



NATIONAL  
FOR CANCER

COALITION  
SURVIVORSHIP

# 6 NETWORKER

Summer, 1988

Volume 2, Number 3

## SURVIVORSHIP: GAINING MOMENTUM

Third Annual Assembly Opens November 18

Participants in the National Coalition for Cancer Survivorship's third annual assembly November 18-20, will address a wide variety of survivor issues, from peer support and family problems, to physical and mental fitness.

Meeting in Albuquerque, New Mexico, where the organization was founded by a handful of people less than two years ago, and a year after more than four times that number met again to "Chart the Course," this year's assembly will continue to direct and strengthen the growing survivorship movement.

Among those slated to address the assembly, whose theme is "Survivorship: Gaining Momentum," are the keynote speaker, Grace Monaco, Chairman of the Candlelighters Childhood Cancer Foundation Board, NCCS President Dr. Fitzhugh Mullan, Dr. Robert S. Brown, Clinical Associate Professor of Behavioral Medicine and Psychiatry at the University of Virginia School of Medicine, Harold Benjamin, Founder of the Wellness Community and Mary Lee Fitzsimmons, R.N. of the Hereditary Cancer Consultation Center, in Omaha. A special treat will be the evening performance by Joe Kogel, well known actor/poet.

Conferees will work in plenary sessions, workshops, sharing groups, poster sessions, and round tables to assess survivors' special needs, and enhance support serv-



*Survivors Day! New Haven, CT — Clowning and capering at the celebration sponsored by the Yale Comprehensive Cancer Center and the ACS Connecticut Division (see page 8).*

ices. They will address issues as diverse as workplace discrimination and sexuality, and learn about special physical exercises for survivors and heredity factors in cancer.

They will also consider model programs, including various hot-lines and support groups.

As the Assembly considers ways to build on past efforts, and form partnerships among regional cancer support groups and national organizations, it will hear from representatives of the National Cancer Institute, and the American Cancer Society.

"The growing network of survivors is our strength," explained Barbara Waligora-Seraphin, Assembly Committee Chair, "but the size of the country is a problem. Our first two years have been spent identifying, defining, and beginning to bring together grass roots efforts to provide support for cancer survivors. This year we want to focus on coalescing these efforts."

The Assembly, to take place at the Clarion Four Seasons Hotel, 15 minutes from the Albuquerque airport, will open at 1 p.m. Friday, November 18, 1988 and close Sunday, November 20 at noon. For information about limited funds available to help those who would not otherwise be able to attend, contact the central NCCS office. See flyer included in this issue for further Assembly details.

### *On the inside :*

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## LETTER FROM THE PRESIDENT

*Fitzhugh Mullan, M.D.*

Research, you will remember, is one of the principles on which the NCCS was founded. Characterizing survivorship, studying and understanding the changes that people go through from the time of the diagnosis of cancer, and exploring ways in which to make the experience less onerous are all aspects of survivorship research. So are studies of quality of life, rehabilitation, pain management, vocational and insurance discrimination, and death and dying.

Although there are some important exceptions, a very small portion of funding for cancer research is dedicated to work on survivorship issues (see pp 3-4). The lion's share of the National Cancer Institute (NCI) and American Cancer Society (ACS) dollars are devoted to treatment research with most of the rest to prevention research — two vitally important areas. Yet everyone being treated is a survivor and virtually everyone encounters psychological, social, familial, or vocational problems, many of which have never been examined thoughtfully by investigators. Their skills might well reduce or eliminate such medical consequences of survivorship as secondary tumors, the long-term consequences of radiation and chemotherapy, and sexual and reproductive dysfunction.

The NCCS needs to become a more articulate — even noisy — constituency in regard to research.

We need to make our voice heard where the decisions about research policy are made — in the U.S. Congress, at the National Cancer Institute, and at the American Cancer Society.

Fortunately the NCCS has good allies in this mission, since a number of prominent survivorship researchers are NCCS members and are available to help. The Board has established a Research Working Group and as an organization we have recently joined the Washington-based National Coalition for Cancer Research, an alliance of researchers and consumer groups. These and other developments, including growing interest in survivorship research at the NCI, suggest that we are approaching the time when the NCCS could convene a conference of patients and providers, consumers and research scientists to map out an agenda for survivorship research.

The product of such a conference — a "White Paper on Survivorship Research" — would be the document that we would use to stimulate discussion and funding for a greatly increased program of studies on all aspects of survivorship. This work could be one of the most important contributions that the NCCS can make to future survivors.

See you at the Third Annual Assembly in Albuquerque!

## NETWORKER

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(505) 764-9956

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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 interests of cancer survivors, and encourages the study of survivorship.

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# NCI Devotes Tiny Percent of Budget to Survivorship Research, But Plans To Move Forward

*When Networker told the National Cancer Institute (NCI) that we wanted to interview the official responsible for that \$1.49 billion federal agency's survivorship research, it suggested Carolyn Cook Gotay, PhD, Director of the Division of Prevention and Control's Rehabilitation and Continuing Care program. Guest Editor Natalie Davis Springarn interviewed Health Scientist Administrator Gotay at NCI headquarters on the National Institutes of Health campus in Bethesda, MD, early this summer.*

**Q.** How do you define "survivorship research" at NCI?

**A.** One can look at it in a number of different ways. I personally think it should be defined broadly, to encompass any activities that would contribute to survivors' well being after their treatment is concluded or to help them with the treatments they are going through. Since every cancer patient is a potential survivor, survivor studies should include them as well.

**Q.** NCCS defines a survivor as anyone with a history of cancer, from the point of diagnosis on. Do you agree with that?

**A.** I do in principle. But I think it's important to focus "survivorship research" on developing interventions which promote quality of life among people living with cancer.

**Q.** NCI has a lot on its plate. What percentage of its total \$1.49 billion budget goes to survivorship research?

**A.** We estimated in 1986 that \$3.3 million out of \$108.3 million spent for research grants and contracts in our Division went to "rehabilitation research." I'm loathe to make an estimate for this year because there may be more survivorship research sponsored by NCI-funded

centers and cooperative groups. And it's difficult to categorize grants and contracts; we did not include pain research, for example, in the 1986 estimate.

**Q.** That then, would be less than 1% of the total NCI budget?

**A.** Probably a very small percentage. That's because most of NCI's effort is being made to prevent cancer in the first place and to enable more patients to become long-term survivors.

**Q.** What are your priorities in spending those funds and in program planning now?

**A.** In 1984, we brought together recognized experts in the field of survivorship; they designated childhood survivorship as an area where it looked as though it would be worthwhile to stimulate some research. It's a whole lot easier in many ways to study children. They have a more homogeneous set of diagnoses, developmental events, and at the pediatric centers, the

treatment tends to be more uniform.

**Q.** So, as a result of your 1984 workshop?

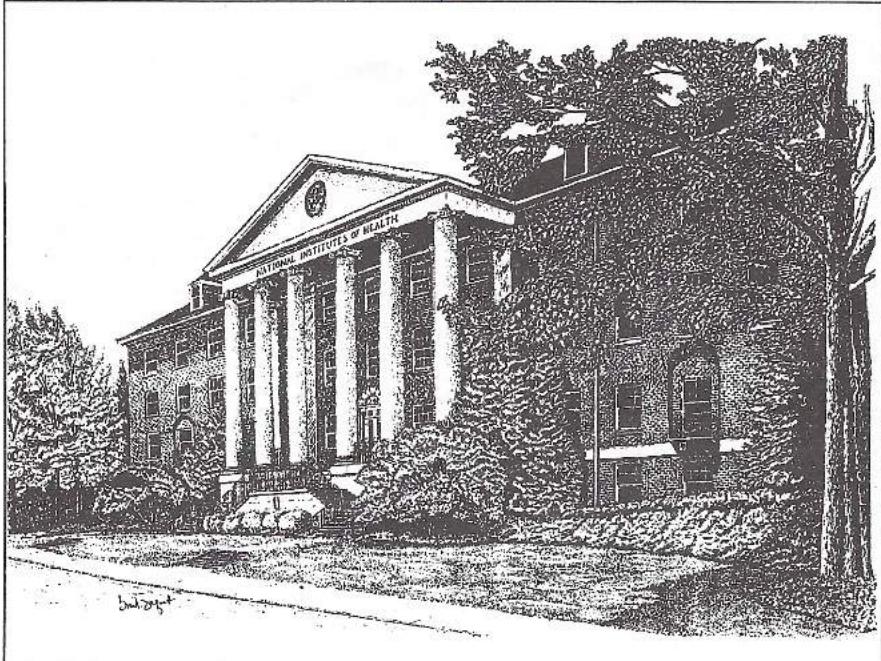
**A.** We developed a request for applications (RFA) to look at interventions that would facilitate functioning in survivors of childhood cancer. As a result, two projects are underway (both funded at about \$225,000 a year for five years). Dr. Shirley Lansky of the Illinois Cancer Council is looking at ways to increase the school attendance of children with newly diagnosed cancer and so to minimize the social and academic difficulties of long-term survivors. Hers is a structured "behavioral management" approach, involving parents, teachers, and kids.

**Q.** Is the other study more oriented toward adults?

**A.** One might say so. Dr. Daniel Hays of the Los Angeles Childrens Hospital is looking at ways to insure that young adults who have had childhood cancer can get jobs commensurate with their training and abilities and adequate health and life insurance for themselves and their families.

*(Continued next page.)*

*Drawing by Brent Jaquet*



## **Survivorship Research**

(Continued from page 3.)

**Q.** What do you hope to get out of such studies?

**A.** We want people to do research on approaches which prevent problems or do something about them. Take employment. There may be good ways to help survivors anticipate questions they'll have to answer when they enter the job market later on. Perhaps this could be best done through counseling, or by showing them videotapes.

You see at this point we think people are not systematically looking at interventions that could be built into the medical system to help survivors deal with problems — medical as well as psychosocial. For example, counseling prior to therapies that have implications for fertility would help people better to cope with outcomes.

**Q.** What other survivorship research is in the works now?

**A.** Several studies in the area of rehabilitation of head and neck cancer patients. In the area of Home Care, we are trying to find out what's going on with an eye to developing interventions, making the system more responsive to the needs of patients and their fami-

lies. We are also looking at concrete needs that patients experience, like transportation, filling out forms, child care — trying to find ways to get them hooked up with community services.

And at two sites, Memorial Sloan-Kettering and Brown University, researchers are looking at ways to address rehabilitation needs. At Memorial it's through an ongoing computerized needs assessment and at Brown, through a case management approach.

**Q.** How about alternative or complementary therapies? Many have not been tested in a rigorous scientific fashion, yet some cancer survivors are very involved with them. **A.** We've had a number of applications to study that very issue, but many did not score high enough in the peer review process to be funded. However, we are supporting a study now by Dr. Barrie Cassileth. She is looking at patient-initiated unorthodox therapies in a California clinic, and she's doing a matched case control, three-year study with conventionally treated University of Pennsylvania metastatic patients to see if the unorthodox therapies actually make any difference in survival and quality of life. The study is very exciting; Dr. Cassileth is matching people

carefully for diagnosis and many other variables.

**Q.** What are your plans for the future?

**A.** Survivorship research is a growing concern, as there are more survivors out there. After all, it's only in the last maybe 15 years we've had some very good survival rates. So survivorship research is an increasingly salient priority within our branch, one of the initiatives we want to pursue. I would encourage researchers to step forward with their ideas.

**Q.** And you anticipate?

**A.** That we will go forward. We started with children, but we know adult survivors are also a critical group. They not only have problems with employment and insurance, but with their families — with decisions about having children, for instance — or worries about second malignancies; some have physical problems associated with treatment that may be exacerbated over time.

**Q.** All the problems NCCS has been pointing to?

**A.** Yes. We hope to build on the data we have accumulated and are accumulating to develop interventions that will prevent problems, reverse them, think of ways to supersede them. In the next two years our program plans call for developing an RFA asking researchers to look at interventions directed at improving the quality of life of adult cancer survivors.

## **At the Assembly....**

- An open NCCS Board of Directors meeting will be held Friday morning, November 18, before the Assembly opens. Please notify the NCCS office if you plan to attend.
- Under Article VIII of the by-laws recently adopted by the NCCS Board, you can participate in NCCS elections if you attend the meeting (either personally or by proxy). The nominating committee will announce at the opening session that any member may nominate any other member; at the closing session the committee will submit its own and member-submitted names.

Officers (President, vice-president, secretary, and treasurer), to be chosen before the directors, will be elected to two-year terms. This year, two directors will be chosen for two-year terms, four or more to one-year terms; in the future, members will vote each year to fill all expired terms and each director will be elected to a two-year term.

Those who wish to suggest names for consideration by the nominating committee before the Assembly may contact Chair Edith Marks, PATH, 410 East 62 Street, New York, NY 10021.

## **THANK YOU, DONORS**

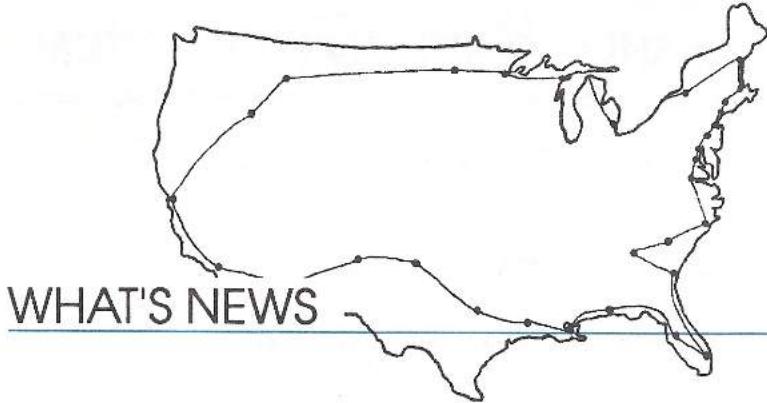
*for your \$5000 gifts:*

Bristol Myers Oncology Division, our first corporate sponsor, and Convatec, A Squibb Company, makers of ostomy products.

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*for your gifts to BikeAmerica:*

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Hank and Frank's Bicycle Shop (equipment and public relations)  
McDonald's (meal coupons)  
Photographic Rental Services (camera)



## WHAT'S NEWS

### Brad and Joanne Pedal Away

Cancer survivor Brad Zebrack and his friend Joanne Kelleher topped the news this summer when they left California for Idaho and Montana — the first leg on their one-year, 13,000-mile bike trip on behalf of the nation's five million cancer survivors.

"Riding up some of these hills and mountain passes," Brad reports, "reminds me of chemotherapy. 'Take one day at a time' was my motto during treatment. 'Only do what I'm capable of doing each day.' ... To take each climb, pedal-by-pedal, the bicycling becomes easier

and more bearable, and most often, enjoyable."

Along the way, Brad and Joanne will meet with survivor organizations, treatment center patients, and community groups to:

- show that there can be an exciting life after cancer; and
- raise funds for the National Coalition for Cancer Survivorship.

If you or your group want to meet with Brad and Joanne, contact NCCS Vice President Barbara Hoffman, 9 Madison Road, Cranbury, NJ 08512, (609)799-9199.

#### Their schedule:

Escanaba, MI (8/23/88)  
Detroit, MI (9/3/88)  
Buffalo, NY (9/10/88)  
Portland, ME (10/5/88)  
Boston, MA (10/5/88)  
Hartford, CT (10/9/88)  
New York, NY (10/17/88)  
Princeton, NJ (10/22/88)  
Philadelphia, PA (10/25/88)  
Baltimore, MD (11/11/88)  
Washington, DC (11/18/88)  
Richmond, VA (11/29/88)

Wilmington, NC (12/10/88)  
Columbia, SC (12/16/88)  
Atlanta, GA (12/23/88)  
Savannah, GA (12/31/88)  
Miami, FL (1/17/89)  
Tampa, FL (2/2/89)  
Pensacola, FL (2/2/89)  
New Orleans, LA (2/24/89)  
Dallas, TX (4/1/89)  
Amarillo, TX (4/1/89)  
Albuquerque, NM (4/15/89)  
Phoenix, AZ (5/8/89)  
Los Angeles, CA (6/5/89)



### Storming the Barricades

On July 14, Bastille Day, a group led by BreastPac founder and NCCS Advisory Board member Rose Kushner stormed the Congressional barricades to ask for more money for breast cancer research. Meeting on the Capitol terrace, the group heard speeches by four congressional supporters, and voiced the need for support to develop a vaccine and to identify and "splice out" the gene some scientists believe causes pre-menopausal breast cancer.

Pointing out that the number of breast cancer patients has risen from 91,000 in 1978 to 135,000 today, Kushner is asking for at least one single dollar for every lump a woman has had to elect candidates who fight for more money to conquer breast cancer. You can reach BreastPac at P.O. Box 224, Kensington, MD 20895, (301) 949-2530.

### An Oscar For "Patients And Doctors"

NCCS board member and Net-worker guest editor Natalie Davis Spingarn has won a first place gold award in the Communications Category for her film "Patients and Doctors: Communication is a Two Way Street." The award was presented at the end of June at the John Muir Medical Film Festival, in Walnut Creek, California.

The short, 21-minute documentary, which highlights the crucial importance of a strong and open dialogue between cancer patients and their physicians, was one of 29 gold awardees out of a field of 476 entrants (from 21 countries), and was nominated as one of the three best films for professional audiences. Produced under grants from the American Cancer Society and the Picker Foundation, it is available from the National Health Policy Forum (attention Helen Klepac), Suite 200, 2011 Eye Street, NW, Washington DC 20006, and from ACS divisions.



## SURVIVORSHIP: GAINING MOMENTUM

### THIRD ANNUAL ASSEMBLY

**WHEN?** Friday, November 18, 1988, 1 pm to Sunday, November 20, 12 noon

**WHERE?** The Clarion Four Seasons Hotel, Albuquerque, New Mexico

**WHY?** In its Third National Assembly, NCCS seeks to build on the efforts of the past two years to promote awareness of and advocacy on behalf of survivors' rights and needs, to strengthen the shared goals of those of us who are survivors and those who care for survivors, to provide care and support to one another, and to develop initiatives to address neglected aspects of survivorship.

**HOW?** Join us in Albuquerque; participate as we work toward our Assembly objectives:

- to be part of an organized voice to promote survivors' rights;
- to share individual and organizational concerns with peers and colleagues;
- to help further explore the issues and the definition of cancer survivorship;
- to discover and develop cancer survivorship resources, and be involved in the continued development of NCCS.

### TENTATIVE PROGRAM

**Friday afternoon and evening.** Keynote address by Grace Monaco, Chairman of Candlelighters, President Fitzhugh Mullan's address, and a plenary session on peer support, followed by small sharing sessions for all conference participants. A delight is in store for Friday evening: a performance by well known actor/poet Joe Kogel.

**Saturday morning.** Two sessions: The first, focusing on the cancer survivor's world, will be geared to help empower cancer survivors. Choose between groups addressing the workplace, insurance, sexuality, and family issues. The second, to follow, will feature model programs (participants will choose between four types, each presenting four models): hotlines, grass-roots community organizations, hospital-sponsored peer support programs, and social service agencies.

**Saturday afternoon.** The Wellness Community's Harold Benjamin will be the luncheon speaker. Post-lunch sessions will focus on physical and mental fitness for cancer survivors, and how organizations promote fitness for their members. Other afternoon sessions will address hereditary cancer, exercises for survivors, and "reinforcing survivorship skills," as well as a research forum and poster session. **To end at 4 p.m.** Evening free.

**Sunday morning.** Plenary session. Election of the NCCS Board of Directors; a look at the coming year for NCCS. Discussion, focusing on collaboration within the survivorship movement, will include presentations from the National Cancer Institute and the American Cancer Society, as well as an open forum.

# REGISTRATION FORM

(May be duplicated)

Name \_\_\_\_\_ Phone(s) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Organizational Affiliation, if any \_\_\_\_\_

**Optional. Please check one or more:**

- cancer survivor       family member  
 health care provider, specify profession \_\_\_\_\_       other

## ASSEMBLY FEE

includes Saturday luncheon and Joe Kogel show.

**Registrations postmarked by October 15 will receive a \$10 discount.**

Non-members\* \$85.00       NCCS members\*\* \$60.00       Early registration \_\_\_\_\_

## HOTEL REGISTRATION

NCCS will handle all hotel arrangements. Hotel reservations must be received by October 28 to insure availability and rates.

- single occupancy (\$48 + \$4.92 tax per night)  
 1 night: \$ 52.92       2 nights: \$105.84       3 nights: \$158.76  
 double occupancy, (\$24 + \$2.46 tax per night, 2 double beds)  
 1 night: \$ 26.46       2 nights: \$ 52.92       3 nights: \$105.84
- Please arrange a roommate for me.       I will be rooming with \_\_\_\_\_

*Please indicate which nights you will be staying:*

Thursday       Friday       Saturday       other \_\_\_\_\_

## DISPLAY TABLES

*Please indicate if you would like a display table*

- Full table (6ft.): \$50, non-members\*; \$25, members  
 Half table: \$25, non-members\*; \$13, members

TOTAL ENCLOSED \$ \_\_\_\_\_

Make checks payable to NCCS. Mail to 323 Eighth Street SW, Albuquerque, NM 87102. For questions call: (505) 764-9956.

\* To join NCCS, see the membership form on page 11.

\*\* Any member or employee of an NCCS Organizational or NCCS Institutional member may pay the reduced assembly fee.

**Other information:** Those interested in facilitating sharing sessions or participating in poster sessions, please contact NCCS Executive Director Catherine Logan at NCCS for further details.

**Transportation:** The Clarion Four Seasons Hotel, 2500 Carlisle, NE, in Albuquerque is located 15 minutes from the airport. Free shuttle service is available; call the

hotel from the direct line in the airport baggage area.

**Scholarships:** NCCS has limited funds to help those who would otherwise not be able to attend the assembly. Please help us reserve these funds for those who really need them. Contact the NCCS office for more information.

## Celebrants Caper, Learn, Get Awards, Even Marry on First Survivors Day



Balloons soared and church bells rang as cancer survivors, their families, friends and supporters across the country celebrated the first National Survivors Day June 5 (the date sponsored by Coping Magazine and the American Cancer Society with NCCS' endorsement).

Celebrations of the achievement of a full life after cancer drew crowds of as many as 100 to 1000

people in cities from Berkeley, California and Boise, Idaho to Cleveland, Ohio, New Haven, Connecticut and Charlotte, North Carolina. Participants laughed with clowns, enjoyed skits, listened to speeches by fellow survivors and assorted VIPs, took part in workshops, learned at seminars and received awards for their courage and commitment. The Denver, Colorado celebration in Chessman Park ended with an exchange of wedding vows by a young couple, Edward and Shari Mora; the groom had just finished leukemia treatment.

In several places, including Pittsburgh, Pennsylvania, survivors built a "tree of life." As Susan Silberstein, PhD, founder and executive director of the Delaware Valley Foundation for the Advancement of Cancer Therapy put it, celebrants were showing that "the Big C that once stood for the unmentionable word 'Cancer' now stands for Caring and Compassion (on the part of the caretakers), and Courage and Commitment (on the part of the patients they serve)."



*Lower left: Cleveland, OH — Balloon lift off at "Expo 88: Recovering from Cancer." After workshops on topics like nutrition and insurance, the crowd celebrates at the Cleveland Clinic Cancer Center (which has launched a Northeast Ohio Survivors Group).*

*Upper left: Beverley Hills, CA — Kids join in the fun at a picnic sponsored by Vital Options, NCCS, Camp Ronald McDonald for Good Times, The ACS Coastal Cities Unit and the Wellness Community.*

*Above: Boise, ID — On the Statehouse steps, survivors mingle and enjoy the event sponsored by the Mountain States Tumor Institute, the ACS Idaho Division and Coping Magazine.*





## ADVOCACY UPDATE

Cancer survivors won two partial victories these past months, one in Congress and one in the courts.

### Medicare Coverage Extended

The Medicare Catastrophic Coverage Act of 1988, signed into law by President Reagan on July 1, expands Medicare coverage in these ways:

- Screening Mammography: Beginning in 1990, Medicare will reimburse 80% (maximum \$40) of the actual charge for a screening mammography. Although all beneficiaries age 65 and older will be reimbursed for a mammogram every two years, coverage for the small groups of younger recipients under Medicare will vary depending on age and level of risk for developing breast cancer.

- Prescription Drugs: By 1993, Medicare will reimburse 80% of

the cost of prescription drugs (after a substantial deductible). Reimbursement will begin for a few people in 1990.

- Hospital Care: Beginning in 1989, Medicare will pay 100% of hospital costs without any limit on number of days; the annual deductible is estimated at \$564.
- Physician Services and Medicare-covered Outpatient Services: Beginning in 1990, beneficiaries will pay a maximum of \$1,370 out-of-pocket each year.
- Nursing and Home Health Care: Medicare will reimburse 150 days of nursing home care per calendar year and 38 days of continuous home health care per year (after an eight-day deductible).

Who pays for all this? The bill provides complicated formulas, but Congress expects it to boil down to this: One third of the cost

### NCCS-affiliated Group Formed in DC Area; GWCCS Slates Conference November 5

History was made last spring when the Greater Washington Coalition for Cancer Survivorship (GWCCS) was formed and became the first new survivor group to affiliate with NCCS. The group, operating under the NCCS umbrella, seeks to:

- Act as a networking organization to help patients and survivors connect with appropriate support service resources;
- Serve as a voice for survivors and survivorship interest, and help make the public more aware of survivor needs.

GWCCS has scheduled an all day conference on Saturday, November 5, at the National Rehabilitation Hospital, to explore survivor needs in the Washington area. Workshops will address barriers to employment and insurance, support groups, forming a partnership with your physician and other issues including changing relationships and sexuality, the concerns of men and young adults, adoption and stress management. Contact Jerry Z. Palazzo at (301) 963-7983.

will be covered by an increase in the monthly part B premium (which is normally deducted from social security checks), and two thirds by a surtax on the income tax paid by Medicare beneficiaries.

### Tobacco Company Ordered to Pay \$400,000 for Lung Cancer Death

Rose Cipollone died of lung cancer after 40 years of smoking. On June 13, a Newark, New Jersey jury awarded \$400,000 to her husband on the ground that the Liggett Group (makers of Chesterfields) 1950s ads claiming that cigarettes were safe were a "warranty" that the company breached by selling a cancer causing product. There is both good and bad news in the verdict.

The good news:

- This is the first time a court has required a tobacco company to pay damages for tobacco-induced cancer.
- The case produced volumes of evidence of tobacco company misconduct that will be of use to plaintiffs and their attorneys in the future.

The bad news:

- The jury found that Liggett and the other two defendants (Phillip Morris and Lorillard) did not conspire to hide the dangers of smoking.
- Rose Cipollone, represented by her estate, was barred from collecting damages because she was found to be 80% responsible for her decision to smoke.
- The verdict reinforces current case law that tobacco companies are not liable for harm done to smokers after 1966 (the year the Surgeon General's warning began appearing on cigarette packages and in ads).
- Protracted appeals will delay the payment of damages.

## LETTERS

(Continued from back page)

recovered patients is one where they serve as peer counselors supporting others.

Since I am a social worker, I have the skills to organize a survivor's support group. I spoke at a conference recently, where oncological social workers were enthusiastic about such a group. However, it

has been difficult to reach prospective group members.

REGINA KORNSPAN LEVIN,  
ACSW  
Media, PA.

### We Need to Push . . .

The issues that seem most important to cancer patients and

survivors I have worked with in the past five years include (in order of priority):

- 1) health coverage and/or insurance;
- 2) job discrimination in seeking new employment and/or switching jobs;
- 3) negative reactions of family/friends/general public toward cancer.

I maintain a hot-line/crisis line (907-488-1532) for cancer patients and most of the calls are in regard to lack of health coverage, especially here in Alaska with so many people losing jobs. Most people wish there were some type of mandatory health coverage, especially when they are refused treatment because of a lack of money. I think we need to push for mandatory health insurance for cancer survivors.

CHERI NIEDZWIECKI  
North Pole, AK

## Resources



*Bibliography of Employment and Insurance Concerns of Cancer Survivors*, March 1988. Three pages. National Coalition for Cancer Survivorship, 323 Eighth Street SW, Albuquerque, NM 87102, (505)764-9956.

*Breast Cancer Bibliography*, June 1987. 12 pages. SHARE, Barnes Hospital Plaza, St. Louis, MO 63110, (314)362-5585.

*Cancer Survivorship: An Overview of Psychosocial Research on Long-Term Survivors*, April 1988. Five pages. American Cancer Society, Sacramento/Amador Unit, Barbara J. Carter, R.N., DNSc(c), UCSF-Nursing, 1005 South Eliseo Dr. #4, Greenbrae, CA 94904, (415) 925-0861.

*The Candlelighters Foundation Bibliography and Resource Guide*, (childhood cancers), revised 1987. 35 pages, \$10.00.

Candlelighters, 1901 Pennsylvania Ave., NW, Suite 1001, Washington, DC 20006, (202) 659-5136.

*PATH's Health Insurance Resource Guide*, Literature, Organizations, Services, July 1988. Four pages. PATH, 410 East 62nd St., New York, NY 10021; (212)207-3292. Send a stamped, self-addressed

envelope.

*Psychologic Aspects of Cancer: 424 Citations in English*, January 1978-July 1981. 31 pages. Literature Search, National Library of Medicine (no. 81-18), National Institutes of Health, Public Health Service, U.S. Department of Health and Human Services.

*The Resource Guide*, (brain tumors), 1986, revised 1987. 27 pages, \$4.00. Friends of Brain Tumor Research, 2169 Union Street, San Francisco, CA 94123, (415)563-0466.

*Sherman R. Selix Videotape Library*, a four-page listing of over 65 films dealing with various aspects of cancer. Regional Cancer Foundation, 2107 Van Ness Ave., Suite #408, San Francisco, CA 94109, (415)775-9956.

NCCS Networker will regularly publish lists of other resources that might be useful to its readers. On the agenda: Informational Newsletters, Hot Lines. If you know of other lists that supplement those published in this issue or that are planned for the future, please write the NCCS office; if possible, send copies of the lists.

### Wanted: Film and Video Titles

For a resource list, we are interested in identifying and previewing films and videos which might be appropriate to be shown at support group meetings for cancer patients and their families. We would welcome recommendations from your membership regarding any films they have found particularly helpful, including information on the distributors.

LOIS LORENZ, MSW  
American Cancer Society, New Jersey Division  
Box 2325, Morristown, NJ 07960

Networker welcomes letters for publication. They must be signed and include the writer's home address and home and business telephone numbers. Letters may be edited. Send them to NCCS at the address on the masthead.

## PEOPLE WATCHING



### Barbara Waligora-Serafin

BWS, as she is known to her NCCS colleagues, chairs this year's annual assembly committee. A founding member of NCCS, this nurse clinical specialist, educator, researcher, and manager, has been involved in cancer care for 20 years and considers psychosocial oncology a major interest. She now serves as the Director of the Don and Sybil Harrington Cancer Center's Division of Supportive Care in Amarillo, Texas, where her goal is to develop a survivorship clinic.

Barbara, a native New Yorker, moved to Amarillo in 1981. She is a volleyball fan and in her free time is involved in a special ministry to help people, particularly teenagers, deal with divorce, separation, and death. She says she has learned "what surviving life is all about from cancer patients and their families."

### Neil Fiore

Neil jogs in the hills of Berkeley, California when he's not seeing patients in his therapy practice or consulting with companies about wellness and stress management. The psychologist-author of *The Road Back to Health: Coping with the Emotional Side of Cancer* (Bantam 1984, 1986) and *Conquering Test Anxiety* (Warner, 1987), is a 14-year metastatic cancer survivor, a founding member of NCCS and a

frequent speaker at survivor celebrations. He also serves on the American Cancer Society, California, Division's Service and Rehabilitation Committee. Neil is currently working on his third book, *The Now Habit* (Tarcher/St. Martin's Press, 1989) which he hopes will ease stress for procrastinators.

### Denise Heassler

The executive director and co-founder of the state of Washington's Operation Uplift says that organization grew out of



her own experience as a breast cancer patient, as well as that of the late Donna Willets. The two women started over five years ago talking to women one-on-one, and demonstrating the benefits of a positive attitude. They soon began to hold monthly meetings, publish a newsletter, and hold fund raisers.

"It seems there was no stopping us," Denise reports. Operation Uplift is now a respected part of the Port Angeles, WA community, well funded and accepted by physicians. Among its successful efforts are special programs for men's clubs, which had formerly considered breast cancer a "back burner, woman's issue."

## JOIN / SUPPORT NCCS

### Annual Membership Options

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## LETTERS TO THE EDITOR

### Paris in the Springtime (Age 77)

In January 1960, I went for my yearly physical feeling absolutely wonderful and an hour later found I had cancer of the ovary. The tumor was as large as a grapefruit.

I was in the hospital for three months going through x-ray treatment. One night I was very ill and I saw three doctors standing by my bedside and I could hear my husband crying. I realized I must be dying and when my husband came over to my bed I said to him, "Well, I guess I will never see Paris."

The next day my husband went out and bought two tickets to Paris. He threw them on my bed and said, "Come on honey, you have to get well as we are leaving for Paris."

Two months later we left for Paris and a trip around Europe. I have now been to Paris 12 times and have travelled all over the

world with my husband, from New Zealand to the Arctic Circle — every year another trip. We live in an old house, drive an old car, and have old furniture, but we TRAVEL.

So you see miracles can happen and one can be healthy again after cancer. I am now 77 years old; the cancer never returned.

MARGERY WINDES  
Silver Spring, MD

### NCCS, Where Have You Been?

I have survived so long that I am now suffering from the effects of radiation exposure that saved my life in 1963. Only in this current decade have I learned to cope with the traumatizing effects of my initial ordeal — and I did it largely on my own out of sheer determination to be somewhat normal and content with my life, and most importantly, myself. My (brain) tumor went undiagnosed for six

years, at the very least.

So, where have you been the larger part of my life? Now I am faced with a new situation with which I am either going to have to learn to cope anew, or go under. At the age of 44, I feel that I have a large indebtedness which is due for payment. I would like to find out if my experiences and thoughts through the medium of a pen and the postal system could be of any value or assistance to anyone. I still believe that I have a large capacity to give.

MYRNA BROWN  
Rosemead, CA

Although I am cured (of ovarian cancer suffered in 1981), my emotional adjustment is an ongoing process. As I reached out for support in the Philadelphia area, I realized that hospital and American Cancer Society-sponsored supportive services were oriented for the newly diagnosed and those in treatment. The only service for (Continued on page 10.)

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

Come to the  
Third Annual  
Assembly!  
Albuquerque, NM  
November 18-20, 1988



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