

Winter 1990 Volume 4, Number 1

NCCS HEADS FOR WASHINGTON AND FALL ANNUAL ASSEMBLY

With the nation's capital as a backdrop, NCCS' fifth annual meeting will address the issues of paramount concern to the nation's increasing millions of cancer survivors, including insurability, employability, and acceptance by the wider community. Titled "Speaking Up for Survivorship: An Agenda for the Nineties," the assembly will meet from Thursday, November 8 to Sunday, November 11, and will highlight advocacy for oneself and for fellow survivors.

In workshops and plenary sessions, conferees will focus not only on issues like access to quality medical care, but on such treatmentrelated issues as patient-doctor communications, interpersonal/psychosocial issues (such as dealing with family, friends, and co-workers, sexuality and the mind-body connection), community action, and minority group concerns. Building on the great success of last year's Los Angeles conference, 1990 planners are shaping a substantive program on living a life of optimum quality with cancer within a schedule that will permit time for networking and exchange of ideas.

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NCCS COSPONSORS SURVIVORS DAY SLATED FOR SUNDAY, JUNE 3

As their number continues to rise, cancer survivors across the country will celebrate the Third Annual Survivors Day June 3. The National Coalition for Cancer Survivorship will join the American Cancer Society (ACS) and Coping magazine in sponsoring the event.

Pointing out that Survivors Day is the time to honor survivors and recognize those professionals who are helping them fight the battle, ACS Board Chairman John Seffrin, PhD, said that doing so communicates to all Americans the message that survival is real and fear and ignorance about cancer are the en-

"National Cancer Survivors Day provides the platform to speak on issues like opportunities for employment and insurance and access to quality follow-up care and rehabilitation," he added. "The addition of the NCCS as a new sponsor will add new energy and resonance to the event. For the first time NCCS will be playing a major role in Cancer Survivors Day."

ACS, whose Cancer Facts and Figures — 1990 recently raised the number of Americans living with a cancer diagnosis from five to six million, will stage an event in Atlanta as a backdrop for celebrations

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WHAT'S NEWS

New Survivorship Coalition Forms in Colorado

The survivors pictured here volunteer in Denver to promote wellness and quality lifestyles after a diagnosis of cancer. They are part of the newly formed Cancer Support Network of Colorado.

CSNC has been formed to promote statewide:

- Networking among similar support groups and professionals and project collaboration between individuals and organizations;
- Cancer education and the dissemination of survivorship information;
- NCCS' mission and membership. Like the Greater Washington Coalition for Cancer Survivorship

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SURVIVORSHIP! Denver survivor/volunteers, from 1 to r, with type of cancer and time from diagnosis: top row, Bernie Stecklein (breast, 10 years), Bill Larson (lymphoma, 6 years); middle row, Mike Garratt (testicular, 7 years), Jerry Bjork (colorectal, 4 years), Susan Doherty, (ovarian, 10 years); bottom row, Gordon Rixford (lung, 6 years), Sheila Kane (bilateral breast, 6 years), Jean Kangas (cervical, 2 years).



When I was diagnosed with cancer, the first thing that I wanted to know was, when will I be cured? When will I be well again? When will I have this monkey off my back?

It was not that simple. I, like most people with cancer, never celebrated a "cure day." I could never be sure when the disease passed out of my life and I certainly never found a clinical date — like one year or five years — to be very satisfying. And for many of us, of course, cancer remains a regular part of our lives as we deal with recurrences and ongoing therapy.

What really mattered to me, I found, was survival — the day to day victory over the disease that meant continued life and hope. That victory was clear and important, and

FALL ANNUAL ASSEMBLY

(continued from page 1)

The Greater Washington Coalition for Cancer Survivorship (GWCCS), which operates under the NCCS umbrella, will host the Assembly, scheduled to take place at the beautifully renovated Ramada Renaissance Hotel in Washington's West End (with easy access to the major airports and the capital's deservedly popular METRO subway system and within walking distance of the Kennedy Center and historic Georgetown.) The Networker will keep you posted with specifics on room rates, early registration, travel, and other details which will make early planning possible. (Contact: Assembly chair Ellen Stovall, 301-340-2127).

LETTER FROM THE PRESIDENT

Fitzhugh Mullan, MD

yet it was easily overlooked amidst the daily hassles and fears of the cancer battle. Survival is the common denominator of everyone ever diagnosed with cancer, whether their lives last a few months or many decades. Survival, which NCCS is founded on and dedicated to, is worth celebrating.

Hence, Cancer Survivors Day.
This is a day to plant trees, sign up and be counted, make a donation, make a volunteer commitment, hug, and walk barefoot in the grass. We need to celebrate in every town in the country and in all our hearts.

The NCCS is proud to join with the American Cancer Society and Coping magazine in sponsoring National Cancer Survivors Day, 1990. We urge you to plan an event in your community or join one already underway. We need to let America know about survivorship. Bring a friend. Bring ten friends. Stand tall for survivorship on June 3.

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

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

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Survivors Day (continued)

LOCAL CELEBRATIONS: THE SKY'S THE LIMIT

Local celebrations of National Cancer Survivors Day will be limited only by the imagination and resources of the communities involved. Events and features, geared for adults and children, will range all the way from picnics and puppet shows to educational panels.

Here are some possibilities:

Groups could pick up the central tree planting theme. In this scenario, which originated in Pittsburgh, PA with NCCS founding member Estelle Weissburg, survivors and perhaps family members pin their names (and any other information they wish) on a tree or a large drawing of one.

Other ideas: speaker panels, composed of local survivors, civic officials and medical leaders (how about the Cancer Survivors' Bill of Rights as a topic?); interdenominational sunrise services. Still more: events in local malls, at baseball games, entertainment featuring standard fare like a live local band or survivors playing instruments, singing, performing in plays, skits, or puppet shows; athletic events like softball and volleyball contests or relay races; parades, health walks, art exhibits, poster and essay contests and, for a finale, fireworks.

The American Cancer Society will honor local courage award recipients, representing survivors in their communities. Other ACS events will include "Celebration of Life" conferences, mini-science writers seminars for the media, and early detection projects.

Survivors Day planners will seek to include hospitals, corporations, community organizations, churches and synagogues, local merchants, and local medical association chapters. Churches will be asked to offer prayers and sermons carrying the day's message of hope and ring their bells at an appointed hour.

ACS RESEARCH CHIEF LISTS POSSIBLE PAYOFFS

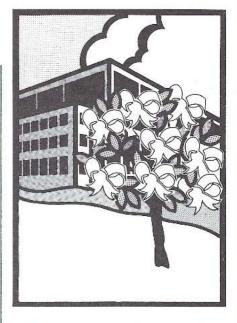
Hard as it is to predict the future, John Laszlo, MD, American Cancer Society Senior Vice President for Research, feels educated guesses based on past progress — can be

As planning for Survivors Day, with its message of hope, gets underway, Dr. Laszlo listed some of the areas where the hard scientific work of the past decades may result in dramatic payoffs:

Risk Assessment: Scientists may be able to devise tests to identify either oncogenes or their protein products which may be circulating in the blood of cancer-prone people. This will permit high-risk groups to get specific advice about types of screening and lifestyle modifications (like diet changes or use of chemopreventive agents).

Early Diagnosis: Improvements in body imaging will result in more accurate and earlier diagnosis of certain cancers; one will use monoclonal antibodies targeted for particular cancers to make such diagnoses and pinpoint recurrences.

Vaccines: Watch for vaccines that will:



 prevent the viral infections that lead to certain forms of cancer (e.g. cervix, liver, and nasopharynx).

 markedly reduce liver cancer through exciting technology using

hepatitis B vaccines;

 reduce the risk of breast cancer through a safe anti-estrogenic compound.

Behavioral Research: New knowledge could allow health professionals better to help people not only to quit smoking and reduce sun exposure — two known causes of cancer — but also to lower health

(continued on page 6)

I'm One of Over Six Million Cancer Survivors Name: Your Message:		
Return to:	National Coalition for Cancer Survivorship	
werent to.	323 Eighth Street, SW	

ters on June 3, 1990. Your name will be used for no other purpose.

WHAT'S NEW

In Survivorship Research by Julia Howe Rowland, PhD

Anger toward what he has referred to as the "wish-away-yourcancer" crowd prompted psychiatrist David Spiegel and his colleagues at Stanford and UC-Berkeley to undertake in 1985 a study whose results were published last October 14 in the British journal Lancet. This research used data collected 10 years earlier to follow the fate of 86 women with similar metastatic breast cancer, all receiving standard cancer care. The women were randomized into two carefully controlled groups, one to receive one year of weekly supportive group therapy with hypnosis for pain control (but no cancer imagery or any suggestion that participation could affect survival time) - and a control group with no intervention.

The research team expected to find improvement in quality, but not quantity of life in the intervention group. What they did find surprised them and excited the medical world: The intervention group not only significantly improved the quality of their lives but also lived on average 18 months longer.

What does this breakthrough study — the first unbiased, controlled prospective study of its type — tell us? Interpreting the results, the authors felt strongly that social support played a critical role in mediating survival, providing a place to belong, to express emotions, and counter feelings of isolation.

The data reviewed provide compelling evidence that personality or attitude at the time of treatment may be less important than what the person does subsequently (injecting a note of hope and perhaps obviating the need for controversy over whether there is a "cancer-prone" personality). They also show that even patients with advanced illness can be taught to cope better and perhaps comply more fully with medical treatment, since women in the intervention group, led by trained therapists, experienced a significant reduc-

tion in levels of depression, anxiety, and pain.

These results, combined with the significant survival value of group participation, provide a strong rationale for self-help efforts in cancer and underscore the need for a strong NCCS.

The Spiegel study does not give us all the answers to the questions involved in this complex issue. For instance, can patients in early as well as late stages of illness benefit from such interventions? Are they as successful with males as females? Can groups which run for only six months or use a self-help or peer support model be as effective as yearlong groups run by mental health professionals? Can the results of this study be replicated?

Certainly the Spiegel research does not end the mind/body/cancer debate. Likely it will heat it up. But the questions it raises should be an active focus of cancer research in the next decade.

What's News

(continued from page 1)

(GWCCS), the Colorado group will be affiliated with NCCS, whose executive director, Catherine Logan, will address a Denver informational meeting April 20. Contact: LaMarr Bomareto (303) 466-7551.

Rose Kushner Memorial

"The living legacy of Rose Kushner will be to fulfill her unfulfilled dream of a comprehensive national policy to fight this disease," Rep. Mary Rose Oakar (D-OH) told some 600 people crowding a National Institutes of Health auditorium January 30. Paying tribute to the late breast cancer activist and NCCS advisory board member, the Congresswoman described three "Rose Kushner breast cancer bills" she has introduced: One providing annual screening mammography for women covered by Medicare, another mandating informing patients of their options, the third earmarking \$25 million for basic research.

Another speaker, National Cancer Institute Director Dr. Samuel Broder, spoke of Rose Kushner's understanding of the scientific method, and impatience with arrogance and self importance. He advised the Bethesda, MD audience "to keep the flame alive" by internalizing what she stood for and wanted to do.

Brain Tumor Conference

All agreed that the National Brain Tumor Foundation's February conference was a resounding success. Close to 500 people, 15-20% of them caregivers, participated in formal sessions and workshops on such issues as employment and insurance discrimination and nutrition, and chatted in the corridors of the San Francisco Hilton. For some physicians, such close give and take with survivors and their families was a new experience. One Belgian neurosurgeon said he would have radically to rethink how he deals with his post-operative patients as a result of the conference. Contact: Michael McKechnie, (415) 296-0404.

On The Agenda ...

- MINORITY CANCER AWARE-NESS WEEK will be celebrated April 15-21. Sponsored by the National Cancer Institute (NCI), the awareness week will seek to highlight mammography and prostate screening. Individual regions will tailor their messages to their varying concerns (the New York area, for example will focus on teenagers and smoking). Contact Alejita Ortiz, (212) 302-2400 or NCI (800) 422-6237.
- The second updated version of the National Alliance of Breast Cancer Organizations' excellent *Resource List* is now available. This 24-page publication lists a large number of new resources: books, pamphlets, charts, fact sheets, articles and slide, audio and video material, much available free or at a nominal charge. Contact: NABCO, 1180 Avenue of the Americas, New York, NY 10036, (212)719-0154.

NETWORKER READER

HER SOUL BENEATH THE BONE: Women's Poetry On Breast Cancer, Edited by Leatrice H. Lifshitz with an foreword by Rose Kushner (University of Illinois Press, 1988, \$19.95 hardback, \$8.95 trade paperback). This women's collection indeed contains fine poetry. But it offers something beyond that: an opportunity to know at close hand the stages of intense emotion that must be endured before a final acceptance of such drastic illness is possible.

The variety of vision explored by these writers is remarkable. Not for the fainthearted, it ranges vividly through the basic themes of diagnosis, treatment, mastectomy, doctors and technicians, post surgery, and reflections on loss and eventual recovery of self esteem.

There is humor, as in the "Poem for the Woman Who Filled a Prosthesis with Birdseed, and Others" (Sally Allen McNall). The humor is often ironic (Patricia Goedicke):

The metal teeth of Death bite But spit me out One more time: When the technician says breathe I breathe.

Despite the weightiness of the subject, these poets treat it with refreshing artistry (Pat Gray):

You dream a peasant lover, a bold Serb ... harrowing your breasts. When you wake, one is missing: this slash, his sign.

A note of triumph is sounded by Deena Metzger in "I Am No Longer Afraid:"

I am no longer ashamed to make love.
Love is a battle I can win.
I have the body of a warrior who does not kill or wound.
On the book of my body, I have permanently inscribed a tree.

What gives the book special power is the immediacy of the experience the poems convey; they inspire rather than depress the reader. This is a collection of concentrated courage.

- Mariquita Mullan

SURVIVING CANCER: A Practical Guide for Those Fighting to Win! Second Edition, by Danette G. Kauffman (Acropolis Books, 1989, \$8.95 trade paperback).

Danette Kauffman, a five-year breast cancer survivor, gets right down to brass tacks in the first chapter of Surviving Cancer, "Immediate Mobilization." Cancer is the enemy, the newly diagnosed person is the general and the troops are family, friends and "the health care team." Her own battle plan, the one she offers to the reader, is to seek out available resources and use them. Each chapter covers a specific area - surgery, radiation, communication, even handling the bills and includes names, addresses and telephone numbers of support agencies or the titles of applicable publi-

Comprehensiveness is the hall-mark of *Surviving Cancer*, from the extensive table of contents, backed up by an index, to the range of resources listed as well as a glossary of cancer-related terms and a separate list of nationwide 800 telephone numbers. Yet this is not only a reference work but also an unblinking account of the experience of the author, complemented by some straightforward advice on treatment and survival issues. (See p. 7).

- Ed McCartan

IT'S ALWAYS SOMETHING by Gilda Radner.

(Simon & Schuster, 1989, \$17.95)

As I read this human, honest book, I felt as if I were talking to Gilda about her three-year struggle for her life: chemotherapy treatments so numerous I lost track, losing her hair, and the devastating news that she needed radiation when she thought she was all through with treatment. When her Connecticut oncologist denied her hope, she became so demoralized that she gave up on chemotherapy and went macrobiotic. Finally, her husband, actor Gene Wilder, persuaded her to try another oncologist.

Importantly, Gilda was blessed with the gift of comedy and although she admits that cancer has to be "the most unfunny thing in the world," she deals with it with great humor. Who can resist the picture of her clowning with a friend's child, comparing her new growth of hair with the baby's first growth? Or her account of her prediagnosis doctorhopping (they said her pains were Epstein-Barr virus or plain old "Mittelschmerz," and she began calling herself "Queen of Neurosis")? Or her brave struggle to maintain at least a semblance of normalcy by continuing to plan her career, even appearing on "It's Garry Shandling's Show"?

Some might find all this grim reading, especially since the author has since passed away. But for me—and I'm sure for many survivors and their families who have been through it all—it has a strong message of living each day to the fullest, because no one can predict with certainty when he or she will die and so there is always hope.

— Alice Cave

Mariquita Mullan's poetry has appeared in many publications, including The Webster Review, Poet Lore, Visions, America, and The Christian Science Monitor. She is the mother of NCCS President Fitzhugh Mullan. Ed McCartan (see p. 7) and Alice Cave are Networker editors. A two-year survivor of bone cancer, Alice is a technical writer in the Washington area.



Strength in numbers, an underlying philosophy of NCCS, is especially important when we make our voice heard in Washington.

To apply this philosophy, NCCS has joined forces with three selected national health and civil rights coalitions with whom we share common goals.

We have most recently joined the National Health Care Campaign, a coalition of 130 national organizations, including health, labor, civil rights, and religious groups. Initially formed to prevent cuts in Medicare and Medicaid coverage, the Campaign now supports health

insurance reform. Efforts include public education on the current state of our health insurance system and lobbying for state and federal insurance reform.

Our membership in the highly successful Coalition on Smoking OR Health enabled us to be part of the effort which attained passage of a law banning smoking on virtually all domestic airline flights (as of February 25, 1990) as well as the push to force R.J. Reynolds to withdraw plans to test-market its new Uptown cigarettes in predominantly minority neighborhoods. Formed by the American Heart Association, American Lung Association, and the American Cancer Society, the Coalition works to:

- Prohibit the sale of tobacco to minors;
- Restrict the advertising and marketing of tobacco;
- Increase education about the hazards of tobacco;
- Authorize the Food and Drug

Administration to regulate tobacco as it does other drugs;

- Increase taxes on cigarettes;
- Protect the rights of nonsmokers;
- Inhibit tobacco exports to Asia and the Third World;
- Eliminate federal price support for growing tobacco.

The Consortium for Citizens with Disabilities, a coalition led by the Epilepsy Foundation of America, works for the passage of the Americans with Disabilities Act (ADA). NCCS helped the Consortium locate witnesses. We also provided written testimony to Senate subcommittee hearings last May to explain how this bill prohibiting private employers from discriminating against someone with a handicap or history of a serious medical condition would benefit cancer survivors.

The resources of these coalitions make it possible for NCCS to effect legislation of vital interest to cancer survivors.

Survivors Day

(continued from page 1)

across the country. Staff and volunteers will plant a Celebration of Life tree on the grounds of the Society's new headquarters building. Ribbons encircling the tree will symbolize cancer survivors from around the United States.

To participate in this event staged with the goal of encouraging national media coverage, survivors will be asked to mail in a coupon (page 3). When survivors' names are received, they will be attached to a ribbon on the tree as a lasting tribute to the senders' hope and courage Contact: (800) ACS-2345 or (505) 764-9956.

NCCS' LA Conference is featured in *Doctor/Patient Intercom's* January, 1990 audio magazine. Cost: \$5 an issue, \$49.80 a year. Contact: 800-423-2308 (in Calif. 800-232-2165).

Research Payoffs

(continued from page 3)

risk by making changes in, for instance, the way we eat and exercise. In addition, this new knowledge could be used to help minimize anxiety and pain.

- Treatment: There are several promising approaches to making some cancer cells less able to resist chemotherapy. If drug resistance can be overcome, cancers of the breast and lung can be treated much more successfully. Other possible advances:
 - Refining the application of immune cells and other forms of immunotherapy to treat cancers such as melanoma and kidney;
 - Enhancing understanding of the normal immune system to exploit its natural disease-fighting skills;
 - Revolutionizing the treatment

of bone marrow disorders stemming from the inability to reproduce enough normal blood cells, through elements in the body (like enzymes and hormones) that cause cells to grow. Since such growth factors could have the power to increase bone marrow, they could be administered with chemotherapy and so lessen its toxicity and enable doctors to give higher doses and achieve many better adult cure rates.

- Developing anti-growth factor antibodies to halt tumor growth (because certain cancers will not grow in the absence of specific growth factors);
- Developing the capacity to treat people by suppressing oncogenes and keeping them turned off.

On National Cancer Survivors Day, spread the good news!

People Watching

Danette G. Kauffman



The author of Surviving Cancer: A Practical Guide for Those Fighting to Win (see p. 5) manages a 14-person staff of communicators for

MCI, the multi-billion dollar telecommunications corporation. A firm believer in the power of information, she used the wealth of resources she learned about during her fight with breast cancer to write her book.

Born in Cleveland, OH, Danette earned her MA and MS from the University of Chicago. Now a Washington, DC resident, she has taught high school English, worked at Gallaudet University and for the past decade has combined volunteer work with her MCI job. Recently

named to NCCS' board, she serves on the area Advisory Board of Look Good...Feel Better, coordinates local fundraising opportunities for the University of Chicago, serves on the University's Centennial Planning Committee, and coordinates her church's activity for So Others Might Eat.

Ed McCartan



After surgery for cancer of the parotid gland three years ago, and subsequent radiation, publishing consultant Ed McCartan did

some vigorous networking and discovered NCCS, which put him in touch with the newly formed Post-Treatment Resource Program at Memorial Sloan-Kettering Cancer Center (where he is now a volunteer). "I seem to have a mysterious predilection for new organizations," he says, and this has been a feature of his career in both the profit and non-profit fields. He was a cofounder of a publishing firm specializing in Large Print books and also established a company publishing works on maritime history.

In a previous incarnation, according to Ed, he was a career naval officer, serving on many ships and stations. A highlight was, not surprisingly, placing a new ship in commission as its first commanding officer. Now he lives in the heart of Manhattan, and has two married daughters (one in publishing on the West Coast and the other with her own market research company on the East Coast) and four grandchildren — one girl and three boys.

Shireen McKen



NCCS' newest international member was born in the West Indies, and became a dental nurse in Trinidad. She married a dentist.

Dr. David McKen, and they have a five-year-old son, Pepito. In 1980, she was diagnosed as having choriocarcinoma (which involves the placenta), previously unknown in Trinidad, and was successfully treated with chemotherapy both at home and in Washington, DC.

Without a network of survivors or support groups in the Islands, Shireen discovered NCCS and came to the Fourth Annual Conference. Calling it her "first support group meeting," she found it was what she had been looking for. "I feel as though I have been to the University of Cancer and my graduation was in Los Angeles," she says. At home in Port-of-Spain, she is working to establish support groups for survivors in Trinidad.

JOIN/SUPPC	ORT NCCS
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LETTERS TO THE EDITOR

The Net Works!

Our Cancer Survivors' Support Group continues to grow. Our newest member attended the NCCS conference in California and returned home wanting to be more involved in the survivorship movement. She found her way to our group and joined us as well. THE NET WORKS!

> MAXINE SOLVAY, Ann Arbor, MI

She's 80 and Loves to Help

I am a 15-year survivor, free from cancer for the last four years. Now I have heart problems and will be 80 in March. I live on a fixed income. So if membership goes up as everything else does, you will have to count me out. I am the Reach to Recovery representative for our county and work with Hospice. I love to be of help to others. I just wish I were physically able to do more.

WINONA REED, Clay Center, KS

Even if memberships fees increase, all those wishing to remain in NCCS will

be welcome for whatever price they can afford to pay. — Editor

Philadelphia Area Women's Group

It seems difficult for women to make an emotional commitment (to a group) let alone a physical one, if they are going through treatment. I am continuing to run an ongoing Women's Support Group. We are meeting every other Saturday afternoon at Turning Point, Inc. in Ambler. I am the contact person (215) 572-1053.

MARLA FISHER, Wyncote, PA

Misplaced, an Outcast

When I returned to high school as a senior after treatment for Hodgkin's Disease, I felt very misplaced, an outcast, and wiser beyond my 17 years. I had come through the most important years of adolescence by myself, isolated from my peers, yet was supposed to integrate as if nothing had happened. I moved to Florida so that I could get away from the stigma I felt living in a small town. My love of Maine caused me to return and

I'm doing well as a University senior. I only wish that I had some sort of support while I was sick and when I was trying to gain some normalcy in my life.

LEANNE TINGLEY, Portland, ME

HELP WANTED

WANTED: People with expertise willing to work on a volunteer basis to help find funding for NCCS programs and ongoing operations.

programs and ongoing operations. QUALIFICATIONS: Experience in writing, submitting, and following up with grant proposals, and willingness to volunteer time to help the cause of survivorship.

CALL: Executive Director Catherine Logan (for the Development Committee) at (505) 764-9956.

WANTED: READING LIST SUGGESTIONS. NCCSers who would like to submit names of their favorite books dealing with cancer should send the title, author, publisher, place, and date of publication to Barbara Carter, RN, DNSc, 1005 South Eliseo Drive #4, Greenbrae, CA 94904. Please explain what each book is about and why you liked it.

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

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