



NETWORKER

NATIONAL COALITION FOR CANCER SURVIVORSHIP

Summer 1990
Volume 4, Number 3

Fifth Annual Meeting Blockbuster Assembly Opens In Capital November 8 Participants to Address Advocacy, Personal Cancer Issues

Paul Tsongas, former Senator from Massachusetts and cancer survivor, will keynote the 1990 National Assembly, "Speaking Up for Survivorship: An Agenda for the Nineties," to be held November 8 - 11. Sharing the keynote position will be Samuel Broder, MD, Director, National Cancer Institute.

In his first speech to a national cancer group since he left the Senate and in other ways changed his life after his diagnosis with non-Hodgkin's lymphoma, Tsongas will lead the discussion of advocacy, building on last year's intense debate on health insurance issues.

NCI's Dr. Broder will describe national research efforts bearing on the personal issues affecting every person with cancer.

Chief among these personal issues to be addressed at the fifth annual Assembly is the mind-body connection. Among the leading experts who will discuss such questions are Memorial Sloan-Kettering psychiatric chief Jimmie Holland, MD, Barrie Cassileth, PhD, Director of Psychosocial Programs, University of Pennsylvania Cancer Center, Michael Lerner, PhD, Commonwealth president and David Spiegel, MD, Assoc. Professor of Psychiatry and Behavioral Sciences at Stanford University School of Medicine.

"Making Your Voice Heard" will be the title of the welcoming speech by Reed Tuckson, MD, former DC Public Health Commissioner. Esther Peterson, consumer advocate who has held high-level posts under three US Presidents and served as advisor to business and international groups, will define "advocacy" for the Assembly. Her presentation will be followed by panels focusing on three aspects of advocacy: "for ourselves" (the doctor-patient relationship), "for personal others" (families, friends and loved ones) and "for the community" (access to health care — the insurance dilemma). A workshop on lobbying at the state and federal levels will give practical hints for those who wish to "speak up for survivorship."

A number of workshops will include the popular "Look Good Feel Better," a sexuality workshop, and workshops on nutrition, long-term survivorship, and the feelings

of significant others.

NCCS executive director Catherine Logan will take the lead in three separate sessions on networking: a workshop on successful community-based models, an informal information-exchange among assembly participants, and a focus group, "NCCS: Building a Program to Serve Member Organizations."

The Book Fair will return by popular demand, again chaired by Helen Samuels. Authors will autograph their books, including several new ones, and video tapes will be



The discovery of his lymphoma dramatically changed Paul Tsongas' priorities, leading him away from a successful political career and into a different kind of fulfillment as a husband, father and private citizen (a role which now includes competitive swimming).

available. A research poster session will be coordinated by NCCS board member Barbara Carter, RN, DNSc.

Assembly At a Glance

Title: Speaking up for Survivorship: An Agenda for the Nineties

Date: Thursday, November 8 to Sunday, November 11, 1990

Place: Ramada Renaissance Hotel/Downtown
1143 New Hampshire Ave., NW, Washington, DC
To reserve rooms, call toll free 1-800-526-7495

Rate: \$80 per night, single or double occupancy

Travel: Special discounts available on American Airlines. Call 1-800-433-1790, ask for STAR file # S-01NO7X

Registration: Members - \$65, Non-Members - \$90. Registration will be taken in order of receipt as space is limited to 400 participants.

Queries: Assembly Chair Ellen Stovall: (301)230-0831

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LETTER FROM THE PRESIDENT

Fitzhugh Mullan, MD



Every year one million Americans are newly diagnosed with cancer — 83,000 a month, 19,000 a week, 2,700 a day. In a sense, a new small town, a town of 2,700 cancer survivors, comes into being every day. Every month, new survivors constitute a new small city and each year a metropolis of 1,000,000.

These survivors, of course, live all over the country and, for the most part, do not know each other. The community that they are creating is defined by their illnesses, their needs, and their potential to help one another rather than by a common geography. It is, in fact, the very ubiquitous nature of cancer — its incursions against all ages, races, and parts of our society that has made it difficult for survivors to organize to meet their needs in the way that people in a small town or a large city do. We survivors are spread so far and wide that, despite our numbers, we have found it difficult to come together to identify and speak up for our common interests.

Hence **ADVOCACY**. What can we do to focus attention on the problems that we face together? What can we do to make our special needs known? What can we do to improve the well being of the cancer survivor community? This is the theme underlying the fifth National Assembly of the NCCS — “Speaking Up for Survivorship:

An Agenda for the Nineties.”

The conference will draw on the excellent work in cancer community organizing carried on nationally by groups like Candlelighters and Y-Me as well as community-based groups like Make Today Count and a hundred others. The Assembly will explore and promote advocacy — speaking up and out on behalf of ourselves, our fellows, and the community.

It is not an accident that this is the theme selected for a conference in Washington, DC, perhaps the greatest city for advocacy that the world has ever known. It is in the nation's capital that issues such as insurance coverage, research priorities, preventive health, reimbursement and the like are debated. We need to be in the front ranks of those debates.

We're bringing our town to your town. It will be a great meeting. Do come!

THANK YOU ...

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323 Eighth Street SW
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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 interest of cancer survivors and encourages the study of survivorship.

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"Keep Your Face Toward Delight:" Survivors Day Celebrates Life

On the shores of Lake Michigan, they launched 200 homing pigeons, carrying a message of hope. In Jacksonville they paraded along the Riverwalk. In Los Angeles they laughed with the clowns. In Boise and Albuquerque they enjoyed pollution-free balloon arches. At the Pittsburgh Zoo, and in many other places, celebrations centered around building or planting a tree of life.

Across the country, survivors, their families, friends and caregivers found many such ingenious ways to celebrate the third annual Survivors Day June 3 (or thereabouts), co-sponsored this year by the American Cancer Society, NCCS and Coping Magazine. "It was fun, fun, and more fun," said a participant aboard the Memphis Showboat, "plus people congratulating, supporting, and getting to know each other."

"Keep your face toward delight,"

added the author of one of the survivors' messages included at the base of the tree of life at ACS' Atlanta headquarters, "sit, stand, walk, or run. Each step is an expression of faith in survival." The same message was sung loud by the *Voices of Praise* at the thanksgiving celebration sponsored by the ACS District of Columbia Division and the Greater Washington Coalition for Cancer Survivorship; the singers are returning by popular demand to the fall Assembly.

Celebrations of the achievement of a full life after cancer drew crowds of as many as 100 to 1600. The events included ranged from panel discussions, speeches, and readings of the Cancer Survivors Bill of Rights to a carnival featuring a "Dunk Your Favorite Doctor" booth at Oklahoma City's Baptist Medical Center.



Above, 8 year old lymphoma survivor Nicole Haines wears the "Celebrate Life" T-shirt she designed for all the participants in the Survivors Day Celebration at the Ireland Cancer Center, University Hospitals of Cleveland, OH.



Opposite, NCCS President Fitz Mullan with actor Jack Klugman at the ACS headquarters tree planting ceremony in Atlanta, GA. Above, hundreds of Jacksonville, FL, survivors celebrate "Living Beyond Tomorrow" as they parade along the banks of the St. Johns River. Right, with a little help from 200 homing pigeons, the University of Chicago Hospitals launch "Triumph Over Cancer"—a new program of education and support services for survivors.



Above, at the huge Pittsburgh, PA Zoo gathering, survivors young and old join in creating the first segment of a mural expressing their messages of thanks, hope and encouragement.

WHAT'S NEWS

Hot Off the Presses

■ The National Cancer Institute's *Facing Forward: A Guide for Cancer Survivors* is scheduled to be available in November, in time for the 1990 Assembly. John Burklow of NCI's Office of Cancer Communications (see p. 11) worked closely with NCCS' Larry Moore and others on both the content and style of this 36-page guide, holding discussion groups and conducting a needs assessment among NCCS members. Once a draft was written, two focus groups in Pittsburgh and Baltimore gave the authors feedback on the tone and design options.

Primarily geared for survivors who have completed treatment and their families, this guide will be of interest to those in treatment as well, since it provides helpful information and practical hints on many survivor issues, including maintaining physical and emotional health, insurability and employment concerns. Every NCCS member will receive a copy. For additional copies, call 1-800-4-CANCER.

■ Prostate Cancer Awareness Week is scheduled this year for September 16-23. To find out more about this disease, which kills 30,000 men a year, send for *Prostate Cancer: Some Good News Men Can Live With*. This free brochure, which discusses the myths and facts about the disease and emphasizes the importance of annual exams, was developed by the Prostate Cancer Educational Council with NCI. Call 1-800-4-CANCER or write to the PCEC, JAF Box 888, New York, NY, 10116.

■ DES Action USA, established in 1975 by DES mothers, daughters and concerned health workers has published *Breast Cancer: Risk, Protection, Detection and Treatment*. This up-to-date booklet in concise language with clear illustrations is available for \$2.50 from DES Action USA, 1615 Broadway, Oakland CA 94612.

Top Survivor Concerns

Their greatest concerns, 200 former Memorial Sloan-Kettering cancer patients told interviewers were, in order of priority: (1) general physical health and disease recurrence, (2) ability to plan for the future, (3) finances and (4) general frame of mind. Results of a needs assessment survey done during the planning process for the Post Treatment Resource Program (PTRP) and published in the *Journal of Psychosocial Oncology* (Vol.7[4]1989) showed that 32% of the group had received no help or information from any source (pre-PTRP).

NCCSers on The Move

■ Advisory Board member Richard A. Bloch realized a dream with the dedication in June of a new Cancer Survivors Park in midtown Kansas City, MO. In the middle of the park, the first of many he hopes to develop in cities around the country, are plaques on pedestals, each with a message of support leading to a large arch. According to Bloch, the arch denotes passage: "You go out to that area and it's a celebration of life."

■ In a June ceremony at Cancer Care headquarters, Ed McCartan, NCCS Board Member, was presented with an Outstanding Service Award by Executive Director Diane Blum for his work, as a volunteer, in planning and organizing a computer-based cancer resource directory for the Greater New York Metropolitan Area. In 1989 a coalition was formed by representatives of Memorial Sloan-Kettering's PTRP Cancer Information Service and Cancer Care and has since grown to include 21 public and private support organizations in the Greater Metropolitan area and New Jersey.

■ On April 1, *The New York Times Book Review* featured a lead article by a former editor, Anatole Broyard, titled "Good Books about Being Sick." Ill himself with prostate cancer, the author wrote he preferred fiction (such as Thomas Mann's "The Magic

Mountain) and was "for the most part disappointed" in the non-fiction books about illness. But he singled out "two of the better books:" the late columnist Stewart Alsop's *Stay of Execution* and *Networker* Editor Natalie Davis Spingarn's *Hanging in There: Living Well on Borrowed Time* (available from NCCS' Book Mart).

■ That soft English-accented male voice you hear when you call the Albuquerque office is that of Alan Bartholomew, NCCS' newest staff volunteer. A retired educator, Alan has worked in England as well as Massachusetts, New Jersey and Arizona, finishing his career as Deputy Director of the Navaho Nation Education System. He is a six-month prostate cancer survivor.

Happy Birthday, Candlelighters

Since 1970, the Candlelighters Childhood Cancer Foundation has provided support, education and advocacy for families dealing with childhood cancer. In July, the group gathered in Washington, DC for a 20th Anniversary Conference to celebrate progress made in treatment, a new public awareness, and increased consumer participation in treatment and adaptation. In the 1990s, Candlelighters will also continue to focus on legal and economic rights of survivors of childhood cancer.

Canadians Call for Volunteers ...

Survivor volunteers between the ages of 18 and 50 who have been free of cancer for at least six months, have never participated in a wilderness challenge experience and would be willing to fill out two brief questionnaires, are wanted for an evaluation of an Outward Bound Wilderness School program, the first held for Canadian cancer survivors. Contact: Dr. Ross Gray, Department of Psychology, Suite H 332, Sunnybrook Health Science Centre, 2075 Bayview Ave., North York, Ontario, Canada M4N 3M5; (416)480-4872.

The Fifth Annual Assembly National Coalition for Cancer Survivorship

November 8 - 11 1990

“Speaking Up for Survivorship: An Agenda for the Nineties”

Communications
Advocacy
Networking
Coalescing
Education
Research

- ♥ *To promote the organized voice of cancer survivors;*
- ♥ *To define and teach effective means of survivor advocacy — for ourselves, for personal others, and for the community;*
- ♥ *To identify ways of living life — no matter how long or short — to the fullest by examining the role of the mind/body connection, spirituality, and other personal issues;*
- ♥ *To focus on and enhance networking among survivors, and with individuals, organizations, and institutions involved in survivorship activities;*
- ♥ *To share existing and new resources about survivorship issues.*

Tentative Program

Thursday, November 8

Registration

Evening Program:

Welcome to Washington — Making Your Voice Heard — Reed Tuckson, MD, former DC Commissioner of Public Health, Senior Vice President for Programs for the March of Dimes Birth Defects Foundation; Entertainment

Friday, November 9

Registration

Welcome and President's Address:

Ellen Stovall, 1990 Assembly Chair and
Fitzhugh Mullan, MD, NCCS President
What is Advocacy? Hon. Esther Peterson

Panel: For Ourselves — Doctor/Patient Relations: The State of the Union, Moderator — Natalie Davis Spingarn, *Networker* Editor; Sherrie Kaplan, PhD and Sheldon Greenfield, MD, Institute for the Improvement of Medical Care and Health, New England Medical Center; Larry Moore, Vice President, NCCS

Panel: For Personal Others: Family, Friends and Loved Ones
Moderator: Danette G. Kauffman, MA, MS, Maggie Strong,
Author, Howard Johnson

Picnic Lunch

Keynote Addresses:

Hon. Paul Tsongas, former United States Senator, State of Massachusetts; Samuel Broder, MD, Director, National Cancer Institute

Panel: For the Community — Focus on Access to Universal and Comprehensive Health Insurance
Panelists will include experts from the US Congress, the Insurance Industry, the Health Policy and Survivorship Communities

Concurrent Workshops (Group I)

- A. Getting the Job/Education You Want: How to Deal with Employers/Educators. Barbara Hoffman, JD, Vice President, NCCS
- B. How to Lobby at the Community Grassroots, State and National Levels. Marguerite Donoghue, Vice President, Capitol Associates; Joy Wilson, Director, Health Committee, National Conference of State Legislators
- C. Getting the Facts Out: How to Get What We Need From People in the Know. Mildred Lehman, Communications and Public Affairs Consultant; Susan Okie, MD, the *Washington Post*; Sharon Sutton, Chief, Information Projects Branch, National Cancer Institute
- D. Community-based, Regional, and National Cancer Support Organizations — Successful Models. Catherine Logan, Executive Director, NCCS.
- E. Everything You Want to Know About Health Insurance and Don't Know Whom to Ask: A How-to Workshop for Specific Insurance Problems. Irene Card, Medical Insurance Claims, Inc.
- F. Advocating for Multicultural Groups — Panel Presentation
Moderator: Alejita Ortiz, Chair, NCCS Task Force on Multicultural Groups and the Poor

Reception:

NCCS and You ... Community, Regional, and National Programs, Networking Together

Saturday, November

Panel: Lifestyles — The Many Faces of Cancer Survivors. Moderator: Barbara Waligora-Serafin, RN, Harrington Cancer Center, NCCS Board of Directors

Panel: The Mind/Body Connection and Cancer. Moderator: Pat Fobair, LCSW, MPH, Stanford University Hospital; Barrie Cassileth, PhD, Director of Psychosocial Programs, University of Pennsylvania Cancer Center; Jimmie Holland, MD, Chief, Psychiatric Services, Memorial Sloan-Kettering Cancer Center; Michael Lerner, PhD, President, Commonweal, David Spiegel, MD, Professor of Psychiatry and Behavioral Sciences Stanford University School of Medicine

Concurrent Workshops (Group II)

- A. Sexuality and Cancer. Wendy Schain, PhD; and Lucy Waletzky, MD, Co-director, Medical Illness Counseling Center
- B. Nutrition and Cancer: Can Broccoli Make a Difference? Tazewell Banks, MD, DC General Hospital
- C. Facing Forward: Health Care for the Long-Term Survivor. John Burklow, MEd, Patient Education Program, National Cancer Institute; and Susan Leigh, RN, NCCS Board of Directors
- D. The Other Survivors: Family, Friends, and Loved Ones. Ivan Barofsky, PhD, Institute of Social Oncology; and Michael Stefnick, PhD, Johns Hopkins Oncology Center
- E. Heroic Self-Healing and Cancer: Empowerment Needs of Cancer Survivors. Ross E. Gray, PhD, Dept. of Psychology, Sunnybrook Medical Center, University of Toronto
- F. Look Good/Feel Better. Marcia Lavine, ACSW, Director of Service and Rehabilitation, American Cancer Society, DC Division, Eivend Bjerke, Lucien and Eivend
- G. Acute and Long-Term Anxiety: Fear of Recurrence and How to Deal With It. Deborah Dozier-Hall, LICSW, President, National Association of Oncology Social Workers, George Washington University Medical Center

Research Poster Sessions

Focus Groups:

NCCS: Building a Program to Serve Member Organizations, Catherine Logan, Executive Director, NCCS

Delivery of Quality Medical Care: A Report on a Survey of Cancer Survivors. Ellen Tobin, President, Health Surveys and Marketing, Inc.

The Role of Spirituality: Faith and Doubt. Reverend James R. Adams, Rector, St. Mark's Episcopal Church; Voices of Praise, Florida Avenue Baptist Church

Book Fair and Exhibits

Sunday, November 11

NCCS Annual Meeting, Election of Board of Directors

REGISTRATION

(Please fill out other side of form also)

Name _____ Phone _____

Address _____

City _____ State _____ Zip _____

Organization _____

Please check one or more (optional):

- cancer survivor family member
 health care provider other _____

Registration Fees:

- Non-member \$90 NCCS member \$65 * Amount Enclosed \$ _____

Please enclose check with your registration. You can post-date the check November 8 and we will hold it until registration. Payment will be by check only.

Hotel Registration:

The Ramada Renaissance Hotel/Downtown, 1143 New Hampshire Avenue, NW, Washington, DC, will handle all arrangements. To insure a room call 1-800-526-7495 BY OCTOBER 7, and be sure to specify this address (there are two Ramada Renaissance Hotels in Washington). Room rates are \$80.00 per night, single or double, and non-smoking rooms are available. The Ramada is easily accessible from Washington National Airport by cab or by Washington's clean, safe Metro subway (Foggy Bottom station, Orange OR Blue line).

Airline Reservations:

American Airlines is again offering a group discount of 5% off the lowest discount fare available (with an extra 5% off for senior citizens) or 40% off the full coach fare. American Airlines has made a commitment to refund in full any paid reservations canceled due to illness (with a physician's note). To make reservations, call 1-800-433-1790 and specify STAR file account S0IN07X.

Exhibits:

A limited number of exhibit spaces are available. Past exhibitors will be given first priority. Contact: Dan Moscowitz (301)621-8999.

Important:

Due to space limitations, registration is limited to the first 400 applicants and is being offered to NCCS members before release to the general public. Make reservations NOW.

Scholarships:

NCCS has limited funds to help those who would otherwise not be able to attend this assembly. Please help us reserve these funds for those who really need them. Contact: Alejita Ortiz, Cancer Care, 1180 Sixth Avenue, New York, NY, 10036 (212)302-2400.

*Representatives of NCCS organizational and institutional members may attend for \$65 member fee

WORKSHOP REGISTRATION

Please number your first and second choices for workshops in both Group I and Group II. This is not a reservation, but an indication of your interest for planning purposes only.

Friday, November 9 (Group I)

- Getting the Job/Education You Want
- How to Lobby at the Community Grassroots and State Levels
- Getting the Facts Out
- Community-Based Cancer Support Groups
- Insurance Troubleshooting
- Advocating for Multicultural Groups

Saturday, November 10 (Group II)

- Sexuality and Cancer
- Nutrition and Cancer
- Facing Forward
- The Other Survivors
- Heroic Self-Healing and Cancer
- Look Good/Feel Better
- Acute and Long-Term Anxiety

Mail your completed registration form and check to:

NCCS
P.O. Box 406
Rockville, MD 20848

For further information, call 301-230-0831.

NCCS Board Elections at Assembly

NCCS' 1990 Annual Meeting will take place Sunday morning, November 11 at the Ramada Renaissance Hotel in Washington, DC. Any individual member in good standing is eligible for nomination and election as an officer or member of the Board of Directors. You may nominate yourself or another member by presenting the nomination in writing to nominating chair Estelle Weissburg.

The nominating committee will call for nominations during the opening session of the Assembly. Those wishing to submit names prior to the Assembly may contact Ms. Weissburg, Cancer Guidance Institute, 1323 Forbes Ave., Pittsburgh, PA 15219. You can participate in the election if you attend the meeting, either personally or by proxy (evidenced in writing).

One Way Up, One All the Way Down

This summer, your lobbying efforts as part of the NCCS contributed to the Congress' passage of two important measures: the Americans With Disabilities Act, signed into law July 26 by President Bush, and the Family and Medical Leave Act which was vetoed by President Bush. So much for the kinder gentler society when it comes to the needs of today's families.

Americans With Disabilities Act

Although the ADA does not specifically protect cancer survivors, federal courts and agencies are expected to apply the law to them. Passed in the Senate with fanfare and near unanimity, the law was signed by the President in a July 26 ceremony. Remember the date, for ADA's employment discrimination provisions do not take effect until

July 26, 1992. ADA, which will prohibit employment discrimination against a qualified employee because he or she is disabled, has a history of a disability, or is regarded as being disabled, will:

*Cover private employers, regardless of whether they receive federal funding (from mid 1992 to mid 1994, employers with more than 25 employees will be subject to the law; after mid 1994, employers with 15 or more employees will be subject to the law);

*Prohibit employers from requiring pre-employment examinations that are designed to screen out individuals with a disability, including a cancer history. An employer can ask you medical questions only after you are offered a job and only if the questions are specifically related to that job.

Family and Medical Leave Act

Last June 14, Congress passed the Family and Medical Leave Act, which would prohibit large employers (those with at least 50 employees) from firing an employee who has to take time off because either the employee or a dependent has a "serious health condition," including cancer. The measure provides unpaid job security for up to 12 weeks.

Although most industrialized countries mandate *paid* leave for employees with medical emergencies, the President vetoed the bill, saying that the federal government should not tell employers what benefits to offer workers. So unless you work in a state that has a medical leave law, you may find yourself unemployed when you try to return to work after a few months of cancer treatment for yourself or a dependent.

WHAT'S NEWS

In Survivorship Issues: Pain Control

CATHERINE LOGAN, NCCS Executive Director

Although about one third of people with metastatic cancer suffer severe pain which interferes with their daily activities, the experts tell us that as many as half of these receive inadequate relief. Some claim cancer pain is almost universally badly managed.

More and more attention is being paid to cancer pain control, as a consumer right which can be effectively achieved with current therapies that are neither expensive nor high tech. These may include medication, from aspirin to narcotics; psychological techniques, from hypnotherapy to relaxation; physical therapy, from massage to electrical techniques, and when necessary, surgery. Often a combination of modalities is used.

Under leaders like Memorial Sloan-Kettering's Kathleen Foley MD,

and Charles Cleeland, PhD, who headed a World Health Organization demonstration project in Wisconsin to improve cancer pain management, progress has been made.

There are now 12 states involved in cancer pain initiatives. Such programs face the fact that though readily accessible, pain management is often blocked by society's resistance to pain control. Health care providers as well as patients with limited knowledge may regard pain as an inevitable part of cancer and its treatment. There is little understanding of the positive role narcotics can play in achieving long-term relief without abusive behavior or significant toxicity. If you are dealing with cancer pain, here are some suggestions to help you advocate more effectively for yourself:

Examine your beliefs about cancer pain; know that —

- Pain is not an inevitable part of cancer which must be tolerated;
- Adequate treatment for cancer pain is available in a variety of modalities;
- Treating advanced cancer pain with narcotics can be part of maintaining an active, productive life; it is not a sign you are near death or "giving in;"
- Use of strong drugs will not make them less effective if needed at a later date;
- Psychological dependence on narcotics is not an issue when used to relieve advance cancer pain, unless you have had a history of drug abuse (and even then it is not always a problem).

(continued on page 12)

NETWORKER READER

Handbook of Psycho-oncology; Psychological Care of the Patient With Cancer edited by Jimmie C. Holland, MD and Julia H. Rowland, PhD (Oxford University Press, \$95).

As survivors sort through the burgeoning literature on the interaction between psychology and cancer, this book can provide a reference anchor. Although it is called a handbook, its size and intellectual weight give it the status of a textbook defining a field. The authors, the majority from the Memorial Sloan-Kettering Cancer Center in New York, survey current research as it bears on practical issues

Putting into perspective what is little known but often quoted.

of patient care and suggest research strategies to their professional audience. But certain chapters provide an overview for anyone who is asking about the social or psychological effects of cancer illness and treatment.

Drs. Holland and Rowland review the effect of cancer diagnosed in different stages of life, the pattern of stress over the course of illness, and the psychological sequelae in survivors. Two chapters address psychosocial considerations in cancer cause and survival: One, by Dr. Holland, reviews research on behavioral and psychosocial risk factors for the development of cancer — from smoking, diet, and alcohol to personality traits, coping style, psychiatric syndromes and grief reactions; a second by Dr. Dana Bovbjerg summarizes research in psychoneuroimmunology and cancer, putting into perspective what little is known but often quoted. Other subjects treated include the family and the cancer patient, alternative therapies and how they intermingle with orthodox treatments, and how our culture places responsibility on the patient to improve his own biological or psychological function

with special nutrition, spirituality, psychological treatments, or immunotherapy.

Knowing that current science can limit pain, vomiting, anxiety, and depression offers the possibility of comfort and control. Behavioral treatments, mutual support and self-help programs and psychopharmacological treatments are viewed. Some chapters deal with specific cancers, problems of children or the elderly. Even if the focus here is too technical, the reader will get an overview of the array of resources and excellent bibliographies.

— Donna Greenberg, MD

Dr. Greenberg is an internist and psychiatrist who practices psychiatric oncology at Massachusetts General Hospital.

MAINSTAY: For the Well Spouse of the Chronically Ill, by Maggie Strong (Little Brown and Co., \$17.95, Penguin paperback, \$8.95).

A serious long term illness like cancer puts a very real strain on the marriage contract. No one is trained to be the well spouse of an incapacitated mate, and until this tender, insightful, and practical book was published there was almost no guidance on how to handle the anxiety, guilt, frustration, and even anger experienced as a couple's expectations of one another change. In *Mainstay*, Maggie Strong describes the division that comes when two spouses are "in two different states, and you, the well one, will take care of the other. Except you're married... Your spouse is supposed to be protecting and caring for you equally. You lose your expected future first, and then your marital equality."

She writes of her personal struggle to keep her individual identity and help her husband maintain his, while taking on more of the responsibility for home and children, social life and health care. As the husband of a cancer survivor, I shared the author's experiences and emotions, learning that my own in dealing not only with my wife, but with health care profes-

sionals and even friends and family, were normal and expected under the circumstances. I also profited from the practical advice (with names, addresses and phone numbers) and the checklists other couples will want to review together.

— David Owen

David Owen and his wife Ona live in Louisville, Kentucky, where he is a training consultant.

UP FRONT: Sex and the Post Mastectomy Woman, by Linda Dackman, (Viking, \$17.95).

Studies show that the majority of people who are comfortable with their sexuality before breast cancer continue to be so thereafter. The author of this book — a young, unmarried woman — fits into that group. Her account of the emotional roller coaster she rode for several years as she learned to cope with the psychological and sexual losses of breast cancer is gripping. I read it through at one sitting, and think people with all kinds of cancers and their sexual partners, as well as health professionals working with cancer, will find it thought-provoking and useful.

In a country which emphasizes physical beauty, health and fitness, the single breast cancer patient faces social discrimination problems similar to those of others with physical disabilities. In her account of her fears of rejection and of intimacy, Linda Dackman shows us that overcoming stigma is usually a complicated and gradual process, even when you are as open, or as flamboyant, as she (before her surgery she and her friends decorated her breasts with flowers and photographed them). If she is less understanding of the fears, anxieties, and "turn offs" of sexual partners than of her own, she is keenly aware of the value of psychotherapy. (Some who have had sexual problems before cancer will need sex therapy in addition or instead).

— Lucy R. Waletzky, MD

Dr. Waletzky, psychiatrist and sex therapist, is co-director of the Medical Illness Counseling Center, Washington, DC, and a member of the NCCS Advisory Board

People Watching

Ellen Stovall



"1990 Assembly Chair" is only the latest role for Ellen Stovall in a long career of dedicated survivorship advocacy. She

has survived two bouts with Hodgkin's Disease, the first in 1971 (when she was given a 40% chance of living for two years) and the second in 1984. Her experience led her into work for cancer patients and their families, forming support groups and engaging in personal peer support. Later, she became a panelist and featured speaker on survivorship issues, not only appearing in television interviews, but assisting in network production.

As Director of DateABLE, Inc., Ellen heads a non-profit social and dating service, primarily for people with illness and disabilities. A former coordinator for CanSurmount in the District of Co-

lumbia, she has served on the American Cancer Society's Service and Rehabilitation Committee, and is now Vice-President of the Greater Washington Coalition for Cancer Survivorship and directed its first (and highly successful) one day conference. She lives with her architect-husband and son in Gaithersburg, Maryland and is active in community affairs there.

John Burklow



A public health educator in the National Cancer Institute's Office of Cancer Communications, John will lead a workshop at the

1990 Assembly on health care for long-term survivors with NCCS Secretary Susan Leigh. He holds a BS in Communication from Southern Illinois University and a Master's in Public Health Education from the University of North Caro-

lina at Greensboro.

John came to NCI as a graduate intern in 1986. Since that time, he has worked on a variety of public education programs for the agency—including his two-year coordination of the Cancer Survivor Education Project. In this role, he worked closely with other NCCS members in producing *Facing Forward* (see p. 4). He also directs a new education initiative targeted to older Americans, which is part of NCI's special effort to address the needs of the elderly.

Elizabeth A. Finchem



The "short" of it, says Elizabeth Finchem, is that she was 42, married, with three children at home in Michigan and three in college,

working part time as an actress, clothing consultant, and volunteer when, in 1978, she developed a sarcoma in her larynx which required a laryngectomy, followed by radiation and extensive speech therapy.

And the "long of it"? Her lengthy and difficult rehabilitation involved increased proficiency with an electro larynx when esophageal speech was complicated by unidentified medical problems. After many Laryngectomy Rehabilitation Seminars and International Association of Laryngectomees (IAL) Voice Institutes she began to teach alaryngeal speech. Eleven years post-op she is a California divorcee, a teacher serving as president of the California Association of Laryngectomees (CAL), and the Los Angeles Coastal Cities New Voice Club (which will host a major CAL meeting next October in Santa Monica). "Accentuate the Positive" is her theme as she speaks to health care audiences on the team approach to rehabilitation. She will appear on a "Lifestyles" panel at the Assembly.



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LETTERS TO THE EDITOR

One Strike and I'm Out; Are You Next?

Two years ago I was diagnosed with breast cancer. Recently my husband received a letter from Great Republic Insurance Company beginning: "This is notification of the cancellation of the Master Policy under which you are a certificate holder."

Our insurance agent says that Great Republic is dropping a block of people for whom the company feels that the loss-ratio has been too high (he also says that nothing like this has happened before in his experience). We've been with Great Republic four years and, even though I had a mastectomy and eight chemotherapy treatments, it is unlikely that our premiums exceeded the \$360 paid monthly for our policy.

Great Republic says that we are eligible for a "Conversion Privilege." This means that for \$1,100 a month we could have had an extremely poor plan with total lifetime benefits of \$100,000, for which the premiums needed to be increased at least every six months. By offering this conversion policy, the company is, we are told, acting within the letter of the law.

Then isn't the law wrong? Isn't something grossly unfair and unethical happening here? Those in

the cancelled block who do not have pre-existing conditions such as breast cancer will be obliged by Great Republic with a new policy similar to the one cancelled. Or they may choose to go to another insurance company. But we must live with the fear of not being adequately insured, while metastasis, or a new cancer in my remaining breast, is always possible.

CINDY VICTOR
Fullerton, CA

Since writing NCCS, Mrs. Victor has joined an HMO. — Editor

Wanted: Contact with others with the same diagnoses:

- Diane M. Pearson (adenocarci-

Clarifications — Spring, 1990 *Networker*

- In the RESOURCES column, send \$3.00 (not \$1.00) for Consumers Union's *Beyond Medicare*; health insurance reports published in August and September 1990 will both be available in October (reprints available a month after publication).
- In LETTERS TO THE EDITOR, the answer to Deborah Roper's letter should read, in part, "To qualify for social security disability benefits, you have to wait five months; after you receive disability cash benefits for 24 months you are eligible for Medicare (even though you are not yet 65)." SSI (Social Security Income) is a cash income, needs-tested, welfare program for which there is no waiting period.

— Editor

noma, metastasized to the lung), 551 Barton Lane, Wayne, PA 19087;

■ Margie Levine (mesothelioma), 24 Copperwood Dr., Stoughton, MA 02072;

■ Julie Gay (three primaries: breast, ovarian and endometrial, as well as Lynch Syndrome, which gives her a 90% chance of getting colon cancer), F-8, 1505 NW 41st St., Rochester, MN 55901.

Pain Control

(continued from page 9)

Learn to communicate clearly about pain —

- Don't minimize your complaints — to yourself, your family, or your health care team; remember cancer pain tends to be under reported;
- Find a comfortable, clear way to define your pain to your doctor, perhaps on a scale of 1 to 10 or in terms of what activities the pain limits or discourages;
- Never avoid talking about your pain or taking pain therapy in order to be a "good patient" or for fear of being bothersome;
- Ask for additional time to discuss your pain; don't be afraid of discussing it with your doctor because this will take too much time or divert attention from your cancer treatment.

National Coalition for Cancer Survivorship

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