

Hillary Clinton Named Honorary Chair Of NCCS Congress



First Lady Hillary Rodham Clinton has accepted an invitation from NCCS to serve as honorary chair of the first National Congress on Cancer Survivorship, set for Fall 1995 in Washington, DC. NCCS announced Mrs. Clinton's acceptance during the celebratory "paint in" at the 9th Annual Assembly.

In a written message to Assembly participants, Mrs. Clinton said: "As honorary chair of 'Seasons of Survivorship,' I am grateful for your efforts to promote awareness and offer support and hope in the battle against cancer. Almost all of us have a friend or family member whose life has been threatened or lost because of cancer. ..."

"I commend your participation in this creative forum and encourage your continued commitment to those who are fighting to overcome this threatening disease."

Mrs. Clinton chaired the President's Task Force on National Healthcare Reform and championed a number of issues, including universal coverage, generally favored by cancer survivors.

The 1995 Congress will bring together organizations and individuals from the national cancer community to set an overall agenda of priorities for the movement. A series of Town Halls across the country will set the stage for the congress.

Consumer advocate Esther Peterson and Harold Freeman, MD, will co-chair the honorary committee for the event. (An interview with Dr. Freeman, who received the NCCS Public Leadership Award at the Assembly, appears on page 8.)

O'Connor, Town Hall, Paint-In Top Assembly

by Terrence Campbell

With a riveting speech that made national news, an energetic Town Hall meeting that made survivors' voices heard, and a "paint in" that made colorful artworks, NCCS' 9th annual Assembly made memories for the hundreds who attended.

Supreme Court Justice Sandra Day O'Connor opened the first full day of activities with a heartfelt keynote address in the early morning. Her inspiring message and warm delivery had Assembly participants buzzing all day. By evening, all the major news networks broadcast her story across the nation.

"I'm a survivor," O'Connor declared, and with those 3 words made an unbreakable connection with the audience that held strong until well after she said her final "thank you" and received a standing ovation.

And that was just the beginning. "Seasons of Survivorship," which ran Nov. 2-6, 1994, in Washington, DC, offered much more.

The first-ever NCCS Town Hall sustained the candid tone set by O'Connor's address. Participants voiced their opinions, concerns, and ideas about their cancer experience. They talked about money worries, insurance problems, stress in the family, employment woes, and the dearth of supportive care for long-term survivors.

Survivors' stories formed the heart and soul of the discussion. In one especially wrenching moment, a cancer survivor declared that her finan-

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O'Connor, Town Hall, Paint-In Highlight Assembly

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cial burden from medical bills had overwhelmed her ability to pay. "I am declaring bankruptcy on Monday," she declared, sparking sympathetic gasps from the audience.

Moderator Ellen Tobin, president of Health Surveys and Marketing, Inc., lauded the meeting as a good start in providing a model for the regional Town Halls. The Assembly Town Hall functioned as a dialog between members and NCCS representatives, while subsequent forums will involve survivors, medical and legal experts, corporate officials, and community leaders.

A brighter mood prevailed during the "paint in." Assembly participants joined area residents to create dozens of colorful mural panels depicting butterflies, toucans and natural scenes. A duet performed lyrical flute and guitar music to inspire the people as they hunched over canvas panels.

John Feight, executive director of the Foundation for Hospital Art, provided outlines of the basic images and guidance on color. Feight has led many paint-ins all over the world.

Most of the art was donated to area hospitals. The National Institutes of Health accepted a set of butterfly mobiles for a lobby display—its first acceptance of such a gift from the private sector.

"It was a magical event," said Executive Director Ellen Stovall afterward. "Painting is something that everyone can enjoy. It's a great way to bring a community together." NCCS will host another paint-in at next year's Congress.

Workshops, panel discussions, and award presentations filled out the Assembly schedule. Diane S. Blum, ACSW, Stuart Grossman, MD, and Ada Jacox, MD, received special recognition awards for their contributions to public education on cancer pain. Natalie Davis Spingarn presented the writer's award in her name to Susan Sontag in abstentia. The Catherine Logan Award for Service to Survivorship went to Edward Kaps.



At paint-in, NCI's Sam Broder (left) receives mobile from artist John Feight.

Harold Freeman, MD, who received the NCCS Public Leadership Award, inspired a heartfelt ovation with his acceptance speech.

John Anduri emceed an emotional closing ceremony in his own inimitable style that seemed to combine elements of the Oscar awards, the Old Time Gospel Hour, and Mitch Miller's Sing Along. It seemed a fitting response to Justice O'Connor's opening declaration, "I'm a survivor." For most of those gathered at the close, the joyful affirmations and songs seemed to say: We're all survivors. That, after all, fulfills the meaning of every NCCS Assembly.

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The *Networker* is a quarterly publication of the National Coalition for Cancer Survivorship. NCCS is a network of organizations, institutions, 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.

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In Pursuit of Pain Relief: A Survivor's Story

by Ellen Hermanson

Networker Editor Ellen Hermanson, a 6-year survivor of breast cancer, participated in an Assembly panel discussion on cancer pain management. Her remarks clearly struck a chord with the audience. Following are excerpts from her presentation. Please note: References to specific drugs reflect the writer's experience and do not represent the opinion of NCCS.

I have approached cancer the way I've dealt with most experiences in my life—that is, as a student and as a reporter. I've researched, read, asked questions, and sought out as much information as I could—and sometimes more than I was comfortable with—to get answers. But I have been so consumed with learning about treatment options, in all their seemingly infinite variety, that I have sometimes minimized the importance of pain relief and understated how uncomfortable I have been.

Not only am I a student of cancer, I'm a teacher as well. Not just because I'm a patient at a major teaching institution, where I often think my job is to be "Miss Manners" for young physicians and instruct them about how to behave. It's also my job to teach them about what's important to us cancer survivors. And that led me to conclude that I haven't been a very effective teacher. I haven't articulated clearly my concerns about pain.

Specifically, I haven't told my doctors that I've often made the choice to live with pain rather than fiddle around with drugs and dosages because I've been afraid of side effects. I have never explained that I have balanced how much pain I could put up with, versus how much discomfort or nausea I could stand from Percoset™ or MS-Contin™. I didn't spell out that severe constipation and hemorrhoids deterred me from taking Tylenol 3™. I never asked how to counter these side effects. So I now



Hermanson: Don't expect the patient to do all the work.

realize that I unintentionally conspired in diminishing my quality of life.

Still, my doctors and nurses know all about side effects. They could have told me that any opiate causes constipation but that Colace™ and Senokot™ work wonders. They did not stress that other side effects can be managed, nor have they pointed out that there are a lot of painkillers in the pharmacy. They could have been more creative.

I had a frustrating experience last spring. A doctor prescribed MSIR™, a morphine-based drug which, I knew from experience, would also make me sick. He encouraged me to just tough out the nausea for 36 to 48 hours and then, he assured me, I would get really good pain relief. Well, I don't know about you, but I don't have 2 or 3 days to waste feeling like hell. When I asked him about anti-emetics, he suggested Compazine™, another drug I can't tolerate. He reported that oral Zofran™ was unlikely to work with painkillers. I felt so discouraged by this exchange that I just gave up.

That was the low point in my pursuit of pain relief. Shortly after that, a chemotherapy nurse suggested a different drug—Darvocet™—that worked well. Since then, I've been more assertive about getting pain relief.

Pain relief takes a lot of energy to achieve. It can take a long time to get it right. But time, for many of us, is a problem. Doctors, nurses, and patients often just don't have it. Appointments

are crammed full of important, complicated things that we need to discuss. Pain assessment is just one.

I've learned that pain management is a balancing act. The balance changes, sometimes almost every day, because pain changes, every day. Pain is influenced by a host of variables I can't always identify. Some of them have nothing to do with cancer, including the weather, how tired I am, and how active I've been.

I've learned that pain management is a team effort, even if it isn't presented that way and even if it seems that the team is pretty dysfunctional. Some of the best suggestions I've gotten have been from chemo nurses, who see me week after week and who always inquire about my level of pain and what I'm doing about it.

I have wasted hundreds of dollars on pain pills. I now know to try new drugs in small amounts. If my doctor prescribes 50 tablets, I ask my pharmacist for 10. If the new pills work, great. I can easily get more. But if they don't give relief, or if I can't tolerate them, as has often been the case, I haven't thrown my money away.

Maybe it shouldn't be my job—and I certainly think we cancer survivors have enough to deal with—but it's up to me to make sure I ask about possible side effects of pain medications and how to manage them.

And I've learned that as my pain changes, so must the drugs I take to control it. I've gotten better about not waiting to feel wretched before I mention that pain medication isn't working.

We need advocates—a spouse or family member, or a friend. When I'm distracted by pain, I can't always stand up for myself.

And if you treat cancer pain, I hope you'll remember how emotionally and physically draining pain is, and that you can't expect tired, frightened and sick patients to do all the work in achieving control over their pain.

Justice Sandra Day O'Connor: A Personal Testimony

Excerpts from NCCS Assembly keynote address

"I'm A Survivor"

In a powerful and intimate keynote speech, Supreme Court Justice Sandra Day O'Connor described, for the first time in public, the crisis of her breast cancer diagnosis 6 years ago.

"I'm a survivor," she proclaimed in her address before an appreciative audience of Assembly participants. Her remarks drew knowing laughs and nods—and, in the end, a standing ovation—as she described the trajectory of her experiences. Many of those present could identify with the feelings and events O'Connor described so poignantly.

"The best thing about all this is that I had a job to go to," she said. "I didn't miss anything, and it was hard, but I'm so grateful that I had my work to do." President Reagan appointed O'Connor to her "job" in 1981, making her the first woman to serve on the High Court.

"Tears were shed," she said, referring to her own ordeal, but it also described the effect her words and demeanor had on the Assembly audience. And they were not the only ones profoundly moved by her candor and warmth.

C-SPAN broadcast her remarks live, and rebroadcast them several times in response to a strong response from viewers. Tom Brokaw (NBC), Peter Jennings (ABC) and Dan Rather and Connie Chung (CBS) all closed their news shows with footage of O'Connor's address. Thus, with one forthright speech at an NCCS Assembly, Sandra Day O'Connor catapulted the concept of survivorship to a whole new level of public awareness.

It's been 6 years since I underwent surgery for breast cancer. The impact of the diagnosis of cancer that I received is one that has not been far from my thoughts at any time during those 6 years. This is the first time that I have spoken publicly about my experience. And I'm not sure that my experience is any different from anyone else's. In fact, I'm quite sure it isn't. So what I have to say this morning for those of you who are here as survivors or friends or relations of survivors is going to sound hauntingly familiar, I suspect.

When we're dealing with things as basic as life and death and a disease like cancer, there's a universality to the experience. We begin with the anxiety of going through the testing, something that's seen on a mammogram or an x-ray, or there's some little spot on your back—whatever it is. And then you start this round of testing. The initial impact for me was one of general disbelief. I felt fine, just fine, but I was told to go have these tests and find out.

After the usual biopsies and other tests I was told that I had a potentially fatal disease. Now *that* gets your attention. The Big C. The word cancer, it overwhelms the psyche, just the word. I couldn't believe it. I was unprepared for the enormous emotional jolt that I received from the diagnosis.

I can remember, all of a sudden my face and hands, my whole body tingled. I couldn't believe I was hearing this. It couldn't be true. I'm too busy! I feel fine! You can't be serious!

Well, the next thing was reality set in. But I was quite unprepared for the suddenness and the urgency of the rapid treatment decisions to be made. I had planned to go through a couple more rounds of oral argument in court, and I said, well maybe in December we can work this out. I

was told that was not an option. So I was simply lacking in appreciation for the fact that everything had to stop and I had to focus on this and I had to start educating myself about what it was I had and what the treatment options were. This was a very tough time.

I discovered I needed other ears than my own because I was so emotionally involved in this situation that I wasn't sure I was hearing everything. I brought my husband along because I thought he could listen with greater objectivity, and we both tried to take a few notes so we got everything down. This was a world that was new to us. We didn't know the medical terms, we didn't have any experience with this, and I wasn't sure I was even equipped to absorb the information I was hearing...

What added to the stress was that I had to make so many decisions about the course of my treatment. I thought if I got sick, I went to my doctor, the doctor said what ought to be done, and that was the end of it. Right? Wrong! With this disease, it isn't always that way.

It helped to have close friends to talk to, people who had gone through the same experience. I discovered that a lot of women I had gotten to know quite well in Washington as well as one who I considered a good friend had gone through this thing not once but twice. She immediately became a good resource for me because she had twice the experience and had survived and was in good spirits about it and led a wonderful active life. And it was amazing how many people would send me a letter or come up to me and say, I've had that too, my mother had that, oh my aunt had that. So this was good, because I then could start to come to grips with the fact that this wasn't the end of the line and I was going to

have a life that was going to go on... and many people do and you can begin to look at the positive side.

Now it is clear that the decisions about what to do, what treatments, had to be made promptly. And you just have to sweep in every bit of information you can possibly absorb, just become a real student, like cramming for an exam in college. And then I did what I do at the Court. When I'm at the Court faced with a case I try to find everything out about that case that I can. I do as much research as I possibly can do and then I make my decision and I don't look back, I do not look back and say, oh what if I had done the other thing, or I should have done something else. Don't do that. Just do the best you can to get everything you can together, make that decision, and move on.

Now for me the decision was to have a mastectomy, and the postoperative period was depressing. I felt weak. I felt very emotional. I was hearing things that I didn't want to hear, I was in some discomfort. It was really a tough time. And yes, I think there were a few tears shed along the way, and it was so intense that I called that friend and I said, could you come down to the hospital by any chance, do you have time, could you come down and see me. And she did. She dropped everything and came down and we shed a tear or two together and we talked everything over. And that helped.

I was told I was going to have some chemotherapy and this would take some months... and part of it was learning to visualize treatment and recovery. Now this was tough for me. So I had to try to figure out how am I going to start doing all this visualization and seeing the little good cells running and stabbing the bad ones...

I was tired. That was the main thing, and I'm not used to being tired. I had a lot of energy in my life, and I couldn't believe I needed all that sleep. Well, I could hardly get up, and in the afternoon I felt like I need-

ed a nap. And this was frightening.

It wasn't just me. My condition was causing distress to my family. My husband was affected by it, my children were.

I felt grateful that I had my work to do. I wonder how people who don't have work to do get by. If all you do is worry about yourself, that's a lot harder than if you have some outside activity to be concerned about, to take your attention away from your problems.

It also helped me to resume physical exercise as soon as I could. I'm someone who loves to have an exercise class every morning of my life. I was told for at least 6 weeks you can't do X, Y, and Z. But long before the 6 weeks was up, I went back to my exercise class and there was a lot I couldn't do. But I did a little. I did what I could.

Now what was the worst? The worst was my public visibility, frankly. There was constant media coverage. How does she look? When is she going to step down and give the president another vacancy on the court? She looks pale to me, I don't give her 6 months. I mean, this was awful. There were people in the press box with telescopes looking at me in the Court room to see just what my condition was. I didn't like that. People would call my office and say they'd heard all these dire rumors and I better tell them exactly what was what or they were going to publish them all.

Even that negative has an upside, as most things do, because I'm a survivor. And because of the media coverage, I can see that we all need basic information. We need clearing-houses for getting support and educa-



O'Connor: "I was told that I had a potentially fatal disease. Now that gets your attention."

tion and help when we need it...

Having this disease made me more aware than ever before of the transitory nature of life here on Earth, my own life. And it made me value each and every day of life more than ever before. It fostered a desire in me to make each and every day a good day a better in every contact I have with other people. It also made me aware that as a survivor maybe I could make a little bit of difference for other people.

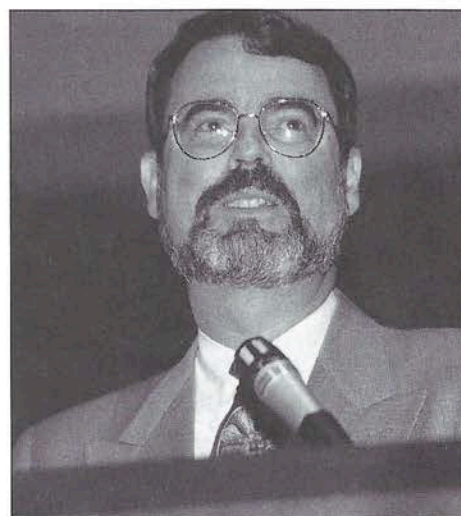
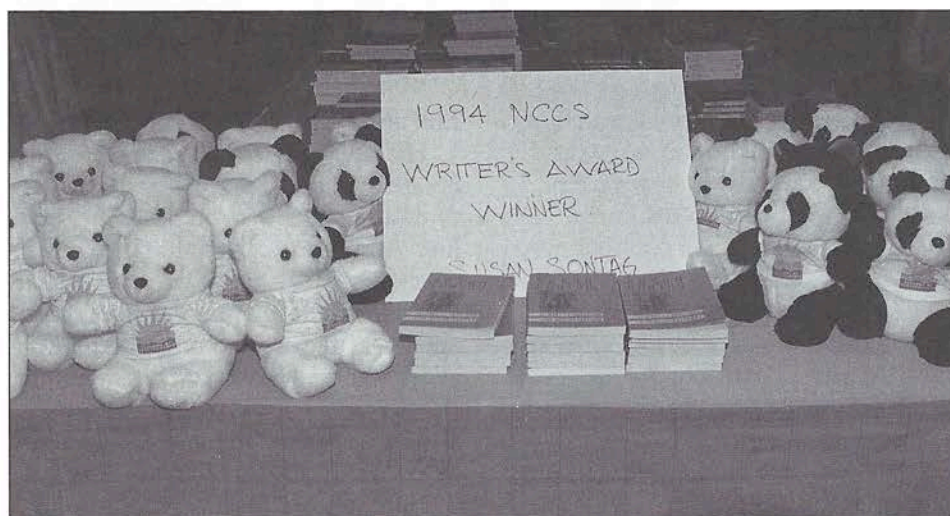
How many of you here today remember that eye-popping cover on the New York Times Magazine a year or so ago. It featured the uncovered torso of a woman artist showing her mastectomy scar and her remaining breast. It was a very powerful image. It wasn't just her damaged chest, but her resilient dignity that was so powerful. It was someone *surviving*.

Thank you.

Video Available

At press time, NCCS received permission to reproduce a video of Sandra Day O'Connor's keynote address. To order, contact the NCCS office at 301/650-8868. (If you have already inquired, you will automatically receive ordering information by mail.)

THE '94 ASSEMBLY



"Seasons of Survivorship" Scenes

Top left: Say a few words, Nathan! Deputy Director Susan L. Scherr presents gift to Nathan Lewis for his generous and dedicated support of NCCS over the past several years.

Top right: Networker editor Ellen Hermanson and NCCS President Susan Leigh, RN, both cancer survivors, relax during a break between sessions.

Middle left: Scholarly polar bears and pandas, smartly attired in "Seasons of Survivorship" shirts, add warmth and fuzz to the normally cerebral NCCS book fair.

Middle Right: Author and NCCS Chair Fitzhugh Mullan, MD, recalled the coalition's history during remarks at the opening night welcome reception. His landmark essay, "Seasons of Survival," helped launch the survivorship movement and inspired the Assembly's theme.

Left: How is it? Cancer survivor Nancy Roth awaits verdict on the food from Beverly Zielinski of Ocala, FL. Roth, of Maryland, volunteers for both the National Bone Marrow Transplant Link and NCCS.

ALL PHOTOS BY ANNETTE PORTER. Porter, a cancer survivor, is an independent photographer based in Seattle. She recently exhibited photographic artworks in a group show in San Francisco.



WASHINGTON, DC



"Paint In" Magic

Left: Joseph Cunliffe of musical duet Flutar inspires paint-in participants with sensitive performance.

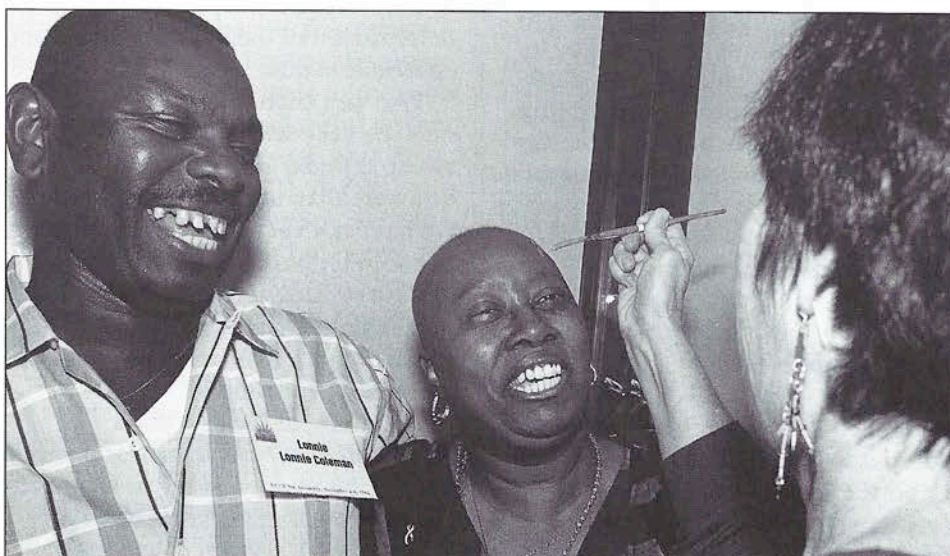
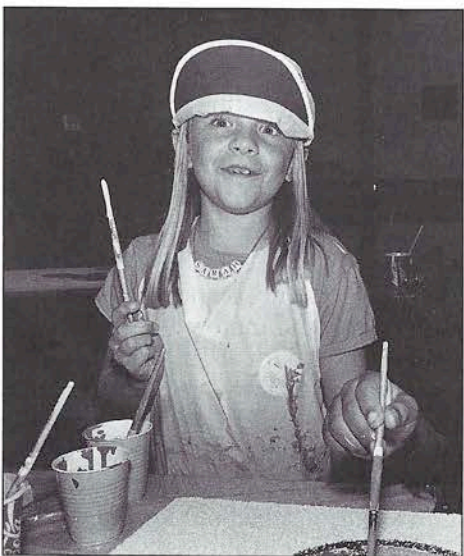
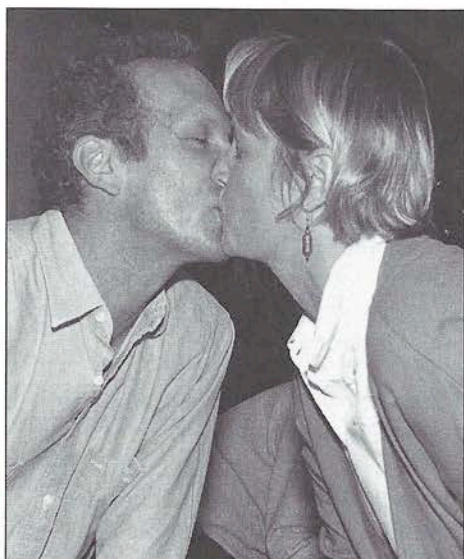
Below left: The Kiss of the Thriver Woman—Cancer survivor Dani Grady shares a smooch with fiancé Ralph Greenspan of New York. Grady heads the Thrivers Network in San Diego.

*Below center: Kathy LaTour and daughter Kirtley, age 9, team up on a butterfly panel. LaTour, author of *The Breast Cancer Companion*, serves on the NCCS board and chairs the communications committee.*

Below right: Sure, it's art, but not SERIOUS art. Geraldine Herbert, co-director of the Creative Center for Women with Cancer in New York, gets into the spirit of things.

Bottom left: With cap flipped back and brush poised, Sarah York looks ready for anything. Sarah, age 7, came to the paint-in with her grandma Betsy, a.k.a. Elizabeth Johns Clark, PhD, President-Elect of NCCS.

Bottom right: I'll do anything for art—Joanne Coleman, supported by husband Lonnie, entrusts her head to Susie Leigh for previously unscheduled face painting.



Race, Poverty, and Cancer

Interview with Harold Freeman, MD • Conducted by Terrence Campbell

The rates of cancer incidence and death run higher for minority groups than for whites. Why is that so?

Cancer is not merely a scientific problem. Cancer always occurs under human circumstances—social, economic, physical, cultural, and political circumstances.

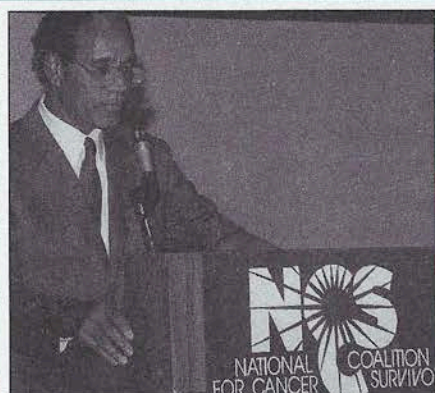
Poor Americans have a 10-15% higher cancer mortality rate. This is related to what poverty means. Poor people tend to have substandard housing, low educational levels, and a risk-promoting lifestyle characterized by high smoking rate, high alcoholic intake, and high-fat diet. Poor people also have diminished access to preventive and early healthcare. Poverty and cancer therefore are usually a lethal combination.

African-Americans have a lower 5-year survival rate—38%, compared with 55% for white. But the disparity in survival is primarily related to economic status. About 33 percent of Black Americans are poor, compared with 11 percent of white Americans. Black and white Americans in the same economic status show very little difference in survival rates.

Poverty does not respect race. Any group with inadequate income, housing, and education will suffer a higher death rate, whether they're white Appalachians, Black New Yorkers, or any other group.

That's a major point. If the disparity in survival rates was primarily due to race in itself, that would drive a different solution to the problem. We'd probably need to explore molecular biology or genetics for solutions. But clearly the major disparities in outcome between races are due to social factors, which suggests a different approach.

Poverty is not a problem that affects only a certain segment of society. It concerns everybody. Many middle class people—whites, Blacks, and others—become poor. Anyone could lose their insurance or their job, or both. Few people could miss 2 consecutive paychecks without potentially severe consequences, such as loss of



Harold Freeman, MD, chairman of the President's Cancer Panel, received the NCCS Public Leadership Award at the 1994 Assembly. Throughout his career, Dr. Freeman has distinguished himself internationally as an eloquent advocate for minorities, the poor, and the medically underserved. He serves as director of surgery at Harlem Hospital Center in New York.

health coverage. We should therefore not see the poor as "others." We should see reflections of ourselves in the eyes of the poor.

Of course, race and racism influence cancer outcome. If you grow up as an American Indian, you have a devastating history. If you're Black, you have emerged from a long history of slavery and legalized segregation. The history of a people is a powerful determinant of their current social and economic status.

We can't change history, but we must be very sensitive to it and not sweep it under the rug. We must also be aware that, despite much progress, we have not yet achieved a completely fair society. But the effects of racism on Native Americans and Black Americans is related more to the momentum of history, as opposed to current race relations.

Certainly, living as a Black American today has to be less onerous than living under slavery or legalized segregation. But 250 years of slavery followed by 100 years of legalized seg-

regation has been a powerful determinant of current conditions. It is also true that changes in laws do not necessarily change the hearts and minds of people.

Successful racial and ethnic groups don't achieve prosperity in one generation. You probably can't catch up in 30 years. African-Americans are not doing as well as the majority today. They tend to have less access to healthcare and tend to be uninsured. These are not accidents. They are historical developments.

Poverty and racism are two distinct, destructive elements in American life. Therefore it is necessary to separate the strategies we use to fight poverty from those we use to fight racism. If you confuse those issues you will confound the solution. Certainly we need to fight racism. Whenever you find unfairness toward any group you must fight it. On the other hand, poverty is a universal phenomenon. It affects people irrespective of race. When you fight poverty, you're fighting a humanitarian battle for all people.

How can we begin to untangle the net of poverty and cancer?

First, we should understand that poverty is not a hopeless condition and that we can help people deal with it. Too many people lack insurance or access to care; a humane society should feel compelled to address that. The nation, the taxpayers, won't save money by not treating people who have cancer. In fact, we will lose money. A person with cancer who is untreated early will enter the hospital late, need longer-term and more-expensive treatment, and will likely die. Early diagnosis and treatment saves lives, and money as well.

We know a lot about preventing and treating cancer. We need to apply what we already know to all segments of society. About 50 percent of those diagnosed survive cancer now. If we universally applied our knowledge, 75 percent would survive.

Survivors Speak Out At NCCS Town Hall

In opening the coalition's first Town Hall meeting at the fall Assembly, NCCS President Susan Leigh, RN, declared: "It's time for us to go to the people."

And the people were ready. Approximately 100 cancer survivors, their loved ones and others packed the room to speak out about their personal struggles with cancer, and the issues they face in their daily lives.

NCCS conducted the meeting to create a members' forum and to establish a model for regional Town Halls around the nation. Those meetings, in turn, will help set the agenda for the 1995 National Congress on Cancer Survivorship.

Moderator Ellen Tobin, President of Cancer Care Strategies, asked the participants to define the "big issues." They responded with a rapid-fire list (see box below).

The discussion intensified when Tobin shifted the focus from the general to the personal by asking the group, "What's the worst thing about



Ellen Tobin directs verbal traffic at fast-paced Town Hall.

living with cancer?"

Participants responded with a tide of stories. Some described their confusion during the early stage of treatment: too many complex decisions to make, the struggle to gather information, conflicting professional opinions, the nagging questions (am I making the right decision? Did I gather the right information?), a sense of emotional isolation.

Pocketbook issues emerged, with stories of financial strain ("I was forced to sell my house") and even bankruptcy caused by unmanageable medical bills, insurance woes (getting it, keeping it, reimbursement battles), and the way those problems interfered with access to care.

A number of participants described psychological stresses on self and family engendered by cancer. They cited marital crises, lack of professional support systems for children and teens, panic attacks following treatment, and indifference to needs of longterm survivors.

Several participants called for stepped-up political action on local and national levels ("each of us is a potential conduit for change"), with some calling for a more militant approach borrowing from the AIDS movement ("maybe we should tie ourselves to the Golden Gate Bridge").

This way of hearing the views of survivors will be repeated several times throughout the year at different locations, according to Executive Director Ellen Stovall.

Groups in Florida, San Diego, and

Albany have started planning for Town Halls.

NCCS staff is producing a Town Hall "how to" kit, available in February 1995. The package includes guidelines, a video of the Assembly Town Hall, and a model survey form for feedback from participants. Call the NCCS office (301/650-8868).

Bulletin Board

"Cultural Diversity, Public Policy and Survivorship," Fifth Biennial Symposium on Minorities, the Medically Underserved and Cancer runs April 22-25, 1995, in Arlington, VA. Speakers and plenary sessions exploring survivorship issues for minorities, including health and lifestyle, family history, diet and nutrition, the environment, and early detection. For information, call Donette Walker, 713/798-4617.

"Economic and Quality of Life Outcomes in Oncology: A New Focus for Healthcare Providers, Payers and Policy Makers," a symposium sponsored by St. Mary Medical Center, runs March 4 and 5 at the Hyatt Regency Hotel in Long Beach, CA. Nationally recognized speakers will explore economic implications of healthcare delivery and reimbursement. Call the Cancer Care Center at 310/491-9997.

"Research, Resources, Recovery: A Brain Tumor Conference for Patients, Families and Health Professionals," sponsored by M.D. Anderson Cancer Center and the National Brain Tumor Foundation, March 11, 1995, at the Houston Marriott Westside in Houston. One-day conference features special set of workshops on needs of children with brain tumors. Other topics include sexual health, returning to work, helping spouses cope with stress. Individual registration: \$35 before Feb. 24. Call 713/792-2222.

The Big Issues

Cancer survivors at the Assembly Town Hall compiled the following list of what they see as the major issues in their lives:

- Access to state of the art care
- Access to psychosocial support
- Continuity of care
- Inclusion of women in research
- Holistic family care, such as daycare and meals, hospice style
- Support for spouse, partner, and children
- Insurance (universal coverage, pre-existing conditions, clinical trials, off label use of drugs)
- Long-term side effects
- Information, education
- Pain management
- Early detection
- Employment

WHAT'S NEWS

Panel Urges Congress: Change Cancer Tactics

The U.S. will lose its war on cancer unless the government takes "urgent action" to improve delivery of health-care to all citizens, according to a report released in September.

The report notes an overall increase since 1971 in cancer incidence (up 18%) and mortality (up 7%). It cited 4 problems:

- Many people—especially the poor, elderly, and uninsured—receive inadequate cancer care.
- Current laws, public policy, and government regulation undermine the cancer war, with tobacco policies playing a major role.
- The U.S. fails to rapidly develop advances against cancer.
- "Unprecedented opportunities" in basic research will be wasted without increased funding.

The study also urged Congress to restore top level coordination in the

fight against cancer. The National Cancer Program, established in 1971, originally mandated an integrated cancer effort involving federal and nonfederal programs under the authority of the National Cancer Institute.

The report, "Cancer at a Crossroads," was issued by a special Subcommittee to Evaluate the National Cancer Program. NCCS Executive Director Ellen Stovall served on the subcommittee, chaired by Paul Calabresi, MD, of Brown University School of Medicine.

Cancer may become the leading cause of death in the U.S. within 5 years, according to projections in the report. The National Cancer Institute estimates that 1.25 million people will be diagnosed this year.

For a copy of the study, call NCI at 800/422-6237.

NCI Chief Broder Resigns

Samuel Broder, director of the National Cancer Institute, announced in December that he would resign. Broder, a veteran of 22 years of service in the public health sector, including 6 years as NCI director, said his resignation would take effect in April 1995.

In a letter to Broder following his announcement, NCCS Executive Director Ellen Stovall praised his "exemplary leadership," expressing special appreciation for "the many ways over the past several years in which you ensured that the voice of cancer survivors became a part of the process of evaluating and strengthening" cancer research programs in the U.S.

Broder, 49, will move on to IVAX Corp., a pharmaceutical firm in Miami, to serve as senior vice president of research and development and chief scientific officer. He received the NCCS Public Leadership Award in 1992.

Fund Raiser to Aid NCCS

The Potomac chapter of Meeting Planners International will host a "Roaring '20s" fund-raising gala to benefit NCCS on Feb. 25, 1995, in Washington, DC, at the Willard Inter-Continental Hotel. For information, contact Laurie Sharp at 202/624-7710.

"Best Loved Books" Out

NCCS' newly updated "Best Loved Books" a bibliography of survivorship literature, is now available. Former board member Barbara Thorne, MSIS, a cancer survivor, compiled the list of over 100 titles. For a free single copy, contact the NCCS office.

New Year Brings Changes on Board

NCCS' board of directors starts the year with changes at the table.

Elizabeth Johns Clark, PhD, former vice president for operations, becomes president-elect, and will replace President Susan Leigh, RN, when her term ends next year. Clark directs the division of diagnostic and therapeutic services at Albany Medical Center Hospital.

Diane S. Blum, ACSW, takes over as vice president for development for Danette G. Kauffman, MA, MS. Blum is executive director of Cancer Care, Inc.

Board member Judith S. Blanchard, MS, is now vice president for programs. Blanchard serves as director of community support services at Hollings Cancer Center, and she co-founded the LowCountry Coalition for Cancer Survivorship in Charleston, SC.

Linda B. Johnson, senior vice president of Franklin National Bank in Washington, DC, assumes double

duty as secretary/treasurer.

Michael McKechnie, executive director of the National Brain Tumor Foundation, completed his term as treasurer. Author Kathy LaTour, who completed her term as secretary, remains on the board.

Other new board members include Daniel Fiduccia, a consultant with expertise on the Americans with Disabilities Act; Pat Fobair, LCSW, MPH, a clinical social worker at Stanford University Hospital; Jane Rodney, director of the Breast Cancer Resource Center in New Jersey; Sandra Millon Underwood, RN, PhD, associate professor at the University of Wisconsin (Milwaukee) School of Nursing; and Karrie Zampini, CSW, director of the Post-Treatment Resource Program at Memorial Sloan-Kettering Cancer Center.

Bobbie de Cordova-Hanks, Barbara Thorne, MSIS, and Zora Brown also completed terms.

BOOK REVIEWS

Cancer, Soul, and Meaning

The Healing Path: A Soul Approach to Healing by Marc Ian Barasch.
Tarcher/Putnam, Los Angeles, 1993;
431 pp, \$22.95 (hb), \$11.95 (pb).

Reviewed by John Anduri, MA, MDiv

In an age of clinical specialists and psycho hucksters, a cancer survivor has explored—in refreshingly humanistic, non-medical guise—a full range of issues that confound, confront, and encourage cancer survivors. Like a kind of Hermes, Marc Ian Barasch in *The Healing Path* guides the reader through the abundant and textured terrain of the soul and its healing, opening a world alive with possibility.

After completing medical treatment for thyroid cancer, Barasch embarked on a 7-year exploration of the meaning of cancer in his life.

Barasch's story is his own, ultimately as private as the experience of pain, but his commitment to describe—instead of pre-scribe—opens his quest for meaning to anyone who has had fundamental questions rekindled by the threat of mortality. In large measure that is because he is unwilling to restrict the range of events that might be germane to the quest, and accordingly, everything turns out to be essential.

Early in the book, Barasch recounts the dreams he had the year prior to his diagnosis. One especially striking image was his "crawling through the dusty bone-filled corridor of an ancient Maya Necropolis." Upon waking, he mused over the "Neckropolis" (a hint, he understood only later, of his impending cancer). But then he was off to work again as *New Age* magazine's editor, a "wired, effusive, light-emitting, 78-rpm version of myself," who eventually workaholicked himself out of anything resembling normal life.

Exhausted, overweight, and captive to a grandiose vision of "building a new national institution," Barasch finally deferred to his girlfriend's insistence that he see a doctor—and

learned he had cancer. (For those of us fervently committed to the cause of cancer survivorship, Barasch's opening confession is a vital reminder, a warning of the hazards of overdoing the things we love.)

After successful treatment, Barasch went prospecting in the experiences of 40 cancer survivors with unusual recoveries. He respectfully relates each story to the fabric and dimension of his "own, still dark interior." His history is thereby rescued from the prison of self-absorption, and becomes a kind of communal deposit, which he mines gently but thoroughly, opening its luminous depths.

Barasch offers provocative observations:

"This book is an exploration of pathways, not a repair model." Thank God for that! The culture of oncology is choking with repair models, most of which fail because they try to provide exclusive answers, and thus narrow the range of questions which ought to be asked.

"Healing is idiosyncratic...[what] heals one person may ravage his/her neighbor; what destroys one life may deliver another from death," Barasch observes.

The medical model too often shoves cancer survivors into Procrustean beds of statistics and standardized levels of What's Normal. Barasch reminds us we each have our own unique story and fingerprint; that, literally, a statistic is about no one. He raises controversial and challenging ideas. "Few [oncologists] address the wider significance of the disease... a system that is willing to trade a mounting toll of misery to maintain a consumer economy."

We need more survivors to serve as "canaries in a coal mine" who don't just chirp or silently succumb, who instead squawk our heads off about a carcinogenic economy producing infinite stuff that pollutes, insults our genetic vulnerabilities and numbs our immunologic cues to what is not healthy. Barasch invites us to harness

and direct all that imploded, repressed energy and anger to challenge the systems that profit from making us sick. As Congresswoman Pat Schroeder said in Denver at our 1991 NCCS Assembly, "N-I-C-E is a four-letter word."

In the epilogue, Barasch indicts his frenetic, pre-cancer lifestyle as "glorified running in place." Seven years later, his "outward velocity has slowed." He turns off the phone in the morning, doesn't skip breakfast, and occasionally misses deadlines. "An imperative to be as truthful as I can manage—however wrenching that might be to relationships, finances, or my own peace of mind" marks a new healing commitment.

Reading *The Healing Path* is itself a healing act, melding one's own survivorship journey to Barasch's compassionate guide for the oncologically perplexed. His is a timely contribution to a literary genre new to human history: reflections on life of, by, and for cancer survivors.

John Anduri, a national speaker on cancer survivorship issues who has made presentations at NCCS Assemblies, can be reached at 303/331-2401.

Wanted: Contact With Someone with the Same Diagnosis

Liz Willett, 629 Ely Ave, Pelham, NY 10803; 914/738-4127; breast cancer recurrence, metastasized to bones.

Judy Stevens, 9075 Brookford Rd, Burke, VA 22015; 703/569-8118; melanoma (metastasized).

Elizabeth Wells, 3856 Neals Mill Rd SE, Dearing, GA 30808; 706/556-9742; cancer of the vulva, had partial vulvectomy.

Mike Draper, 830 S. Ivy, Kennewick, WA, 99336; 509/586-9444; Wadenstrom syndrome.

Thanks for the Memories

It takes many hands, and not a few dollars, to assemble an Assembly. The individuals and organizations shown below donated time, effort, money—and sometimes all three—to make the 1994 NCCS Assembly possible. Thank you all for your generosity!

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