivorship issues.

• • • • •

Creation of the National Coalition for Cancer Survivorship has had two distinct results: heightened enthusiasm and mutual sharing. For us in Amarillo, the excitement began when Waligora-Serafin returned from Albuquerque after the organizational meeting of the Coalition. The Harrington Cancer Center wasted no time before joining NCCS as a charter member. We began spreading the good news with articles in the Cancer Center's monthly physicians' publication, in the semiannual newsletter to major donors, and in the monthly patients' newsletter. Together, those publications reached more than twelve thousand individuals, businesses, churches, and nonprofit agencies.

Later, a news release was sent to all radio, television, and newspaper media in our five-state service area, briefly explaining survivorship and the Harrington Cancer Center's role in promoting it. The release was accompanied by reproduced articles on the NCCS and on Dialogue, a weekly educational/support group — sponsored by the Cancer Center and the American Cancer Society — which often addresses survivorshp issues with patients, families, and friends. Media response at that time was good but, predictably, the real interest was generated when we followed up with news releases on the Biaggi bill outlawing employment discrimination against persons with a history of cancer.

That was the first substantial evidence of the NCCS in action. The media jumped on it with zeal, and reporters showed genuine excitement about survivorshop and related issues. For the first time, the Cancer Center received requests for interviews from the farthest reaches of its service area.

Because the Harrington Cancer Center is a nonprofit facility seeking government research grants, policy requires approval by the executive board of directors for any political issues on which the Center wishes to take a stand. In the case of Biaggi bill, the information from the NCCS did not arrive in time to permit action by the board. That dilemma was resolved by arranging news interviews with the understanding that Waligora-Serafin was representing the NCCS, rather than the Center. Fortunately, some of the interviews did provide opportunity to discuss Harrington Cancer Center's survivorshop activities.

When being interviewed for television, it is always necessary to provide "visuals" — in this case, patients. Clearly, we did not want to create animosity by citing specific examples of discrimination against cancer survivors in our community, even though we did acknowledge the existence of such discrimination. Accordingly, interviews involving patients were arranged with the understanding that the focus was to be on the active, productive lives of cancer survivors, rather than on their experiences of discrimination. One of the survivors who agreed to be interviewed was a motorcycle policeman; that man was so pleased and excited with the prospect that he even washed his motorcycle in preparation for the taping. The Amarillo Police Department considered his report a feather in its cap.

The task of creating awareness and grassroots support of the Biaggi bill fell to Mrs. Waligora-Serafin, who used the letter to Congressmen (furnished by the NCCS) as a tool for initiating a community-wide letter-writing campaign. Within a matter of days, Waligora-Serafin personally contacted all local hospitals, the Texas Nurses' Association, the Oncology Nurses Society, and other cancer centers in the state of Texas to generate support for the bill.

Taking a leadership role in the survivorship issue has returned many benefits. The public now recognizes The Don and Sybil Harrington Cancer Center as an advocate of cancer survivors' rights, and it is more aware of the existing discrimination that makes protective legislation necessary. Thus, our cancer survivors know that we are fighting for them. When a patient is excited about doing an interview on his survival experience and is proud to have been asked, we know we are making headway in eliminating the stigma of cancer and the ignorance that perpetuates it.

Networking with organizations in the community and throughout the state has put the Harrington Cancer Center in contact with individuals who have similar interests and concerns. So the base for future efforts of this nature is strengthened.

The excitement continues as we explore future opportunities to develop our advocacy role. The news release on survivorship has prompted a local, independent television station to investigate the possibility of a live, call-in telecast in which survivorship issues are discussed and experts from the Harrington Cancer Center are available to answer questions from viewers. The Cancer Center is planning an educational Survivorship Day in the fall for patients and their families. Related symposia for health care professionals, also, are under considerations. And Cancer Center personnel are looking at survivorship issues and their impact on program planning, development, and implementation.

Being involved with the NCCS provides many rich resources and contacts all across the nation, resources that we probably would not otherwise have. This obvious illustrates the old saying would not otherwise have. This illustrates the old saying that the more one shares, the more one has. Certainly, it demonstrates how powerful and effective each of us can be when we work together. The hope of the staff of The Don and Sybil Harrington Cancer Center is that we can continue to expand on these efforts. Our commitment is to cooperate with the NCCS in developing its enormous potential for helping cancer survivors everywhere.

Opportunities are A'bloomin'

Whenever I see a daffodil these days, I think of it both as the cancer patient's symbol of hope and as a symbol of survival. Why? Because, to commemorate The Don and Sybil Harrington Cancer Center's fifth anniversary last fall, volnteers sold and planted forty-thousand daffodil bulbs throughout the grounds of the Amarillo Medical Center.

The prospect of such a vivid, living symbol of hope was exciting, and we began planning a Bloomin' Parade for the spring. Several weeks of snowstorms eventually brought our parade plans to a freezing halt, but the daffodils continued to flourish, storm after storm. Even after an outright blizzard, most of them raised their heads again. Some even bloomed.

It was Barbara Waligora-Serafin, Director of Supportive Care at the Cancer Center, who drew a clear analogy between those daffodils and the experience of being a cancer patient, enduring unexpected storms, yet surviving with dignity. Of course, Mother Nature called the shots for the daffodils, while cancer survivors must seize their own opportunities. And the opportunities, the are a'blooming'.

Although the Harrington Cancer Center's Bloomin' Parade was cancelled, two people did show up for the event. The chaplain of a local hospital and his wife, who is a cancer survivor, braved the fierce winds in the expectation of celebrating hope. Finding no parade, they picked some daffodils, waved them in the air, marched around and cheered anyway. That is surviving in style — and is a good example of seizing opportunities where we find them.

Follow-up on Art Show

Confronting Cancer Through Art 1987 was the first national exhibit by fine artists who have experienced cancer. It was organized by Art That Heals, a component of the Jonsson Comprehensive Cancer Center at The University of California/Los Angeles and was on display from May 9 through June 2, 1987 in the Brand Art Galleries, Glendale, California.

Represented in the exhibition were the works of thirty-six juried artists and six invited artists of national and international reputation. The majority of the participants are working artists and/or art educators. They came from California, New York, New Jersey, the District of Columbia, Illinois, Missouri, New Mexico, and Western Canada, and nearly all of them honored the show by their presence at a gala Artists and Donors Reception on May 17. The exhibition was well attended by the general public, as well as by members of cancer support groups and others interested in cancer survivorship. In addition, it attracted a considerable amount of attention in the news media.

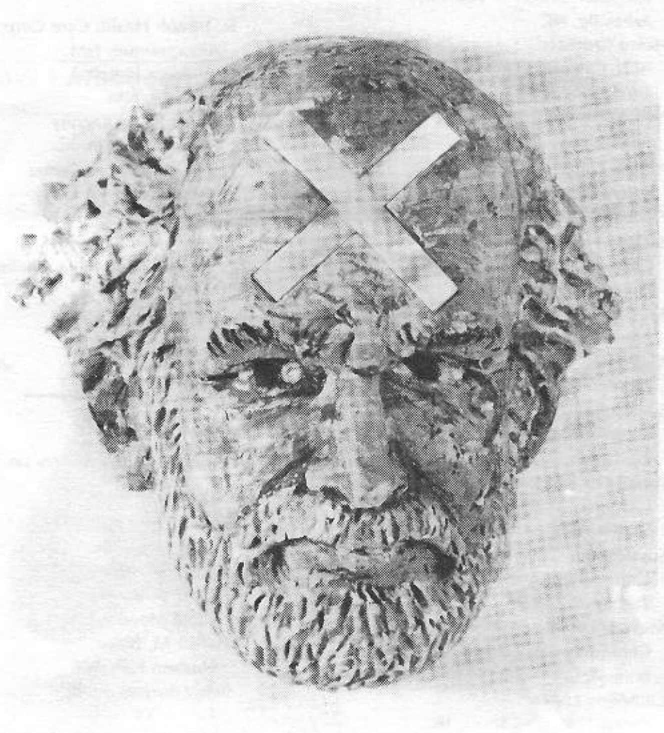
An elegantly beautiful, sixty-page catalog of the exhibition has been published with a cover image, in full color, by the late Corita Kent. That same image, with the words, "Life is a succession of moments, to live each one is to succeed" is also available as a 24" x 30" poster, ready for framing. Both items can be purchased by mail from Devra Breslow

Art That Heals
Jonsson Cancer Center, UCLA
Louis Factor Building 10-247
10883 LeConte Avenue
Los Angeles, CA 90024.

The price of the catalog is $11 per copy, including postage and handling; posters are $22 each. California residents should add 6.5 percent for sales tax. All checks should be made out to : Regents, University of California.

Mrs. Breslow, the Director of Art That Heals, has initiated plans to take a portion of this first show on tour to other galleries, hospitals, and cancer centers. Her plan is to blend into each showing some newly juried works by regional artists with cancer. Over a two-year period as many as 150 additional artists could be represented, along with those already in the show.

Portrait Xed by ceramic sculptor Robert Arneson was one of the provocative images in Confronting Cancer Through Art 1987. Arneson started work on this facial mask the night before undergoing major cancer surgery. He is a professor of art at the University of California and a resident of Benicia, California. His work is the subject of a major retrospective traveling exhibition.



For further information about future plans for the Confronting Cancer exhibition, the exhibition catalog or poster sales, contact Devra Breslow at the address shown above, or call her at (213) 825-4066.

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 of 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 NCCS NEEDS YOUR SUPPORT

☐ $500 ☐ $250 ☐ $100 ☐ $50 ☐ Other ____________________

Name ____________________ Phone (   )

Address ____________________ City ____________ State ____________ Zip ________

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

Founding Members

Julie Becker
  Cancer Share
  Cincinnati, OH
Harold H. Benjamin
  The Wellness Community
  Santa Monica, CA
Peggie Carey
  Life After Cancer — Pathways, Inc.
  Asheville, NC
Helen Crothers
  ACS, California Division
  Oakland, CA
Neil A. Fiore
  Albany, CA
Patricia Ganz
  UCLA Cancer Rehabilitation Project
  Los Angeles, CA
Barbara Hoffman
  Cancer Patients' Employment Rights Pr.
  Philadelphia, PA
Al Hiat
  Albuquerque, NM
Alice Hiat
  Albuquerque, NM
Jan Kinzler
  Oncology Nursing Society
  Pittsburgh, PA
Pamela La Fayette
  Cancer Lifeline
  Seattle, WA
Susan Leigh
  University of Arizona Cancer Center
  Tuscon, AZ
Michael Lerner
  Commonweal
  Bolinas, CA
Catherine Logan
  Living Through Cancer, Inc.
  Albuquerque, NM
Shannon McGowan
  Cancer Support Community
  Point Richmond, CA
Shirley Miller
  Affirmative Cancer Therapy
  Plantation, FL
Fitzhugh Mullan
  Garrett Park, MD
Wendy Traber
  "Surviving"
  Stanford, CA
Barbara Waligora-Serafin
  Harrington Cancer Center
  Amarillo, TX
Yvonne Soghomonian
  The Candlelighters Childhood Cancer Fdn.
  Washington, DC
Estelle Weissburg
  Cancer Guidance Institute
  Pittsburgh, PA

Major Donors

St. Joseph Health Care Corporation
  Albuquerque, NM
St. Vincent Hospital
  Santa Fe, NM
Foundation for Dignity
  Philadelphia, PA
Fox Chase Cancer Center
  Philadelphia, PA
Bike America
  Huntingon Valley, PA
Frank Hoffman, MD & Thelma Hoffman
  Savannah, GA
Lucy Waletzky, M.D.
  Chevy Chase, MD

NCCS Charter Members (as of 6/23/87)

Ivan Barofsky
  Silver Springs, MD
Jane Beatty
  Martinez, CA
Harold Benjamin
  Santa Monica, CA
Marian M. Blake
  Hudson Falls, NY
Breast Surgery Alert
  Dallas, TX
Cancer Counseling Institute
  Bethesda, MD
Cancer Guidance Institute
  Pittsburgh, PA
Cancer Hot Line
  Kansas City, MO
Cancer Lifeline
  Seattle, WA
Cancer Patients Employment Rights Proj.
  Foundation for Dignity
  Philadelphia, PA
Barbara J. Carter
  San Rafael, CA
Gloria Felde
  Seattle, WA
Neil Fiore
  Albany, CA
Joanne Frankfurt
  San Francisco, CA
Barbara Frew
  Alamo, CA
Patricia Ganz
  Los Angeles, CA
Ellen R. Gritz
  Los Angeles, CA
Bruce M. Greenfield
  Santa Fe, NM
Alan Gross
  New York, NY
Harrington Cancer Center
  Amarillo, TX
Al & Alice Hiat
  Albuquerque, NM
Linda Hearn
  Escondido, CA
Joan Hermann
  Philadelphia, PA
Mr. & Mrs. H. Howard
  Virginia Beach, VA
Linda M. Johansen
  Walnut Creek, CA
Mikiko Kurosaka
  Glen Falls, NY
Grady & Donna Leach
  Gadsden, AL
Susan Leigh
  Tuscon, AZ
Edith Lenneberg
  Corrales, NM
Michael Lerner
  Bolinas, CA
Life After Cancer — Pathways, Inc.
  Asheville, NM
Living Through Cancer, Inc.
  Albuquerque, NM
Catherine L. Logan
  Albuquerque, NM
Patricia MacManus
  New York, NY
Make Today Count, Inc.
  Osage Beach, MO
Edith Marks
  New York, NY
Mary Anne Masse
  New York, NY
Shannon McGowan
  Point Richmond, CA
Memorial Sloan-Kettering Cancer Center
  New York, NY
Shirey Miller
  Plantation, FL
Mountain States Tumor Institute
  Boise, ID
Mariquita Mullan
  Washington, DC
National Cash Register Corp.
  Albuquerque, NM
Robert Oldham
  Franklin, TN
Grace Olivarez
  Albuquerque, NM
Oncology Nursing Society
  Pittsburgh, PA
Wilhelm Rosenblatt
  Corrales, NM
St. Joseph Hospital
  Albuquerque, NM
St. Vincent Hospital
  Santa Fe, NM
Share Breast Cancer Support Program
  St. Louis, MO
George E. Spaeth
  Philadelphia, PA
Natalie Davis Spingarn
  Washington, DC
Survivor Network, Phil Cross
  St. Charles, IL
Susan G. Komen Foundation
  Dallas, TX 76006
The Regional Cancer Center
  Springfield, IL
Mr. & Mrs. H. Howard Rudiger
  Walnut Creek, CA
Lucy R. Waletsky
  Chevy Chase, MD
Jean Wooldridge, Cancer Information
  Service for Washington State
  Seattle, WA

Organizational Memberships (6/23/87)

Cancer Care, Inc.
  New York, NY
Cancer Counseling, Inc.
  Houston, TX
Cancer Hot Line
  Tamarac, FL
The Candlelighters Childhood
  Cancer Foundation
  Washington, DC
Hope & Cope
  Montreal, Canada
Gwen MacKenzie
  Detroit, MI
Make Today Count
  San Diego, CA
Operation Uplift
  Port Angeles, WA
Strength for Tomorrow, Inc.
  Marion, MA
Sunrise, Inc.
  Greenville, SC
Women's Resource Center
  Oakland, CA
Fran Yardley
  Tupper Lake, NY
Y-Me Breast Cancer Support Program
  Homewood, IL

Board of Directors

President:
Fitzhugh Mullan, M.D.
  Garrett Park, MD

Secretary:
Barbara Hoffman, J.D.
  Princeton, NJ

Treasurer:
Grace Olivarez, J.D.
  Albuquerque, NM

Pamela La Fayette
  Seattle, WA

Edith Lenneberg, E.T.
  Corrales, NM

Barbara Waligora-Serafin, R.N., M.S.N.
  Amarillo, TX

Estelle Weissburg
  Pittsburgh, PA

Executive Director

Catherine Logan
  Albuquerque, NM

National Coalition for Cancer Survivorship
323 Eighth Street SW
Albuquerque, NM 87102

Address Correction Requested

[redacted]