

## Sandra Day O'Connor to Keynote 9th Assembly

Sandra Day O'Connor, associate justice of the United States Supreme Court, will deliver the keynote address at NCCS' historic 9th annual Assembly, "Seasons of Survivorship: Quality FOR Life," in Washington, DC. The Assembly, launching a year-long public awareness campaign and featuring 2 new programs, will run November 2-6 at the Washington Court hotel on Capitol Hill.

As a breast cancer survivor, Justice O'Connor brings a vital perspective to the High Court. In her remarks, O'Connor will discuss the role of public servants, such as Sen. Paul Tsongas of Massachusetts and Circuit Court Judge Richard Arnold of Arkansas, who have cancer.

O'Connor will open NCCS' most ambitious Assembly to date. In addition to a series of workshops exploring the full spectrum of the survivorship experience, the Assembly offers the first-ever NCCS Town Hall and the premiere of the "Celebration of Cancer Survivorship Through the Arts" program.



Sandra  
Day  
O'Connor

Associate Justice  
U.S. Supreme Court

The Town Hall meeting will present cancer survivors and supporters an opportunity to express their views on the issues that matter to them, and to help assign priorities to NCCS' public policy agenda.

On the eve of the Town Hall, Assembly-goers will mix art with altruism at a celebratory "paint in." Artist John Feight of the Atlanta-based Foundation for Hospital Art will guide a collaborative creation of colorful images on ceiling tiles to be placed at area hospitals.

"I'm excited that we can include this magical event," says Executive Director Ellen Stovall. "I've participated in many. You can't help but love it."

This Assembly will also kick off a nationwide campaign designed to heighten public awareness of cancer survivorship.

Among the bounty of stimulating workshops on tap: "Fear of Recurrence," "Sexuality," "Late Effects," "Loss and Bereavement," "How to Advocate For Yourself" and "How to Lobby Effectively."

NCCS urges early registration for this engaging, high energy event.

### Inside

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Plus the *Health Security Express* (page 3), news, book reviews and more.

### Assembly Profile

#### REGISTRATION

##### Before October 11

Members: \$130  
Nonmembers: \$155

##### After October 11

Members: \$150  
Nonmembers: \$175  
(Nonmember fee includes 1-year NCCS membership)

To register, use the form included in the preliminary program you received in the mail. If you did not receive a program, call NCCS at 301/650-8868.



#### Quality FOR Life

November 2-6, 1994  
Washington, DC

#### HOTEL DISCOUNT RATES

This year's hotel site: The Washington Court on Capitol Hill. Single/double rates per night: \$112, plus taxes. For reservations, call 800/321-3010 (in the DC area, call 202/628-2100), and mention the NCCS Assembly to receive the special rate. **Hotel reservation deadline: October 11.**

#### AIRFARE DISCOUNTS

Society Travel, the official NCCS Assembly travel agency, guarantees the lowest available airfares and will donate a percentage of ticket sales to NCCS. Call 800/348-5869 and refer to NCCS account no. S2504R7.

#### QUESTIONS?

For more information, call Marge Ridgell, NCCS Assembly registrar, at 800/844-2789 (202/265-4704 in the DC area), or NCCS at 301/650-8868.



# For Us, and for Those to Come



## Letter from the Chair

Fitzhugh  
Mullan, MD

Whatever the final outcome of the great healthcare reform wrestling match of 1994, the debate itself holds tremendous importance for us as a people, and particularly for cancer survivors—both current and future.

As a nation and as individuals, we have had to ask ourselves, and each other, some hard questions: Who gets healthcare? Who pays for it? How much is enough? Politicians and people on the street alike would just as soon avoid these tough questions. Yet without such debate—and the decisions it will generate—reform cannot happen.

Healthcare organizations have had to enter the fray as well—including NCCS. I think we have acquitted ourselves well. We crafted an alliance of cancer groups, the Cancer Leadership Council, and argued for a package of cancer-related reforms. Together we called for eliminating “pre-existing conditions” and including “off label” drugs, preventive services, and coverage for investigational treatment.

NCCS also tackled a tougher issue: universal coverage. President Clinton made the concept famous by threatening to veto any bill that did not feature it. While most Americans favored universality, many felt it would cost too much, or erode their current coverage, or simply wouldn't work. Throughout the cancer community and within NCCS, some argued that it would jeopardize or distract from the cancer-specific reforms we seek.

After much debate, we came down for universal coverage and featured it in the NCCS statement on healthcare reform. This, I want to emphasize, was not a political conclusion or the victory of one camp over another.

In fact, a vitally important, cancer-

specific reason compels survivors to support universal coverage. Next year, 1.25 million people will receive a cancer diagnosis. Fifteen percent of them—that's 180,000 men, women, and children—will lack health insurance and thus will have to fight simultaneously the twin plagues of disease and financial ruin. The same thing will happen the following year, and the year after that ...

NCCS must regard those future cancer survivors as part of our present responsibility. We must speak and act on their behalf now. To limit our advocacy to the issues of those currently in treatment without looking down the road at the needs of those who will soon join our ranks would not meet our full commitment to the survivorship community.

All Americans need healthcare coverage. Cancer survivors need it for dear life. And that is why NCCS supports universal coverage.

## Thank You...

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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 nation-wide awareness of survivorship, showing that there can be a vibrant, productive life after the diagnosis of cancer. NCCS facilitates communication among 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.

The *Networker* is delighted that so many organizations want to use material from our pages. Please remember to request permission from NCCS to reprint any items.

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## On the Bus: The Long Haul to Reform

By Natalie Davis Spingarn

I rode the Northeast route of the Health Security Express in early August with 146 other reform riders who lived 5 exhilarating but hard days in the cause of healthcare reform. From Boston to Washington, DC, our 5 buses helped spread the word from town to town and person to person: universal coverage for all Americans.

NCCS staff member Deborah Ash joined me to represent the coalition and cancer survivorship on the caravan. Nationwide, 762 reformers in 19 buses rolled across the nation on 5 separate routes, originating in Portland, OR, Dallas, New Orleans, and Independence, MO, as well as Boston.

We found our jam-packed days exhilarating because we had the chance to share our cancer survivorship story with others, including the press, along the way. At church suppers and giant rallies, we helped our fellow riders dramatize the need for universal health coverage for all Americans. Repeatedly, we told of the pain and disbelief of cancer survivors with "previously existing conditions" denied health insurance or locked into jobs and "insured marriages."

We found our days exhilarating too, because the company was good aboard this bus caravan, which had 3 major sponsors (American Federation of State, County and Municipal Employees, Families USA, and HealthRIGHT). Among those on our bus—specially equipped and used by the Clintons and Gores in the '92 Presidential campaign—a feisty 23-year-old from Oregon, representing her husband with renal failure, who cannot afford the drugs he needs to prevent the rejection of another needed kidney transplant; 2 life-of-the-party New York City furriers, worried that since theirs is a dying industry, their health insurance is in jeopardy; and a carpenter-led family of 4 from

Compton, RI, to whom health insurance and adequate preventive care are simply unavailable.

Minor inconveniences—bumpy roads, delays, 5 a.m. wake-up calls, and bologna and cheese sandwiches



*Top: NCCSers Deborah Ash and Natalie Davis Spingarn, on White House lawn, pause outside Health Security Express bus. They joined 145 others for East Coast health reform campaign. Bottom: At one stop, Spingarn chats with Health & Human Services Secretary Donna Shalala.*

wrapped with a pack of Oreo cookies—hardly bothered most of us. On the other hand, the opposition haunted us from the kickoff at Boston's Faneuil Hall (where Hillary Clinton and Sen. Ted Kennedy addressed us) to the old-fashioned, heady rally on the Capitol steps in Washington.

Though the opposition we encountered, on our route at least, was scant, it got more than its fair share of public attention. For the most part, their signs seemed no more than confused scrawls against "Socialism" or "Communism" or whatever; they did not seem sure.

In Jersey City, where President Clinton spoke to a rally of thousands, the protesters were fenced well outside the audience. But one woman succeeded in sneaking her "Socialism" sign into camera range. The President dealt with her deftly by asking her if she would refuse Medicare.

During the 14-day life span of the Health Security Express, over 1 million Americans lost their health insurance. We need to work with those trying to remedy this, including the labor unions and church organizations that donated most of the 8,800 meals served to us.

Indeed, our friends out there are legion. At all our stops, supporters cheered us—people from groups like the League of Women Voters or the American Nurses Association or with no affiliation. Senators, mayors, and Cabinet secretaries greeted us and joined us on the buses. Entertainers like Peter Yarrow, of Peter, Paul and Mary, lifted our spirits with song.

As Congress struggled to salvage universal coverage this summer, Deborah and I were often asked if the Health Security Express "did any good."

We admit that we often found it difficult to get our points across to news people who sometimes seemed more interested in the ups and downs of a hot contest than the details of a complex issue. We admit too that some failed to grasp the reality of the invisible pain of inadequate or nonexistent insurance, or of cancer problems that leave the sufferer short of death's door.

But we point out that some media and "ordinary" people we met along the way—including occasional protesters—seemed interested in, and open to, our viewpoint. In the long run, repeated often enough and by enough people, our message may well help make a difference.



## HEALTH NEWS

**Aspirin, the original wonder drug, may protect against colorectal cancer,** according to a recent study at the Harvard Medical School and published in the *Annals of Internal Medicine*. In analyzing questionnaires completed by 47,900 male health professionals, researchers found that men who reported using aspirin 2 or more times a week were 32% less likely to develop colorectal cancer. This result matches conclusions from several other large epidemiological studies, which have found a 30 to 50% reduction in the risk of colorectal cancer with regular aspirin use. The only clinical trial testing this connection to date, however, did not confirm the link, suggesting that this topic requires additional study.

**A group of oncologists is questioning the common practice of denying estrogen replacement therapy to women with breast cancer during and after menopause.** As a rule, doctors don't prescribe ERT to women with a history of breast cancer because of concern that the hormone encourages growth of breast cancer cells. The article is described by its lead author as a "preamble" to a request to NCI, to be submitted shortly, for a pilot study that will investigate using ERT along with tamoxifen on several hundred breast cancer survivors. The scientists, members of the Eastern Cooperative Oncology Group, (which comprises 4,000 cancer specialists) want to address an urgent quality of life issue for breast cancer survivors: can ERT and tamoxifen help prevent the onset of osteoporosis and heart disease in women who have already endured cancer and are postmenopausal (perhaps as a result of chemotherapy), and, if so, does this benefit outweigh the possible risk of stimulating breast cancer development?

Whether an association exists between ERT and increased risk of breast cancer in otherwise healthy women is already a very controversial topic.

The article appeared in the *Journal of the American Medical Association*.

**In the latest of a spate of reports questioning tamoxifen's safety,** scientists at King's College School of Medicine and Dentistry in London found that it can cause potentially malignant changes in the endometrium of healthy postmenopausal women. Their results were reported in *Lancet*, and derived from the first randomized, placebo-controlled trial of tamoxifen's effects on this group of women. It supports other research that has linked tamoxifen to an increased risk of endometrial cancer.

Of 64 women who took tamoxifen during the study, 24 had abnormally thickened endometriums. Endometrial cells of 10 women in that group showed potentially malignant changes. Of the 50 women given a placebo, 5 showed endometrial abnormalities, and none displayed any cell changes.

**A recent laboratory discovery has already yielded a test that can tell high risk individuals if they are likely to develop hereditary non-polypoid colorectal cancer, one of the most commonly inherited cancers.** This same genetic defect can also contribute to certain other cancers, including ovarian, uterine, lung, and stomach.

The test, which can determine whether a specific gene—MSH2—is functioning in a defective manner, was announced by a molecular biochemist who is part of a team that has made stunning breakthroughs in locating and understanding this gene. The test has worked to predict cancer in a small group of families he's worked with to date. Already, a blood test can determine the gene's presence in altered form. This new test, however, can demonstrate whether the altered gene is actually working. If it is, doctors can then recommend changes in lifestyle and diet to deter disease onset. And high risk individu-

als who don't have the a working mutated gene can relax.

**Researchers at the Johns Hopkins Medical Schools have developed a test that can predict whether some colon cancer patients will benefit from post-surgical chemotherapy.** By studying tumor cells and determining whether a portion of chromosome 18q remains intact, doctors may be able to predict whether the patient requires further treatment. The test applies to colon cancer patients whose disease has been classified as Stage II, when the tumor extends through the bowel wall but not as far as the lymph nodes. The scientists found that in patients whose portion of 18q was unchanged, their 5-year survival rate was 93%—comparable to that of patients whose cancer is caught early. In patients in which the 18q material was lost, however, the survival rate dropped to 54%, a rate similar to patients with advanced disease. The study was published in the *New England Journal of Medicine*.

**As veterans of hot flashes know all too well, these unpredictable, uncomfortable events can significantly degrade quality of life. Relief may be possible,** however, according to a recent study in the *New England Journal of Medicine*.

Megestrol acetate (trade name Megace), a synthetic hormone used to treat advanced stages of some cancers, can substantially reduce the number of hot flashes experienced by women during menopause, according to researchers at the Mayo Clinic. The drug can also help men who suffer hot flashes as a result of treatment for prostate cancer.

Sources: *New England Journal of Medicine*, *The New York Times*, *New York Newsday*, *Science News*, *The Wall Street Journal*.



# Can Cancer Survivors Survive Managed Care?

by Ellen Hermanson

Recently, an op-ed article in the *New York Times* related the horrifying experience of a 26-year-old woman enrolled in a Wisconsin HMO. Despite worsening physical symptoms and her own persistent efforts, she was told for 3 years that she had no problem.

Except, of course, she had a terrible problem. And the advanced cervical cancer that could soon end her life may well have been diagnosed—and probably cured, since early detection leads to a 95% cure rate for cervical cancer—had the doctors, and the laboratories that tested her pap smears, handled her care competently.

This tragedy embodies everyone's worst fears about HMOs and other forms of managed care: impersonal, incompetent, and uncaring. Critics of managed care point to examples like this to decry the entire concept. Advocates rightly retort that abuses also occur in the fee-for-service sector.

## It's Heeeeeere

For better or for worse, however, managed care is the wave of the future. "In an increasingly competitive and cost-conscious market for health insurance, managed care is rapidly displacing fee-for-service plans," Arnold Relman, MD, former editor of the *New England Journal of Medicine*, wrote in its Aug. 18 issue.

Managed care plans, particularly HMOs, remain the centerpiece of any version of healthcare reform, even in the absence of the comprehensive plan promised by the Clinton Administration. And unrelenting financial pressures will keep motivating employers to switch insurance coverage to managed care plans.

Ideally, managed care plans manage both the delivery and cost of quality healthcare. They do so by negotiating costs with doctors, hospitals, drug companies and other purveyors of services and supplies, and by setting budgets for services, number of hos-

pital days, and other features.

Many pay doctors a monthly fee for each enrolled patient, a practice called capitation.

Many plans also reward doctors who use fewer specialists and tests. "There are subtle pressures not to do things," says Dr. Joseph Bailes, chairman of the American Society of Clinical Oncologists' (ASCO) Clinical Practice Committee. Patients, meanwhile, pay low fees for doctor visits, procedures, and hospital stays after they satisfy the premium.

Although managed care plans come in many varieties, they all aim to shift the focus of healthcare from expensive, advanced treatments to primary care and preventive services. And that poses a real threat to people with cancer, whose illnesses, by their very nature, require the skills and services of surgeons, medical oncologists, radiation oncologists, pediatric oncologists, hematologists, nuclear physicians, and a raft of other specialists.

## Access: A Vexing Issue

In a word, the critical issue for people with cancer is access: to the doctors and hospitals of their choice and to the latest treatments and clinical trials. That simple word, however, embraces a world of vexing issues when it comes to managed care. "Managed care is here to stay, and the task is how to make it more respon-

sive," Dr. Bailes says.

"If access and cost of treatment are based purely on the dollar amount as opposed to the quality of care, then there are some real serious potential problems," states Tim Raftis, Washington representative for the Association of American Cancer Institutes. "Our focus is on ensuring access to patients, coverage, for investigational treatments, and reimbursement rates that take into account the unique costs of research."

Bailes agrees. "Access to specialists and to specialty treatment centers is essential," he says. "Managed care plans need to provide access either within the plan or as an out-of-network service."

Physician choice poses a particular problem in cancer care for children. Few HMOs provide easy access to pediatric oncologists, despite research that demonstrates the improved likelihood of a successful outcome for children who are cared for by these specialists.

Most people with cancer consider their oncologists their primary care doctors. But, typically in managed care plans, a general practitioner serves as gatekeeper, ordering laboratory and other tests vital for diagnosis and treatment decisions. And when people whose cancer is in remission or cured want to keep their oncologists as their primary doctors, managed care plans usually don't let them. That can lead to problems.

"Sometimes symptoms are related to malignancy and sometimes not," says Bailes. "It really takes a specialist who is familiar with the aftermath of cancer treatment" to treat survivors, Bailes says.

Yet another problem lurks. Scant protection exists for cancer survivors whose employers switch from fee-for-service to managed care. All too often, people diagnosed some years ago who suffer a relapse discover that their doctors and hospital do not participate in the managed care network.

(Continued on back cover)

## Correction

The names of the National Coalition for Cancer Research (NCCR), the Association of American Cancer Institutes and the Association of Community Cancer Centers were unintentionally omitted in the last paragraph of "Healthcare Reform: An Absolute Necessity." These groups should have been included in the list of organizations with which NCCS has collaborated during the past 18 months to press for healthcare reform.



# Sexual Survivorship for Men

Interview with Leslie R. Schover, PhD • Conducted by Ted Olinger

*What kind of sexual problems might men face because of cancer?*

Many kinds of cancer treatments put people at risk for developing new sexual problems. I think a big problem that both men and women encounter is, "Who do I ask about these problems, and is it legitimate for me to try to seek some help?" Patients that get to me are only the most determined—people who maybe asked their physician 3 or 4 times, "What do I do about this problem?" before someone finally said, "Aha, we do have a program we can refer you to."

Probably close to 90% of men and women with cancer who develop sexual problems never ask for help. Sometimes they may be hoping that someone will ask them about it and offer help, but very often that doesn't happen because doctors and nurses are so busy and so focused on illness itself that they often don't focus on quality of life issues. Sex is still something that people are embarrassed to talk about, and a lot of doctors and nurses don't have that much training in how to bring it up with patients. It's still an area where people often don't get very good care.

*What kinds of problems do men come to you with most often?*

The most common things we see are men with erection problems, or who have lost their desire for sex. People may be depressed while they're going through treatment or recovering from it, or they may not

feel well, or have a low energy level, and all of those things can impact on sexual desire, as can the change in your own self-concept. You may feel stigmatized, or your physical appearance has changed, or you may be worried about the future and feel like you don't have energy to think about sex today. People are very busy in their lives, and when you get a major illness—especially in our younger patients, who still have kids at home and are working actively—it takes so much energy just to keep the household running that sex really goes to the bottom of the priority list for many people.

*What kind of work do you do to solve these problems?*

Well, a lot of times we work with some common sex therapy techniques that may involve things like helping people focus on what they still can do instead of focusing on the things that become a problem. Very often, when men have erection problems, they will avoid sex altogether and they won't try any kind of lovemaking, and they may even stop hugging their partners or cuddling on the couch for fear that it's going to turn into a sexual encounter that they're not ready for. I often work with couples in trying to get them to go ahead and start touching but with a different goal. Instead of imagining that it's going to end the way it used to before the problems began, we start by looking at sex as something they can enjoy as a couple.

Maybe their goal could be to help each other reach an orgasm without depending on intercourse, if that's comfortable for them. And that may also be a strategy when women are having pain with intercourse.

*What about men with physical problems having sex?*

There are some very specific treatments for erection problems, that are very effective. None of them replaces exactly your natural response, but there are things, like the use of vacuum pumps, that can give a man an erection without any surgery or medication. There are medicines that can help with erection but mainly only when they're injected into the side of the penis with a needle before intercourse. Some men have surgery to have a penile prosthesis put in, which is a little silicone device that will produce an erection. We don't have things that are so successful in terms of medication that restores sexual desire, or ways to restore sensation on the penis, or in the genital area for women, if that's been damaged. Luckily, that kind of nerve damage is pretty rare after cancer treatment.

*What kind of emotional work needs to be done at the same time to make these devices useful?*

I think very often it involves overcoming the fear of being rejected, for men especially. I think many men have a lot of pride about feeling like they can satisfy a woman and that they can get an erection whenever



**Leslie R. Schover**

For the last 14 years, Leslie R. Schover, Ph.D., a clinical psycholo-

gist, has been helping cancer survivors and others cope with the impact of medical treatment on their sex lives. Since 1986, she has worked at the Cleveland Clinic Foundation in Cleveland, OH, in a special clinic that includes both urologists and gynecologists dedicated to addressing the psychological and medical aspects of sexual problems. From 1981 to 1986, Schover worked at the MD Anderson

Cancer Center in Houston, where she founded a sex rehabilitation program for cancer survivors. She is the author of 2 pamphlets published by the American Cancer Society called "Sexuality and Cancer," and co-author of *Sexuality and Chronic Illness: A Comprehensive Approach* (written with Soren Buus Jensen, Guilford Press, 1986).



they want. When they can't do that, they often withdraw emotionally, and so for a lot of couples, affection and romance in their relationship may decrease, too. That's why I like to work with both partners if I can, and talk to them about what they used to do and what they are doing now. I often ask them to do things like go out on a date together, or set the scene for their lovemaking in a way that's going to make them feel relaxed—put a candle in the bedroom, or play some music they both like, things like that.

*What about someone who doesn't have a partner?*

The fear that partners are going to reject a man or woman because of the history of cancer is a real limiting factor for a lot of people going out and trying to date. What I do is ask them about their concerns, what they anticipate, give them some ways to cope with whatever might happen, and get ready to take some risks. And we talk about what it would mean if someone did reject them because of their cancer history.

*Do people have trouble following through with sexual recovery? How do they adjust over the long-term, whether alone or in a relationship?*

What makes the difference is the quality of the relationship and how stable and sound it was before cancer ever came into their lives. Research has suggested that there is no unusual divorce rate among cancer patients. The majority of couples will say that the cancer experience actually brought them closer together. I think the couples most at risk are those where the marriage is already shaky, where there is not a clear sense of unconditional love, or where their communication isn't very good. And I think another kind of marriage that often doesn't weather cancer as well is a newer marriage, especially for young couples who haven't finished their childbearing and where cancer treatment may affect their fertility. That's a big thing to cope with. When a 70-year old man gets prostate cancer and has trouble getting erections because of his treatment, that's very different than a 27-year-old man getting testic-

ular cancer and being unable to father children when he's been married only a year. The number of life tasks that people still have to finish really has an impact on how stressful it is to go through a major illness that keeps you from doing the things you planned.

*What about an illness that doesn't affect your sexual organs or desire, but rather causes disfigurement, so that the problem is interacting with others?*

Head and neck cancer is probably the best example of that, such as someone with a laryngectomy, who may not be able to speak without a speech aid. Again, how well people cope with that depends a lot on what their coping ability has been across their lifetime for other things. Some people are amazingly courageous and resourceful and they deal with things like that and still manage to have a really good social network with a good relationship in their lives and friends and family around them. Others may have already been isolated or had some problems with alcohol use or something like that, and need more help from the medical and mental health system to get through it.

*Does insurance generally cover this type of treatment?*

No, it doesn't cover mental health treatment very well at all. A lot of people have very poor mental health benefits to begin with, and a number of private insurers refuse to cover any treatment for sexual problems. This isn't so true for Medicare or Medicaid. The medical things tend to be much better covered. If, for example, instead of psychotherapy, you want to have penile prosthesis surgery for \$16,000, that's very well covered by everything except Medicaid.

*What can medical professionals do to improve things?*

One thing they could do is to ask at least one question about sexuality whenever they are doing an initial assessment or follow-up. Just saying, "Your sexual health is an important part of your health and I'm asking if you're doing okay here," can really help. Another thing is having a referral list available for patients, whether of mental health personnel who know

about sexual counseling, or urologists or gynecologists who specialize in helping with the medical part of the sexual problem.

I think people in rural areas are going to have the most trouble finding someone to help them because, realistically, health professionals who are trained to treat sexual problems tend to be clustered in big cities. If you do get information from your medical team, try to get a sense if you can—and this is very difficult—of whether they know what they're talking about.

There's a lot of misinformation out there, and some of it, unfortunately, comes from medical professionals. An example: radical surgeries for different sites of pelvic cancer in men—prostate, bladder, rectal, colon—can cause erection problems because they damage some nerves that run between the prostate and the rectum. Very often a doctor tells a man, "After this surgery, you will be impotent," but does not mention (and some doctors really do not know) that he will still have normal sensation on the skin of the penis and can still reach an orgasm, even without an erection, and even though some of those surgeries actually remove the parts of the body that produce semen. A lot of surgeons simply don't know what actually happens to those aspects of men's sexuality after surgery. So they tell men, "You'll be impotent," and the man's expectation is, "Well I won't be interested in sex, my penis will be numb, and I won't be able to reach an orgasm, so there's no point in even trying anything unless I happen to notice that I've recovered an erection."

### **To Learn More**

*Prostate Cancer:  
Making Surgical Decisions*  
by Sylvan Meyer and  
Seymour Mash  
(University of Chicago  
Press, late 1994)

*The New Male Sexuality*  
by Bernie Zilbergeld  
(Bantam Books, 1992)



## BOOK REVIEWS

### Love Story

*When Eric's Mom Fought Cancer* by Judith Vigna. Albert Whitman & Co., Morton Grove, IL, 1993; 32 pp, \$13.95. For ages 5-8. To order: 6340 Oakton St., Morton Grove, IL 60053, or call 800/255-7675.

#### Reviewed by Ellen Hermanson

"Mommy, this is not a sad book, this is a happy book," Leora, my 5 1/2 year-old daughter, announced, after I read her this tale of a little boy's adjustment to his mother's cancer diagnosis and treatment. She likes the book, she explained, because Eric's mother is just like me.

"He missed his mommy when she was in the hospital, and I missed you," she said. "He got to visit her, and I came to see you. He couldn't wait until she got home, and I couldn't wait until you came home."

Leora appreciated other similarities to her own experiences and observations. She identified with many of Eric's feelings and wanted to talk about them. Moreover, the book, which we read 4 days in a row after we got it (and often since), brought to the surface questions about my illness that she had never asked before.

Parents coping with cancer agonize over what—and how much—to tell young children. Until now, there have been few resources for us: some pamphlets from the American Cancer Society and the National Cancer Institute, and Eda LeShan's essential *When a Parent is Sick*.

This short book, illustrated with expressive watercolor drawings by the author, touches important concepts: many people with cancer get better and live for a long time; parents cry; nothing a child does causes cancer; treatment can make people feel lousy; life goes on for the cancer survivor and her family. Eric expresses a gamut of feelings—sadness, loneliness, fear, anger, and disappointment—that his parents and grandmother validate and understand.

The story ends hopefully: Eric and

his father go skiing and enjoy a day-long vacation from cancer. He buys his mother a special hat at the resort, which she promises to wear until her hair grows back—and again the next winter, when she hopes they all will go skiing together.

One caveat: before introducing this helpful book to children, parents might want to acquaint themselves with it first—to assess their comfort level with its approach and to prepare answers about important questions that the contents might elicit.

While the cancer survivor in me would have preferred that the author define "cancer" and the few medical terms she uses and explain why the mother's hair falls out and why she feels tired and nauseated during the unspecified treatment, the mother in me welcomes this book because of the matter-of-fact and truthful way it deals with a parent's illness and a child's complicated feelings about it.

*Ellen Hermanson, Networker editor, has been in treatment since January 1993 for metastatic breast cancer.*

### Support for Supporters

*Guide for Cancer Supporters* by Annette and Richard Bloch. R.A. Bloch Cancer Foundation (4410 Main St., Kansas City, MO 64111; 816/932-8453), 1992; 144 pp, free.

#### Reviewed by Brad Zebrack, MSW

What can I do? How do I treat them? What do I say to them? Will it be the wrong thing? These are often people's first reactions to the news

that someone they know or love has cancer.

In response to the uncertainty and fear that accompany a cancer diagnosis, Annette and Richard Bloch present *Guide for Cancer Supporters: Step by Step Ways to Help a Relative or Friend Fight Cancer*. This brief, easy-to-read, fits-in your-hip pocket paperback offers specific and valuable tips to friends, relatives, and colleagues, and serves as a primer for understanding the facts about cancer, its probable effects on individuals, and likely reactions to the diagnosis. This book can satisfy caregivers' needs to know what words and actions can be most helpful to patients in their fight against cancer.

The book addresses the issues of isolation and helplessness felt by so many people with cancer, and it delineates a role for supporters to help their loved ones overcome these feelings.

The Blochs offer a gentle reminder to supporters that they have no control over the medical outcome. They suggest that the best thing a supporter can do is convince the patient to commit to fighting the disease: "Treat the patient as if you expect them to live. You need not believe they will, you only need to believe they can recover."

One section introduces current cancer therapies and incorporates general information on lesser-known but widely used treatments such as immunotherapy, hyperthermia, hormonal therapy, dye-laser therapy, and monoclonal antibodies.

Another section guides the "casual supporter" to be a constructive and positive force in a friend's fight for recovery, and affirms the survivor's need to maintain a social connection.

There is great value and wisdom, in the Blochs' sharing of their experiences and extensive knowledge of resources and how to gain access to them. Best of all, this book is available to you without charge.

*NCCS board member Brad Zebrack serves on the coalition's nominating committee.*

### Next Issue

A review of *After Cancer: A Guide to Your New Life*, by Wendy S. Harpham, MD. Dr. Harpham will lead a workshop on late effects of cancer treatment at the forthcoming NCCS Assembly. She is a physician and author of *Diagnosis Cancer: A Guide to the First Few Months*.



## PEOPLE WATCHING



### Annette Porter

Seattle, WA

Breast cancer,

3 years

As a photographer, Annette Porter is drawn to strong images, as evidenced by her portfolio of women bald from chemotherapy and vibrantly beautiful. Last year she captured the spirit of survivorship on film at the Seattle Assembly. She is now embarking on her most challenging project: In January, she will join an 18-woman team of breast cancer survivors as they climb Aconcagua, a 23,085-foot peak in Argentina, and she will chronicle the journey with her camera. "I'm training with a vengeance," she laughs, referring to her intense preparation.

The goal of the climb, called Expedition Inspiration, is to raise \$2.3 million—\$100 a foot—to support breast cancer research. All expenses for equipment and travel have been underwritten by corporate sponsors. To date, local fundraising efforts have yielded another \$30,000.

But the team also wants a different kind of involvement from supporters. Porter and colleagues are asking Seattle-area support groups to break the trip into hour-long units. "We'll ask people to think about the climb and to spend some part of that hour doing something about breast cancer—driving someone to chemo, reading about it, doing something to connect," Porter says.

The team has already trained on Mt. Rainier. "It was both an empowering and humbling experience," she reports. On the way down from the summit, the group encountered 2 parents who had seen a story about the ascent on the local news. Their daughter had been feeling discouraged about her own treatment for breast cancer, and they wanted to inspire her

by obtaining autographs from the team members.

Porter marvels at how swiftly a sense of teamwork developed, and how closely that feeling jibed with her experience of cancer treatment. "You personally train and have to put one foot in front of the next, but there's no way I could have gotten to the top without the help of other people," she says. "The rope is like a living thing, connecting you."

For information about the climb and how to support it, call 800/487-0492. Porter's report and photographs will appear in the *Networker* early in 1995.



### Cindy S. Severinsen, LCSW

Tampa, FL

Clinical Social Worker

"The basis of what I do," says Cindy Severinsen, "is to help people empower themselves, help them pull strength out of themselves." Severinsen, co-founder of the Florida Coalition for Cancer Survivorship (FCCS), joined the NCCS board in 1993.

Severinsen's work at the H. Lee Moffitt Cancer Center in Tampa provides her with plenty of opportunities to encourage self empowerment. Her duties in the social work department include counseling cancer survivors and their families, attuning the medical staff to the emotional aspects of cancer, helping people manage their practical affairs during treatment, and facilitating support groups.

Support groups, in fact, are the heart and soul of Severinsen's vocation. She first got involved in the cancer survivorship movement 6 1/2 years ago, when she was asked to lead such a group at Moffitt. Through working with that first group, she says, she became sensitive to the difficulties of long-term survivorship.

The original group not only contin-

ues to meet, but it also has reached out to the community and become a local symbol of the vibrancy of survivorship. Her group has made presentations to area professional organizations.

For public television, they made a video series called "You Can Survive," covering a wide range of issues including self esteem, sexuality, family relationships, communication, insurance, and employment.

"There's something that happens when survivors get together," Severinsen says. "Survivors communicate not only on an intellectual level, but at a gut level. That's a real service that can't be provided in any other way."

### Bulletin Board

The National Cancer Institute recently announced the release of a series of **audio cassettes** from the 5th Cancer Patient Education Conference, "**Cancer Patient Education in a Changing Environment**," held last April. Among the topics: strategies for meeting the needs of African American cancer patients, strategies for educating patients and families about cancer pain, genetic counseling for cancer patients and families, and issues affecting childhood cancer survivors. Tapes cost \$9 each. For order forms, call 717/775-0580.

**Audio and video cassettes of a forthcoming conference for nurses, "Breast Cancer: An Update on Issues and Advances,"** will be available in November. Among the speakers: William B. Peters, MD, director of Duke's bone marrow transplant program; David Spiegel, MD, on cancer support groups; and Theresa Gillespie, RN, on nursing issues and advances for breast cancer patients. For full details, call Audio Magic: 800/679-3646.



## WHAT'S NEWS

### NCCS, Y-ME Urge FDA to Keep Implants Available

NCCS joined Y-ME National Breast Cancer Organization in urging continued availability of saline-filled breast implants in testimony before the Food and Drug Administration (FDA) in June.

The FDA had proposed requiring pre-market approval applications (PMAs) for the implants in January 1993. Much of the public supported PMAs because of fears that implants might cause systemic disorders. But those protesting PMAs for implants decried the lack of credible evidence of health hazards and the virtual elimination of choices for women with breast cancer. To clear the air, the FDA called a full day of hearings with physicians, manufacturers, and cancer

groups.

"I know firsthand how important it is that women with breast cancer have the choice to have an implant for reconstructive purposes," declared Susan L. Scherr, NCCS deputy director and breast cancer survivor.

"NCCS is concerned that, if regulation of these products is too onerous, companies manufacturing implants will exit the market and leave breast cancer survivors with limited, if any, access to implants for breast reconstruction."

Rosemary Locke, Y-ME's Washington, DC, liaison, asserted: "Breast cancer, not implants, kills nearly 50,000 American women yearly." She criticized the insubstantial evidence of implant complications, saying, "What consumers need are facts about safety based on scientific

data," rather than periodic FDA updates and arguments on talk shows.

"It is blatantly patronizing to say to women that science doesn't know if there is a psychological benefit from breast reconstruction," Locke said. "We are not mindless Barbie dolls, programmed by societal factors to act and think as toy robots. We know the benefit each time we dress, or swim, or hold a grandchild close, or undress before a lover."

"Proceeding with a PMA for saline at this time would remove a vital option for cancer patients," Locke concluded.

A few weeks after the hearings, Scherr and Locke met with FDA officials to deliver an addendum to their testimony. Their joint statement urged the FDA to allow implants to remain on the market and to require manu-

### Diane Sheahan: An Appreciation



Diane Sheahan

#### "She Was Always There For Us"

*Diane Sheahan, an early member of the Greater Washington Coalition for Cancer Survivorship (GWCCS) who spurred its growth during her years as its leader, died recently after a long struggle with ovarian cancer. NCCS Executive Director Ellen Stovall spoke at her memorial service. The following is excerpted from her remarks:*

Diane was the consummate survivor. She could have defined the word singlehandedly.

In spring 1991, [NCCS Deputy Director] Susan Scherr suggested that Diane help organize a Survivors Day event. The local

NCCS member organization, a fledgling known as the GWCCS, was in charge of planning the local program, and its president, Pam Onder, was busy getting another organization started (known today as the National Breast Cancer Coalition).

Diane agreed to help. On Survivors Day, Diane and her husband, Jack, drove a van to Union Station, set up folding chairs and microphones, carted books and membership forms, and even apologized that it was such a hot day—as if she might have willed the weather, too. She was so disappointed by the small turnout—about 40 or 50 people, including our friends and family. Diane promised me, "Next year will be bigger and better."

Between June 1991 and June 1992, Diane enlisted every hospital and cancer support group in the Washington area and signed them up for a gala Survivors Day at the Lombardi Cancer Center. Seven hundred people turned out. When I called to congratulate her, she said, "Next year will be bigger and better." And

in June 1993, at the Washington Hospital Center, nearly 2,000 people gathered for one of the largest National Cancer Survivorship Day events in the country.

What a wonderful world it would be if all those who must deal with cancer could have a Diane Sheahan in their lives. She was always there for us in the survivor community. And she made all of us do our jobs better.

In 1992 NCCS gave Diane the Catherine Logan Service to Survivorship award. Diane had grown the GWCCS from a good idea into NCCS' most accomplished community organization.

Those of us who live with cancer, no matter how long it has been since we were diagnosed, live our lives with the ever-present knowledge of the preciousness of life. If anyone could exemplify that the art of dying is the art of living, it was Diane. And Diane truly lived and died in full measure—with honesty and grace.



facturers to monitor their safety with comprehensive follow-ups. These data would augment information from ongoing clinical trials on silicone gel-filled implants. "Y-ME and NCCS support the continued availability of saline implants for women as the FDA proceeds in a thoughtful process to assess product safety and assure consumer needs," the statement said.

*Note: the New England Journal of Medicine June 16 issue featured a study of 749 women that "found no association between breast implants and the connective-tissue diseases and other disorders that were studied." An editorial in the same issue stated the results "cannot conclusively rule out some association of breast implants with the disorders studied," but "because there was no indication of such an association, any possible risk from breast implants in this population could not be large."*

## Jacobs Resigns Alternative Med Post

Joseph Jacobs, MD, director of the NIH Office of Alternative Medicine, is leaving his job in September. Jacobs, a keynote speaker at last year's NCCS Assembly (see Assembly/Winter 1994 *Networker* for coverage and interview), has been under continuous fire since his appointment in 1992.

Jacobs' background made him seem tailor-made for OAM. He is a Mohawk Indian who learned traditional native healing remedies from his mother. Educated at Yale and Dartmouth, he also earned an MBA in health administration from the University of Pennsylvania.

At OAM, Jacobs came under increasing pressure from opposing forces. Mainstream medical professionals pushed him to produce a quick list of therapies considered quackery. Proponents of alternative practices pressed him for fast validations.

Despite its tiny budget of \$2 million, the OAM has been a political hot potato. Last fall, the OAM awarded its first 30 grants to help alternative practitioners evaluate various therapies. Jacobs strenuously championed rigorous scientific inquiry into alternative medical treatments as the only way to assess their efficacy.

## Cancer and Minorities Focus of Symposium

Wherever cancer strikes, it delivers a lifeshaking blow. And nowhere does it strike harder than among minority communities, which suffer decidedly disproportionate rates of incidence and mortality. The 5th Biennial Symposium on Minorities, the Medically Underserved and Cancer will meet from April 22-25, 1995, in Arlington, VA, to explore the complex issues surrounding cancer among minorities.

"Cultural Diversity, Public Policy and Survivorship" offers a comprehensive slate of speakers and plenary sessions exploring the relationship between cultural diversity and public policy, and nurturing the survivorship concept among minorities. The symposium will examine health and lifestyle issues, including family history, diet and nutrition, the environment, and tobacco and alcohol consumption.

Because early detection plays such a vital role in successful cancer treatment, the meeting will offer an indepth look at current research and review model programs in prevention and early detection.

A Congressional reception will honor people who have distinguished themselves in their service to underserved communities. Participants will also visit their elected representatives to discuss healthcare issues affecting minorities.

Lovell Allan Jones, PhD, NCCS board member and chief organizer of the symposium, hopes to raise awareness about the plight of underserved cancer survivors.

"I hope Congress will realize there are people who need some type of reform. The system has heard from big lobbying groups, but not from ordinary citizens. The white Appalachian in Kentucky, the African-American in the Mississippi Delta, and the Mexican-American living near the border, all need serious help with their health needs."

Watch the *Networker* for more information on the symposium.

## NCCS Endorses Mitchell-Gephardt

Affirming its belief in the necessity of Congressional action to achieve comprehensive healthcare reform, the NCCS board of directors officially endorsed the bills sponsored by House Majority Leader Richard Gephardt and Senate Majority Leader George Mitchell in late August.

In a statement released to the press, the board noted that "While neither bill is flawless, we feel that these proposals provide a strong base on which to build an improved, more equitable healthcare system."

The eleventh-hour effort did not sway Congress, which adjourned without passing a bill. But the board considered its action a meaningful effort to give cancer survivors the best chance for real reform. NCCS will continue to press for change following the forthcoming Congressional elections.

### News bites

**Help Wanted**—NCCS relies on volunteer reporters to cover Assembly. Experience helpful but not necessary. Good way to "get into" the Assembly. Write *Networker* Editor Ellen Hermanson at NCCS, or leave message for her at 301/650-8868.

**Assembly Scholarships**—NCCS will provide a few scholarships to survivors who otherwise could not attend the Assembly because of financial difficulty. Please support this effort by sending a tax deductible contribution to the NCCS Scholarship Fund.

**NCCS' 1993 Annual Report**—For a free single copy, write or call: NCCS, 1010 Wayne Ave, 5th Floor, Silver Spring, MD 20910; 301/650-8868.



## Can Cancer Survivors Survive Managed Care?

(continued from page 5)

"Unfortunately, an individual can be stuck," Bailes says. "Without comprehensive health system reform that has federal oversight, a patient's only recourse is to the state insurance commissioner." And that, he adds, yields mixed results.

Even after patients find an appropriate oncologist within a managed plan, however, their battle may not be won. Some plans restrict access to drugs by limiting the choices in their pharmacies. "That makes it vitally important for oncologists to be part of utilization reviews and participate on the pharmacy and therapeutics committee of HMOs," Bailes says.

And psychosocial support, so vital to quality of life during and after cancer, is quite limited in most plans.

### What About Clinical Trials?

Access to the best, or most appropriate treatment poses another challenge.

"Managed care plans don't have a commitment to clinical trials," Bailes says. "Many of these plans will pay for standard therapy even if a clinical trial may offer a better benefit to individuals with cancer."

Yet sometimes a clinical trial offers a cancer patient the best, or only, option. An ASCO position paper notes, "HMOs have been reluctant to allow enrollees to participate in clinical trials, even in circumstances where the HMO has contracted with the particular academic health center conducting the study."

Ensuring that patients can go to an NCI-designated, state of the art cancer center is part of the lobbying efforts of most organizations in the cancer community, as is ensuring coverage for investigational treatments. "We need to end the capriciousness with which coverage is applied now," Raftis says.

ASCO and other organizations

have argued that any national legislation must allow people with life-threatening conditions to obtain treatment, as medically appropriate, in an approved clinical trial or at a hospital providing highly specialized care. Furthermore, insurance companies should pay for this treatment as if it were provided by the HMO itself.

Continued funding of clinical trials is also imperative, as well as economically sensible. Development of successful new therapies will tame all the costs of cancer.

And patients need information, which, in today's environment, can be difficult to obtain.

"One item we've really been pushing is to provide mandatory information," says Raftis, "so that patients understand their options—that they can go out of the network, that there are NCI designated centers. Access means nothing if the average patient lacks information to make informed choices."

**National Coalition for Cancer Survivorship**  
1010 Wayne Avenue, Fifth Floor  
Silver Spring, MD 20910



**9th Annual Assembly**  
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