

Fifth Annual Meeting

Making Our Weight Felt at Rousing Washington Assembly

Larry Moore Elected Coalition President

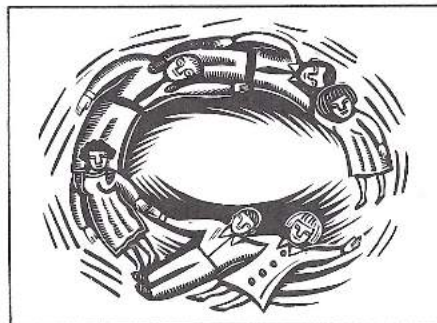
When Larry Moore of Arlington, Texas, walked onto the 1990 Assembly's plenary panel on doctor/patient communications wearing a hospital gown—dramatizing how it is from a patient's point of view—he set the tone for his NCCS presidency.

What he will bring to NCCS, the Arlington, Texas, CPA, said, is a "consumerist approach" which will help bring out the best in cancer care and support services for survivors—"especially when many cancer survivors cannot do this for themselves, either because they are physically unable, and under great emotional stress, or not knowledgeable on key issues which may directly affect them."

With NCCS founder Fitzhugh Mullan moving on to become Board Chair, Moore takes on the everyday administration of Coalition affairs. He served on the Board of Directors for two years and as Vice President for Operations last year. Ellen Stovall, of the Greater Washington Coalition for Cancer Survivorship, Chair of this year's highly successful Assembly, becomes Vice-President; Michael McKechnie of the National Brain Tumor Foundation, San Francisco, Treasurer; and Sally Henderson of CANCare, Charlotte, NC, Secretary.

Though technically off the Board, both Barbara Hoffman, JD, of Princeton, NJ, and Susan Leigh, RN of Tucson, AZ, continue their

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Assembly Impressions

This is Great!

From the start, with those hugable Life After Cancer-Pathways clowns (recognize Peg Carey?), to the end, with its heavenly choir, NCCS' fifth annual meeting burst with energy, laughter, and applause.

Everyone seemed to agree that there were an out of proportion number of bright, vital, witty and yes, good-looking people present. Said a Canadian psychologist: "This is great! People are dressed to kill—as if they're on their way to a business meeting. What is the message? Don't mess with us, we're serious stuff? Illness doesn't have the power to keep us from looking good and being competent?"

Intensity prevailed. Some anger, some distress. ENERGY! Obvious leadership and organization. "Very classy" program.

A preliminary glimpse of our profile, gleaned from a 15% sample, shows we are, by and large, survivors (61%)—of breast and

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Dynamic Program Focuses on Advocacy

With over 450 survivors, family members, friends and caregivers gathered for NCCS' fifth annual meeting November 8-11 in Washington, DC, the Coalition focused on advocacy—speaking up for ourselves, for personal others, and for the community.

Two keynote speakers set the stage for the dynamic, jam-packed program. Calling the formation of NCCS a "life-affirming move," National Cancer Institute Director Samuel Broder, MD, said that the challenge, "only a few years away from the time the word 'cancer' was not spoken directly," is to spread the "exceedingly important" message that many people experience cancer and survive in a vital, courageous way. Dr. Broder asked for each Coalition member's help as an advocate of cancer research and messenger of information, who should know that "a patient needs to participate in his or her treatment," but at the same time, "should never be blamed" if the cancer advances.

Former Senator Paul Tsongas, a seven year lymphoma survivor, stressed the survivor's obligation to avoid self-absorption, giving "some-

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LETTER FROM THE CHAIR

Fitzhugh Mullan, MD



To advocate and to activate! These powerful themes, which emerged from the fifth National Assembly, stand as a succinct mission statement

for the future of NCCS.

"To advocate" means representing the issues of cancer survivors in public forums at the local, state, national and even international level. We need to be heard in legislative debates on matters such as the cancer research budget and patient rights. We must become experts about our troubled insurance system and work for full coverage of all Americans—especially those with cancer. When blue-ribbon commissions convene to discuss topics such as new drug-approval policy or reimbursement for experimental therapies, we should be there, well informed and vocal.

In order to carry out this ambitious role, we will have to spend time educating ourselves, researching the issues and circulating our policy positions. The newly opened NCCS Washington office will help with this agenda as will the generous provision of substantial, *pro bono* legal assistance from a Washington firm that specializes in health law. Over the next year, we will work to make the voice of the NCCS heard more often and with more force.

"To activate" means to stimulate participation in the NCCS at all levels. While our first four years have brought many individuals, organizations and institutions into the Coalition, the six million cancer survivors in the United States represent a huge potential constituency, most of whom still receive little in the way of survivorship services or information.

We are committed to continuing to promote the growth of the cancer

survivorship community movement. Local support groups, hot lines, buddy systems, and publications are at the heart of our organization. We intend further to develop a program of technical assistance that will supplement the consultation provided by the Albuquerque office and the NCCS Speakers Bureau.

As a final note, I would like to congratulate Larry Moore on his election as the new President of the NCCS Board. Larry is a superb leader and hard worker. In addition to his excellent work on development and finances, he labored long and hard with the National Cancer Institute to produce the new booklet *Facing Forward* and has chaired the committee that has written the soon-to-be-published *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*. I look forward to working with Larry in my new role as Chair of the Board of Directors, a position from which I will be able to focus on long-range planning and organizational development.



Larry Moore

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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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Dynamic, Jam-Packed Program

(continued from page 1)

thing back" both to those facing cancer problems and to the larger society—in return for the "enormous resources" that have been put into him or her.

Several other speakers developed different aspects of the advocacy theme. "Pity and compassion mean nothing unless they lead to change," said Reed Tuckson, MD, former DC Commissioner of Public Health and now March of Dimes Senior Vice President. Warning that, without the "vision of the possibility of a meaningful future," neither the individual nor the society will change, he challenged participants to use time constructively to become effective advocates for improving health care at a time of decreasing resources and increasing disease burdens.

President, now Chair, Fitzhugh Mullan, MD, re-emphasized this challenge, reminding survivors that "to advocate, we must all become spokespersons." With the science of cancer driving new treatments, he said, cancer survivors should follow the example set by AIDS patients who have demanded and gained more research and better medical care.

But it was Esther Peterson, adviser to three US Presidents and long-time consumer advocate, who brought participants to their feet



Keynoters Tsongas and Broder with NCCS' Al Siu.

with her message that the best thing each of us has going as we try to make "the stubborn ounces of our weight" felt is ourselves.

A seasoned "lobbyist" for labor and other groups, who lost her husband to cancer,

Peterson advised the group to believe deeply in its cause and to persist. Form alliances with other coalitions, and keep reaching out, drawing the circle wider and wider. Get to the public, work with the media, know the facts and always tell the truth, pick a few issues at a time and concentrate on presenting them accurately.

Americans are pragmatic and compassionate; NCCS' message of hope, self-help, and caring for others as you care for yourself is one of great appeal. As health consumers, she noted, we have been too busy getting the best possible care for ourselves and our families; now survivors must step to the forefront of efforts to improve the delivery of health services.

(Program news continued on page 4)

*You say the little efforts that I make
will do no good; they never will prevail
to tip the hovering scale
where Justice hangs in balance ...
But I am prejudiced beyond debate
In favor of my right to choose which side
shall feel the stubborn ounces of my weight.*

—Bonaro W. Overstreet,
Hands Laid upon the Wind

(New York: Norton, 1955, p 15,
quoted by Esther Peterson, November 9, 1990.)



"The Senator said, be careful of those women consumers, they know what they are talking about." — Esther Peterson

NCCS Priorities

(continued from page 1)

service: Barbara as NCCS General Counsel and Advocacy chair, and Susan as head of the Speakers' Bureau. Others new to the Board include Elizabeth Johns Clark, PhD, Chester, NY; Lovell Allan Jones, PhD, M.D. Anderson Cancer Center, Houston, TX; Bobbi de Cordova-Hanks, Bosom Buddies, Jacksonville, FL; Jessica Miller, Hope and Cope, Montreal, Canada; and Darlene Smith, United Ostomy Association, Irvine, CA. Committee assignments and profiles of new Board members will be published in upcoming *Networkers*.

High on the list of NCCS priorities for the coming year will be the scheduled move of our national office to Washington, DC, which includes the retention of a community services office staffed by Catherine Logan in Albuquerque, and the intensification of our advocacy efforts.

It will be "Denver in November" for the sixth annual assembly, chaired by the Colorado Coalition for Cancer Survivorship's LaMarr Bomareto. Contact: (303)466-7551.

NCCS: Plenty to Do

There will be a lot to do before the next Assembly, if NCCS is to address the organizational needs and concerns of its members. At a workshop on "Advocating for Multicultural Groups," the National Black Leadership Initiative on Cancer's Lisa Charles and Robert DeWitty, MD, stressed the need for special programs to reach underserved and undereducated minority communities with information about cancer. Black Americans suffer the highest cancer-fatality rate in the nation.

The National Cancer Institute's Elva Ruiz added that cancer incidence among Hispanics is growing two to four times faster than the general public rate. There is a great

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Speaking Up for Ourselves

Opening the initial "Speaking Up for Survivorship" panel, "For Ourselves-Doctor/Patient Relations—the State of the Union," moderator Natalie Davis Spingarn, *Networker* editor and author, showed a clip from her film *Patients and Doctors: Communication is a Two-Way Street*. The film emphasized the responsibility of patients as well as doctors to ask and answer questions, and in other ways achieve an open partnership in fighting cancer.

Supporting that view were Sherrie H. Kaplan, PhD, and Sheldon Greenfield, MD, a distinguished husband-wife professorial team from the Harvard School of Public Health. Such doctor/patient communication is essential, they explained, because passivity during office visits relates negatively to health status (determined by measures such as blood pressure). Presenting her doctor/patient relationship research findings, Dr. Kaplan reported that although women patients are slightly more aggressive than men, both are too passive; the average patient asks only four questions per visit. Passive patients do not do as well as patients who take action and intervene—including showing and eliciting more emo-



PATIENT/DOCTOR COMMUNICATIONS — Hospital-gowned Larry Moore and Dr. Sheldon Greenfield.

tion—when dealing with their physicians.

Dr. Greenfield added that patients empowered with intervention and negotiation skills who actively take control in dealing with their doctors, enjoy better overall health care and have fewer symptoms from their illnesses.

As if to prove the point, NCCS' Larry Moore, CPA, MBA, (and self-proclaimed PhD, meaning "Patient hasn't Died") joined the center stage—dressed in a hospital gown, declaring "no wonder we don't ask more questions; we're not put into an assertive role!" He encouraged everyone to bring a pad and pencil to office visits, read, keep abreast of issues, invite a friend to go along to take notes, and role-play before the visit to rehearse intervention techniques.

Among the workshops that later gave survivors specific information on how to become more active in their personal lives were several addressing those important old standbys: food, sex, and beauty. In a popular session on Nutrition and Cancer, Howard University Medical Center cardiologist Tazewell Banks, MD, passed around a 7 pound blob a little larger than a football, "the amount of fat the average American puts into his system every month."

Fat—the enemy of cardiovascular health—causes more cancer than any other substance, and chemotherapy works better on patients who eat less fat, said Dr. Banks. Since we only need 4 grams of fat a day—6 pounds less than we actually consume—and get all we need from vegetables, Dr. Banks' advice is clear: eliminate all the obvious fats from your diet, limit unavoidable fat to 30% of total calories, eat chicken instead of red meat but remove chicken skin before cooking, and be careful even of fatty vegetables: "peanut butter is so fatty it is deemed a co-carcinogen". Generally, follow the American Heart Association Diet, recommended for

everyone over the age of three.

Sexual recovery is a part of the total recovery program, the Medical Illness Counseling Center's Co-Director Lucy Waletzky, MD, told the workshop on Sexuality and Cancer. A psychiatrist with 14 years experience in the area of sex therapy, Dr. Waletzky pointed out that in any relationship, a diagnosis of cancer and subsequent treatment bring up legitimate negative feelings that have nothing to do with loving one's mate.

Participants deplored the fact that some oncologists and other health professionals fail to discuss sexuality, and even when they do, may be unaware of different types of relationships and different issues for different age groups. Among the suggestions offered for sexual well-being after cancer:

- take responsibility for your own pleasure;
- get used to your naked body after surgery;
- get back into intercourse again as soon as possible;
- if you have had breast surgery, tell your partner where and how you want him to touch your breasts;
- plan sex and begin thinking about the encounter several hours before;
- use Kegel (contraction/relaxation) exercises to help to increase libido and decrease vaginal pain;
- resume sexual activity by going slow and doing a lot of touching.

How you look—to yourself and others—can be the key to your ability to come out of the cancer closet and speak up for yourself as a cancer survivor. This was the theme of the Look Good, Feel Better workshop, moderated by the American Cancer Society's Marcia Weiss-Lavine, ACSW, local staff coordinator for the two year old, 38-country program. At this user-friendly session, well-known Washington hair stylist Eivind A. Bjerke and make

up artist **Gustavo Mottola** took time off from their busy Saturday schedules at the **Lucien et Eivind Salon** to show how to enhance the complexion and handle hair loss with the help of turbans and wigs. According to **Eivind**, it's a good idea to cut hair short before starting treatment. Purchase a wig as soon as possible—but in any case, before you lose all your hair—from a reputable shop.

Fear of Recurrence

Because anxiety is so much a part of living with cancer, it is important to recognize the "trigger points" that bring it on, such as the end of active treatment, a cancer-related anniversary, unrelated fatigue, or the death of a fellow survivor.

Some of the pointers offered by **George Washington University Medical Center's Deborah Dozier-Hall, ACSW**, and **Georgetown University Lombardi Cancer Center's Julia H. Rowland, PhD**, at a standing-room-only workshop on **Acute and Long Term Anxiety**:

- Learn to anticipate the things that make you anxious, and find ways to alleviate stress (scheduling follow up visits after treatment is finished);
- Learn how to communicate your anxieties to friends and family so they can be extra supportive (explaining you are especially tense because you're expecting the results of a test);
- Learn how to relax (setting aside specific "appointment times" with yourself for relaxation exercises);
- Learn to think how you can better help your caretakers help you (directing medical issues to providers and delegating burden easing tasks to friends and family);
- Avoid avoidance (do not put off regularly scheduled appointments, or calls and visits to doctors about minor ailments everyone gets, like colds).

Speaking Up for Personal Others



Howard Johnson and Maggie Strong with panel moderator Danette Kauffman.

"Personal others change the landscape of survivors' lives," moderator **Danette G. Kauffman**, NCCS board member and author, told the second major advocacy panel on **"Family, Friends, and Loved Ones."** In two different, but equally dramatic stories, survivorship advocates showed how they had changed not only their families' lives, but the lives of all survivors.

As the wife of long-term multiple sclerosis survivor, homemaker **Maggie Strong** found that not only had she lost her expected future, she had lost the equality of her marriage now it was up to her to do everything, from running errands to initiating friendships. What's more, she felt "invisible" when people ignored her and her needs. "No one looks at the person pushing the wheel chair." She used her experience to write a powerful, well-received book, *Mainstay: For the Well Spouse of the Chronically Ill*, which made her aware of the great need for "support for the supporters," including children who feel too guilty to play and have fun. In 1988, her efforts spawned the Well Spouse Foundation. With 30 chapters in 14 states, this group facilitates the formation of support groups that serve to refresh the well spouse and help prevent burnout.

Counseling psychologist **Howard Johnson** and his wife **Sylvia** were overwhelmed when their daughter **JoAnne**, a student at **Brown**, was diagnosed with leukemia. As **JoAnne** was treated, and achieved a year-long "seductive" remission, they came painfully to realize they had to learn for themselves what

questions to ask and how to find answers. In November, 1989, the Johnsons, who are black, faced a bone marrow transplant and the all-but-impossible task of finding a donor match for **JoAnne** in a 80,000 (instead of the then optimal 200,000) person network; only 800 candidates were minorities.

When others failed to take the initiative, the Johnsons decided to spearhead the search for a match themselves. Support and love poured from churches, high schools and other parts of the community as people volunteered for blood screening. A match was found, but it was too late. **JoAnne's** condition deteriorated. She could not survive the rigors of a transplant and died last February. Despite their tragic loss, the Johnsons demonstrated the desperate need for matching minority bone marrow, and as a result of their efforts, the Red Cross has agreed to expand its program for bone marrow donation.



Sex Therapist Dr. Lucy Waletzky with Assembly Chair Ellen Stovall.

Speaking Up for the Community: Access to Health Care—The Insurance Dilemma

Two survivors set the stage for the Assembly's discussion of health insurance, with their poignant personal stories. Californian Cindy Victor remembered the anger, hurt and fear she felt when she and her husband received a letter from the Great Republic Insurance Co. two years after her breast cancer diagnosis, informing them that their insurance policy was cancelled. After the company stayed within the "letter of the law" by offering them a \$1,100 a month policy, with total lifetime benefits of \$100,000 (they



WAITING IN LINE to ask question and make points at NCCS' 1990 Washington Assembly

refused), she concluded: "Don't get sick until you're 65, or very very poor, or very very rich."

She finally got full coverage by joining an HMO (Health Maintenance Organization). New Yorker Robert S. Mirsky, MD, has not been that lucky yet. When his rare bone marrow cancer (single myeloma) was discovered after an auto accident last February, the 31-year-old Bronx family practitioner discovered that the COBRA policy he had been under since finishing his residency would not automatically roll over into a new policy, as he had expected. He now had a "pre-existing condition," which excluded him from both group coverage by potential employers and by professional associations. Finally he made a temporary arrangement with the hospital where he sends his patients to

extend his coverage until a new policy kicks in.

To forgo treatment was never an option for Dr. Mirsky. But will he have to give up being a doctor? Must he "spend down" and significantly deplete his finances to qualify for Medicaid? Such questions were addressed by the experts on "The Insurance Dilemma" panel, moderated by *Washington Post* Health Editor Abigail Trafford. Some 32 million Americans are uninsured, and about 20 million more lack adequate insurance. The economy is weaken-

ing and more people are finding themselves not only without a job but without the medical insurance an employer often provides. In this situation, according to National Insurance Consumer Organization President J. Robert Hunter, competition within the health-care system for premium dollars

results in exclusion—particularly of those with poor health status who work on their own or for companies that are not big enough to spread the risk of high medical costs.

Judith Feder, PhD, Co-Director of Georgetown University School of Medicine's Center for Health Policy Studies and former Pepper Commission staff director, described the choices before the nation as it tries to deal with such problems. She would neither patch up the existing health care system, (beefing up Medicaid but failing to reach many of the non-poor) nor scrap the system altogether to install National Health Insurance (too expensive a cost to shift to the taxpayers). Instead, she advocates building on the existing system—giving all employees access to affordable coverage through government subsidies/tax

credits to small employers, and replacing Medicaid with a federal public plan which would compete with private insurers for premium dollars, and thus help assure quality.

Lederle Laboratories' Robert L. Jones called attention to an issue of special importance to cancer survivors: reimbursement for experimental drugs or off-label uses of established drugs that insurers do not cover. But consumer advocate Grace Monaco, Chairman of the Board of Candlelighters Childhood Cancer Foundation, is impatient with such efforts. Unless survivors become *proactive* instead of *reactive*, she feels, they will continue to bang their heads up against a stone wall. She urges survivors to educate employers and unions, insisting that they examine and correct deficiencies in their insurance programs.

Beyond that, survivors, their friends and families should realize that there is strength in numbers, and unite to give their business to insurers who will meet their demands. Candlelighters is planning to develop a model policy for pediatric cancer survivors, who will number 250,000 by the year 2000 and are only 4% more prone to adult cancer than the general population. Such a policy aims to create a "safety net for our kids," and Grace Monaco sees no reason why such a net could not be put in place for adult survivors as well.

Among the suggestions of panelists for survivors in need of better insurance coverage who are too ill or for another reason cannot get a job with a large employer: Look in your area for Blue Cross/Blue Shield "open seasons," wherein they cannot turn you away (and previously existing condition clauses are usually time limited), and for high-risk pools as well; go to the library and consult a directory of associations to find professional groups that offer affordable group coverage; familiarize



SIGNIFICANT OTHERS — Joey Battistelli, 12, rests while his dad, Ray, learns about health insurance for Uncle Roger, awaiting cancer surgery in Cleveland, OH.

yourself with state and local assistance, including Medicaid and Hill-Burton funds for hospital expenses (usually more available at the beginning of the year); fight when you are turned down by an insurance company, requesting, for example, a "fair hearing."

Two workshops which attract crowds at every assembly elaborated on this advice. Since insurance is so intimately tied into employment, former NCCS Vice President (now General Counsel) Barbara Hoffman, JD, warned job seekers and job holders alike about discrimination in the work place experienced by 25% of all cancer survivors. Once out of a job, she stressed to the Job/Education workshop, it is hard to get another one, since only four states have medical-leave acts. And in "Everything You Want to Know About Health Insurance and Don't Know Whom to Ask," medical claims specialist Irene Card provided a wealth of practical advice (see box).

How to influence the course of job, health insurance, and other programs? In a compelling workshop, Marguerite Donoghue, Vice President, Capitol Associates, described the lobbying efforts of the National Coalition for Cancer Research (of which NCCS is a member). Encouraging her audience to get involved in the 20th birthday celebration of the National Cancer Act, she insisted that there is nothing magical about gaining power. In fact, all "politics is local" and "follow-up is the chariot of genius." Look at the example set by the AIDS activists and their use of the political system.

Marguerite Donoghue suggested inviting your local congressman and District staff person into your home for coffee. Get them to tour hospitals and meet patients. Then ask them to make cancer research a priority and pressure them to outline what they are prepared to do. Start by "raising the noise level," gather passion and energy and get on radio talk shows, preferably during commuting hours. Use those who can speak from the heart, publish on the national and local level and network with other groups like the Oncology Nursing Society. It is amazing what happens when you demand, "listen to me."

Assembly Impressions

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hematologic cancers—young, but with all "seasons of survivorship" represented. Fewer caregivers and family members were on hand this year. Men, minorities and people over 65 are increasing their numbers among us. (A future *Networker* will bring you more details from Julia Rowland, PhD.)

But whatever their background, most participants burned with intensity and curiosity; they hungered to learn—education, after all, is the key to survival. Those who had been around since the days when cancer was a closely-guarded secret were awestruck by the breadth of resources available today, nationally and internationally (guests from England, Germany, Canada, and of course, the indomitable—and 5-months pregnant—Shireen McKen from Trinidad, added an international flavor).

Death had an unavoidable place at the assembly—standing in the wings listening to survival statistics and the first author of the year prize, awarded, in memoriam, to Barbara Boggs Sigmund (presented to her sister, ABC and PBS television correspondent, Cokie Roberts). But humor was there too—in force—from the opening presentation by "jollytologist" Allen Klein, to the wrapup by the more sobering Joe Kogel.

Sure beats conventions of health professionals.—Ross Gray, David Owen, Lorraine Perona, Natalie D. Spingarn

Job Discrimination

"Even if you don't consider yourself handicapped," job discrimination expert Barbara Hoffman explained, "if your employer treats you like you are, you may have a case." She advised job applicants:

- not to volunteer cancer histories;
- not to be too inquisitive about health benefits before getting a firm offer, preferably in writing;
- to remember that in most states questions about your health can only be asked when they are job-related;
- if you feel you have been discriminated against, get a letter from your doctor testifying to your fitness;
- then, you may want to get an opinion from an attorney and report it your state civil rights agency;
- move promptly; you have just 180 days to file a claim from the time you were discriminated against.

Health Insurance Claims

Here's a checklist to use when filing a claim, from medical claims specialist

Irene Card:

- Understand your benefits—you cannot collect if you don't know what you're entitled to;
- Keep a chart; accurate record-keeping is essential;
- Make copies; keep originals for follow-up unless your company insists on having them, in which case, keep very good copies;
- Submit in the proper order (patient's insurance is always primary, spouse's secondary);
- If your claim is denied for lack of information, get and send the additional information; send claims back for review if you feel your insurer should have paid more; be persistent and don't get frustrated;
- Treat yourself—hire an excellent health claims-processing service to do it for you.

Exploring the Mind/Body Connection

Leading a thought-provoking session, a preeminent expert panel on mind/body issues agreed that, though scientific evidence that you can "cause" or "cure" your cancer is lacking, psychological help of many different kinds can improve survivors' well being—easing anxiety, improving morale and helping people cope. And, in a setting wherein much more research is needed, is there anything wrong with hope?

Claims for the power of the mind over cancer are driven by a wide range of studies in animals and humans which show that stress in various situations affects the disease-fighting immune system, according to **Jimmie Holland, MD**, Memorial Sloan-Kettering Cancer Center's Chief of Psychiatry. But it only "perturbs" that system, and does not suppress it significantly, to the level that it is suppressed, for example, in the case of AIDS.

Referring to other scientific research, Dr. Holland and the panel moderator, Stanford University Hospital's **Pat Fobair, MSW, MPH**, stressed the importance of genetic factors in study outcomes, and said that depression does not cause cancer. Warning that believing something you did or felt brought on cancer can cause guilt and unhappiness, Dr. Holland spoke of the power of belief in personal control (as opposed to scientific information), and the great differences in survivor attitudes toward it. She called attention to the "heroic model" of Canadian psychologist **Ross Gray, PhD**—the widely emulated St. George who slays the cancer dragon with a sword of positive thinking, healing imagery, and personal growth (explained



Jimmie Holland

later by Dr. Gray in a workshop on "Heroic Self-Healing").

Another distinguished researcher in the field, the University of Pennsylvania Cancer Center's **Barrie Cassileth, PhD**, stressed the role the larger society—one which stresses patient participation and self responsibility—plays in the emotionally-charged mind/body debate. In the face of "overwhelming unknowns" and insufficient research, she said survivors yearning for individual victory and impatient with the war against cancer can espouse oversimplified beliefs or be wrongly blamed for their disease.

But it was **Commonweal's Michael Lerner, PhD**, who touched his audience with his advocacy for the "inner astronauts" who could help survivors explore within the "outer edge of the envelope." He said his experience studying healing here and in other countries has left him feeling that survivors have choices many may never have dreamed of—choices in mainstream conventional treatments, for example, where there are different "cultures" and different approaches to therapy, as well as choices in unconventional ones—where it is important to distinguish between what is health promoting and what can be harmful, what is open and what is closed.

An authority in the field of complementary therapies, Lerner said that survivors have to train



Barrie Cassileth



Michael Lerner

themselves to find what works for them. Like other panelists, he stressed the power of hope and the possibility of remission, even for the sickest. Like them too, he reported the excitement in the medical community at the results of California psychiatrist David Spiegel's study showing that patients with metastatic breast cancer in weekly group therapy not only increased their quality of life but lived significantly longer, and stressed the need for further mind/body research.

Editor's note: The US Congress' Office of Technology Assessment (OTA) report recommended by the panelists, UNCONVENTIONAL CANCER TREATMENTS (GPO stock number 052-00301207-3), is available for \$14 from the Superintendent of Documents, GPO, Washington, DC 20402.

Plenty to Do

(continued from page 3)

need for effective outreach in that community. Material in the languages of diverse cultures is especially needed: "Give them what they want, not what you want them to have."

Elsewhere, Executive Director **Catherine Logan** led a focus group on building a program to serve member organizations. Participants gave the *Networker* and the annual Assembly rave reviews, but asked for, among other things, a stronger clearinghouse operation, enhanced networking through an NCCS directory and help in lobbying through model letters and ratings of local congressmen on an NCCS national agenda.

The **Networking Fair**, a new Assembly feature, offered 30 intense round-table discussions on such common interests as survivorship for young adults, FDA drug release policies, and cancer as a feminist issue (which in turn gave rise to an NCCS Feminist Caucus). **CAnCare's Sally Henderson**, who emceed the packed meeting, announced spontaneous requests for additional round-table subjects.

SURVIVOR LIFESTYLES

At an emotionally charged Saturday morning session led by NCCS' Barbara Waligora-Serafin, RN, four survivors shared their stories about how cancer had affected their lives:

"Don't let anyone—including yourself—tell you can't do anything, until you try," Elizabeth Finchem advised. Twelve years ago, she was 42 years of age, married, healthy, active, with three children at home in Michigan and three in college, working part time as an actress, clothing consultant and volunteer.



Elizabeth Finchem

Suddenly, she had to undergo a laryngectomy ("put your hand on your throat and hum—all that you hear was gone"), and the doctor installed a stoma, or "neck breather." Refusing to use an electro larynx, she learned to talk again using her esophagus, and today the California-based divorcee teaches alaryngeal speech and is president of the California Association of Laryngectomees.

Timothy Calonita, Assistant District Attorney in Nassau County, NY, didn't want to be a lawyer, he wanted

to be a cop. But when he applied for police officer training and completed all the tests successfully, the doctor said, "Whoa—



Timothy Calonita

we've got standards here, and our standards say we cannot employ anyone who has a history or presence of a malignant tumor." His automatic disqualification changed Tim, who had considered the cancer (Hodgkin's Disease) he'd been treated for successfully as a teen-ager a "private affair." Realizing "it's up to us cancer survivors to do something," he became an outspoken foe of cancer discrimination, lobbying, testifying, and speaking out on television, radio, and in numerous interviews.

Former congressman John Monagan went into the hospital 49 years ago to have his "appendix out;" instead—he found out much later—the doctors removed a large portion of his colon. In



John Monagan

those days there were few resources, and less discussion of cancer. Using an American Cancer Society kit 38 years later, he discovered a recurrence (he's still grateful to the ACS for that), had more colonic surgery, and has since lived "all these years of pleasant life." So, says the 78-year old retired lawyer, he's "the dog that didn't bark."

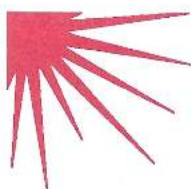
Two years ago, at the age of 29, Kim Allen was told not to expect to see any more birthdays.

Refusing to accept this grim prognosis, this smart and sassy stage-3 breast cancer patient began to remind her doctors that they



Kim Allen

were her employees, and she would be in charge. She treated her disease as a spiritual challenge, forcing herself to find "something beautiful" in each day and combining her modern medical treatment with herbal remedies. Looking at cancer as something that has brought a lot of wealth to her life, she says: "My philosophy is to keep busy and keep around a lot of positive energy; then I'll always have something to do."



ADVOCACY UPDATE

BARBARA HOFFMAN, JD

This year, NCCS has worked to expand the employment and insurance options of cancer survivors by:

- Providing information and referrals to approximately 90 callers who contacted our organization with questions about employment, insurance or public policy;
- Expanding our informal attorney network to 22 lawyers in 10 states

(California, Connecticut, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Rhode Island, Texas and Wisconsin).

NCCS has lobbied to increase and enhance survivors' rights by:

- Supporting bills which became law, notably the Americans With Disabilities Act and significant state legislation, including
- a New Jersey law which provides job security for workers who need medical leave;

— a New York law requiring insurance policies that cover prescription drugs to cover all physician-prescribed chemotherapy that is approved by the FDA regardless of whether the specific cancer is that for which the drug has been approved;

- Fighting for passage of the Family Medical Leave Act, which was vetoed by President Bush;

(continued on page 12)

PEOPLE WATCHING

First-Timers At The Assembly

By popular demand, the *Networker* again interviewed people attending NCCS' annual meeting for the first time. We asked them: "What is the first priority on your agenda for the 1990s?"



Linda Williams, Port Angeles, WA, public schools communications disorders specialist (breast cancer, 4 1/2 years): *To increase networking in our town and to work on health insurance; I'm appalled that there are people who have to face cancer without security.*



Christina Yeung, Coral Springs, FL, homemaker and mother of three (cancer of the thymus gland, 14 months): *To try my best to help the progress of this organization and help see that cancer patients, who have enough problems, won't have problems with health insurance.*



Robert Mirsky, MD, family practitioner, Bronx, NY (solitary myeloma, 9 months): *People having a real partnership with their physicians so they don't feel they are out there alone.*



Linda Watkins, contracts negotiator, Ridgecrest, CA (breast cancer, 10 months): *To help people with cancer in my community find a centralized resource for help with their personal problems.*



Jeanmarie Marshall, Women's Community Cancer Project, Boston, MA (bone cancer, 2 years): *To see people with cancer—women especially—organized to make changes in the system. I'm particularly concerned with insufficient funding for cancer research and bias toward women in research.*



Beverley Freeman, LPN, Washington, DC (colon cancer, 3 years): *To see 1991—and 1992. More than that, it's been very hard for me to find information; I want to see more information sources offered to people.*



William Magee, Vital Options, student, La Crescenta, CA (Ewings Sarcoma, 4 years): *Fair cancer treatment for everyone; personally, I want to grow more new hair—I'm wearing a wig now.*



Mary Venn, deputy manager, Bacup, London, England: *To keep well and happy so I can use my optimism to help keep cancer organizations together so we don't get differences between people and forget what we're trying to do.*



Lorraine Perona, office manager, US Senate, Alexandria, VA (Hodgkin's Disease, 23 years): *To come out of my cancer closet and get to more meetings like this. The people look so good! The program is so professional! The information I've gotten is so authoritative—for the first time I know that my cancer is not my fault. That's a relief; it really is.*



Gregg Goldstein, Austin, TX (brain tumor, 10 months): *To sit down and start working out a solution to the health insurance crisis.*

The *Networker* wishes to thank those who helped with coverage of the 5th Annual Assembly:

Barbara Carter	David Owen
Alice Cave	Susan Perlman
Sue Ducat	Margaret Sanders
Judith Gische	Laura Schramm
Bobbi de Cordova Hanks	Al Siu
Susan Leigh	Debra Thaler-DeMers
Pam Onder	Brad Zebrack
Wendy Oliver	

Special thanks to photographers *George Tames* (Friday) and *Jim Johnson* (Saturday). Pictures taken at the Assembly may be ordered through the Washington office. Phone: (301)230-0831, (1700 Rockville Pike [#295], Rockville, MD 20852) at cost; please identify day on which picture was taken.

"It's amazing what happens when you demand, 'listen to me.'" —

Margurite Donoghue
at the "How to Lobby" workshop

WHAT'S NEWS

Our Almanac is Here!



Almanac authors Logan, Spingarn, Mullan, Hoffman and Fiore.

Consumer Reports Books has announced publication of *Charting the Journey*, the NCCS almanac of resources for cancer survivors, their caregivers and families. Edited by NCCS founding officers Fitzhugh Mullan, MD, and Barbara Hoffman, JD, this comprehensive consumer guide will help you find information on subjects ranging from finding the right doctor and solving health insurance problems to deal-

ing with social and emotional problems.

Authors include the Coalition's Neil Fiore, PhD, Patricia Ganz, MD, Catherine Logan, and Natalie Davis Spingarn. Their work is attractively illustrated and supplemented with appendices, charts, and a bibliography, as well as art and poetry by survivors. The Almanac is available from the Albuquerque office to NCCS members for \$12.00 per copy (sent book rate) or for \$14.95 per copy from Consumer Reports Books, 9180 Le Saint Drive, Fairfield, OH 45014. For purchases of 50 copies or more, call the Albuquerque office or Gerri Fico at (212)983-8250.

And Teamwork to Come...

Lederle Laboratories is funding the publication of *Teamwork*, the NCCS patient/doctor communications guide. Lederle, a leading pharmaceutical company, researches, develops and manufactures chemo-

therapeutic drugs. The comprehensive manual, honchoed by Coalition President Larry Moore, represents a three year nationwide effort by an 11-person NCCS committee as well as health-care providers and other survivorship leaders. Scheduled to be published in 1991, the guide explores every aspect of the two-way street familiar to survivors and their families: giving and getting sufficient information to and from our doctors.

Celebrating Survivorship in 1991

It looks as though there will be several opportunities to kick up your heels in celebration of survivorship in 1991. *Coping Magazine* has named Sunday, June 2, National Cancer Survivors Day. And the American Cancer Society will honor survivorship in the fall, with local divisions and chapters staging their separate events. NCCSers will participate in both celebrations. Stay tuned for further details.

Candlelighters Scholarship Fund

Applications and information requests are already reaching the newly formed (and self-confessed "long overdue") Candlelighters College Scholarship Fund. The tax-exempt fund will be awarding college scholarships to cancer survivors who were diagnosed before their 21st birthday, are US citizens, and have yet to receive their first college degree.

In giving these scholarships, the Fund seeks to establish the first survivor "peer group" for children still in treatment to emulate. It seeks names of childhood cancer survivors who wish to act as role models. The Fund needs and welcomes donations. Contact: Kay McNealy, President, Candlelighters College Scholarship Fund, Inc., 9961 Meadowlark Rd, Vienna, VA 22182, (703)938-6774.

JOIN/SUPPORT NCCCS

ANNUAL MEMBERSHIP OPTIONS

- Individual Membership — \$20 or more
- Individual Sustaining — \$50 or more
- Individual Patron — \$500 or more
- Other (individuals unable to pay the \$20 fee are invited to join NCCCS for any amount they can afford)
- Organizational and Institutional Members (recommended fees)
 - with budgets of less than \$150,000 — \$50 or more
 - with budgets of \$150,000 to \$1,000,000 — \$150 or more
 - with budgets of \$1,000,000 or more — \$250 or more

DONATIONS \$500 \$250 \$100 \$50 Other

This donation is:

- In memory of
- In honor of the (specify milestones) of
- Send acknowledgement to

Please indicate whether you are contributing as an individual or an organization.

Name _____ Phone _____

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Institution (if any) _____ Department _____

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City _____ State _____ Zip _____

NCCCS is a 501(c)3, tax-exempt organization. Send checks payable to the NCCCS to: NCCCS, 323 Eighth St. SW, Albuquerque, NM 87102.

Advocacy Update

(continued from page 9)

- Supporting bills which are currently pending in Congress, such as the **National Public Policies Act** and several bills to limit and tax tobacco;
- Testifying before a Senate committee in favor of allocating more federal funds to cancer research.

Our Coalition has also:

- Joined an **Amici Curiae (friend of the court)** brief written by Action on Smoking and Health in support of the Department of Health and Human Services' efforts to prohibit smoking in HHS buildings;
- Increased our pool of cancer survivors who will be available for media interviews and appearances about advocacy issues;
- Twice updated our popular **employment and insurance articles bibliography** (June, 1990 is the latest issue).

More Assembly stories will appear in the next issue of the *Networker*.

Thank You, Assembly Donors

(\$500-\$25,000)

David Katz Foundation, Honesdale, PA
Medical Illness Counseling Center, Chevy Chase, MD
Arnold and Marie Schwartz Fund for Education and Health Research, New York, NY
Washington Hospital Center Cancer Institute, Washington, DC
In Memory of Helen Miller Obstler, Natalie Davis Spingarn
Liza Prior Lucy and William Andrew Lucy
Amgen, Inc., Thousand Oaks, CA
Computer Data Systems, Inc., Rockville, MD
Wyeth-Ayerst Laboratories, Philadelphia, PA
Henry S. and Anne S. Reich Family Foundation, Inc., Washington, DC
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Eugene and Agnes E. Meyer Foundation,

Washington, DC
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Danette G. Kauffman

...and Givers (\$250-500):

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In Memory of David Katz, Sigmund J. Roos
Mr. and Mrs. Joseph Bulman
Carolyn W. Sanger
Dr. Anita L. and Steven M. Auerbach
Washington Health Care Group, Washington, DC



KICKING UP THEIR HEELS — Assembly Chair Ellen Stovall (center) and Co-chairs Alice Cave and Natalie Davis Spingarn celebrate the success of the 1990 Assembly.

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

There are over 6 million cancer survivors in the United States and your organization speaks for every one of them...Your uniting together is a life-affirming move.

— Samuel Broder, MD, Director, National Cancer Institute, at the 5th Annual Assembly, November 9, 1990, Washington, DC.

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