



Norman Schwarzkopf to Lead VIP Slate at NCCS Congress



General H. Norman Schwarzkopf will top a slate of distinguished national leaders scheduled to speak at the First National Congress on Cancer Survivorship, November 11-14, 1995, in Washington, DC. The National

Coalition for Cancer Survivorship (NCCS) will host the event at the Washington Court on Capitol Hill.

Schwarzkopf, a prostate cancer survivor, commanded Operation Desert Storm during the Persian Gulf war. He will likely share his approach to fighting his own cancer through self education about cancer and treatment options and candid communication with his doctor.

Other luminaries scheduled to appear include Richard Klausner, MD, newly appointed director of the National Cancer Institute (NCI), and Michael Milken, founder and director of CaP CURE, the largest private funder of prostate cancer research in the nation.

Dr. Klausner will describe NCI's plans for working with survivorship groups. Milken will share his personal struggle with prostate cancer and his vision for winning the war on cancer. (Profiles of Milken and Gen. Schwarzkopf appear on page 4.)

At press time, NCCS was working
(continued on back cover)

Congress At A Glance

The First National Congress on Cancer Survivorship

November 11-14, 1995

Special Guest Speaker:
H. Norman Schwarzkopf

HOTEL

The Washington Court on Capitol Hill

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\$150 after Oct. 18

One Day:
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\$90 after Oct. 18

Non-Members:
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\$175 after Oct. 18

One Day:
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SPECIAL EVENTS

Cancer Community SpeakOut
Interactive Workshops
Cancer Online Expo presented by the National Cancer Institute

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Listen to Us



Letter from the Vice Chair

Natalie Davis Spingarn

The following has been adapted, with permission, from letters that appeared in the New York Times (July 25, 1995) and The Cancer Letter (July 28, 1995).

The lethal drug overdose administered to my fellow breast cancer survivor and health writer Betsy Lehman at Boston's Dana-Farber Cancer Institute sent shivers down my withered veins—and those of the 8 million Americans who have heard a doctor say “you have cancer.”

Now, with hospital administrators displaying a new openness in admitting to preventable medical errors, we hear calls for change focusing primarily on catching such errors systematically through management techniques and computer systems analogous to those used in industry to control the quality of manufactured products.

As a 21-year survivor of metastatic breast cancer, I am afraid that in our zeal to pinpoint new and necessary NASA-like systems, we may overlook the fact that the system that broke down most completely at Dana-Farber had little to do with microchips. It is one which is more familiar to us cancer survivors than to investigating committees. It is a human non-system really, called patient-doctor communications, and in this case, it had to do with the fact that a distraught Betsy Lehman warned her caretakers repeatedly that something was terribly amiss.

Grossly swollen, vomiting up, as her husband (himself a Dana-Farber scientist) put it, “the lining of her gut,” this 39-year-old mother of two young children called her caretakers' attention to her misery, as did her husband.

Despite her status as a sophisticated, well-known health consumer, doctors and nurses obviously did not take her

complaints seriously. She called a social-worker friend at another hospital and left a frightened message pleading for help. By the time the message was picked up, it was too late.

A “systems” approach to chemotherapy mistakes will not, by itself, prevent future tragedies. Hospitals can establish computerized techniques for ensuring dosage ceilings, disseminate guidelines for drugs with high toxic potential, and design unambiguous physician order forms. We need such systems, of course. But in the end, they will prove ineffective unless they are supplemented by sensitive professional education and on-the-job training in doctor-patient communications.

As medicine becomes more potent and its rewards and dangers more striking, the stakes are getting higher. It's no longer a question of depressed feelings and noncompliance when doctors fail to pay attention. It's a matter of life and death.

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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.

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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Active Communication

Developing skills to better communicate your needs and ideas can improve your relationships with doctors, family and loved ones. Clear and precise communication also carries tremendous value at the workplace and the insurance office.

Workshop choices:

"I Don't Understand: Clear Communication With Your Doctor": You can become your own best advocate by learning more about your diagnosis and treatment options—and by learning to ask the right questions. This session will help you make the most of each consultation with your doctor—and in the process, become an active participant in your healthcare team.

"On the Job: Talking With Employers and Co-Workers": Learn about your employment rights under the Americans with Disabilities Act, the Family Medical Leave Act, and other laws. Pick up helpful pointers about returning to the workplace after a medical leave. Plus, a discussion on looking for employment after a cancer diagnosis.

"Up Close and Personal: Talking About Cancer With Your Loved Ones": If you have cancer and you have a family, you are not the only one affected by your diagnosis. What questions and reactions can you expect from family and friends after diagnosis? How might relationships change, and what can you do to adjust?

"I Don't Think We're in Kansas Anymore: Health Insurance Now": As our society moves into a managed care environment, we need to "learn the lingo" of health insurance in order

to understand this new world—and to protect ourselves. Understand common insurance terms and learn how to support your claim for reimbursement.

"I Have Cancer and I Vote": Don't leave advocacy to "the experts." You can learn how to establish a relationship with your local and national representatives to ensure that the voice of cancer survivorship is heard where it matters.

Survivorship Back Home

This set of workshops offers practical information that you can use in your organization or program back home:

"We Have A Story To Tell: Publicity That Works": How do you conduct successful membership drives? How can you gain publicity for your organization that makes you known in your community—and doesn't eat up all your precious dollars? How can you connect with other organizations to improve services to cancer survivors? If these are your questions, this is your workshop.

"Building Cultural Diversity": The people who most need the empowerment of the cancer survivorship movement are often the least likely to find it. What can cancer organizations do to establish and strengthen ties with diverse cultures and the underserved? Learn how to implement successful intercultural outreach efforts.

"Let's Get Together: How to Host an NCCS Town Hall Meeting": Bring your community together for an NCCS Town Hall meeting. Hear organizers of this year's NCCS Town Halls tell you how they did it—obstacles, challenges, and solutions.

"How to Chart Your Family's Medical History": Forewarned is forearmed.

Learn how to identify potential health risks, the importance of family behavior patterns, and much more in this introduction to the world of genetics.

"Nothing But the Truth: Men and Cancer": An exploration into the informational, emotional and medical needs of men with cancer. Learn the central issues and practical ways to resolve them.

Death and Dying

This cluster opens with a panel session, moderated by NCCS President-Elect Elizabeth Johns Clark, PhD. Panelists: Kenneth D. Miller, MD, Betty Ferrell, PhD (of City of Hope National Medical Center), and Naomi Sterns, MSW. These breakout sessions follow:

"Healing and Spirituality": This workshop follows up on themes from the opening session and NCCS survey, "Words That Heal, Words That Harm."

"Ready to Live, Prepared to Die": Offers guidance on wills, powers of attorney, advance directives, charitable contributions, and more.

"Caring for Care Givers": Focuses on needs of family members, friends, and healthcare providers. Explores the stresses and challenges of caring for someone with cancer, with practical resources for finding support.

"Living with Loss and Uncertainty": Nothing else in human experience compares with the arduous process of letting go of life—or letting go of a loved one to death. This session explores ways to cope with the extreme emotions engendered by loss and uncertainty.

A General Enlists for the War on Cancer

General H. Norman Schwarzkopf U.S. Army, Retired

General H. Norman Schwarzkopf, a prostate cancer survivor since 1994, achieved national and international renown for his service as commander of Operations Desert Shield and Desert Storm. During Desert Storm, he coordinated the efforts of all Allied forces from August 1990 (just after Iraq invaded Kuwait) to August 1991, when he retired from military service.

During his career, he commanded Army units from platoon through

corps level. He served two combat tours in Vietnam and, during the Grenada student rescue operation, served as deputy commander of the joint task force in charge of U.S. forces.

General Schwarzkopf served in other numerous and varied command and staff assignments throughout the United States, Europe, and the Pacific, in places such as Berlin, Alaska, Hawaii, and Washington, DC.

His retirement from military service did not signal a retirement from public service. Quite the opposite. General Schwarzkopf acts as spokesperson for a number of causes, including prostate cancer awareness. And he has proven himself as a compelling speaker, earning Toastmasters International Best Speaker award in 1992.

General Schwarzkopf chairs the Starbright Capital Campaign (for pedi-

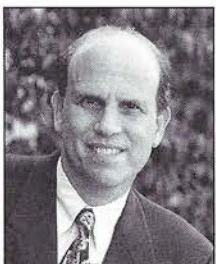
atric pain reduction research). With Paul Newman he co-founded the Boggy Creek Gang, a camp in Florida for children with chronic illnesses. He organized a major nonprofit shooting event, held in Tampa, FL, that has netted over \$1 million for the Miami Project for the Cure of Paralysis.

He has earned numerous awards, including the Presidential Medal of Freedom and the Congressional Gold Medal. General Schwarzkopf was made an honorary private first class in the French Foreign Legion, the only American ever so honored.

It Doesn't Take a Hero, his autobiography, made the best-selling charts in 1992. General Schwarzkopf participated in six critically acclaimed CBS Television specials, including *D-Day*, which won the Peabody Award this year.

A Wall Street Baron Invests in a Cure

Michael Milken Founder, CaP CURE



In 1989, the *Wall Street Journal* described Milken as "arguably the most important financial thinker of the century."

Today, Milken brings to the fight against prostate cancer the same innovative thinking that made him one of the most influential financiers in the nation.

As founder of CaP CURE (the Association for the Cure of Cancer of the Prostate), Milken has launched an effort to accelerate medical research by rapidly funding promising scientific studies, clinical investigations, and biotechnology projects.

In its two years of operation, CaP CURE has become the largest private

funder of prostate-cancer research. So far, the association has awarded nearly \$10 million in grants to more than 70 researchers from 30 institutions worldwide.

CaP CURE's efforts stem from decades of involvement in cancer research, prevention, and treatment by the Milken Family Foundation, which Milken co-founded in 1982 and helped build into one of the largest private foundations in the United States. It has funded projects in education and healthcare and works closely with over 200 organizations and advocacy groups around the world.

The foundation closely focuses on inner cities and minorities, especially minority youth. Its National Educator Awards and Conference has honored more than 750 educators nationwide since the program's inception in 1985.

Milken also chairs the Milken Institute for Job and Capital Formation, where he has brought together top economists and business leaders to study economic growth, job formation, and access to financial capital.

The institute has published numerous monographs and hosted a series of conferences to develop ideas for stimulating the American economy.

Milken's innovations in the world of high finance became a source of controversy in the late 80s. Nonetheless, he played a direct role in building hundreds of companies around the world, in industries ranging from cable and telecommunications to home-building and healthcare. Milken's influence led to spectacular growth for Turner Broadcasting, MCI, and other companies.

"The focus is you're living with cancer rather than dying from cancer," Milken told the *Washington Post* (Sept. 29, 1994). He also made it clear, in the same article, that when it comes to finding a cure for cancer, he means business:

"Time and time where conventional wisdom said it can't be done, the seemingly impossible was accomplished."

Clark: Congress Is "Opportunity to Mobilize"

NCCS President-Elect Elizabeth Johns Clark, PhD, has definite goals for the forthcoming First National Congress on Cancer Survivorship, which she helped organize:

"I hope when NCCS adjourns the Congress we will have a solid agenda to take forward that would help us set priorities. I would also like national awareness of the survivorship movement."

Currently Clark serves as director of diagnostic and therapeutic services at Albany Medical Center Hospital, where she oversees the social work and pastoral care departments, the pharmacy, three laboratories, and nine other departments. She is also an associate professor, teaching part time on campus.

Clark is as sure-minded about her career as she is about her goals for Congress. "My professional career for 25 years has been oncology. I've always worked with people with cancer. A very close family member is a 10-year survivor."

She started out in social work and wanted only to work in hospitals. She opened her career at Presbyterian Hospital in Pittsburgh in the 1970s.

And today she is just where she wants to be. "I like the pace of the medical center," she says. "I like it that Albany has a social conscience. I don't think there's ever been a more challenging time in oncology. I have a crisis personality. I like things fast paced."

In 1989 Clark met NCCS General Counsel Barbara Hoffman at the New Jersey Commission for Cancer Research. Clark was intrigued with the coalition's activities and attended the Assembly in Washington, DC, that year. "I was incredibly impressed and decided to join right away," says



DAVID M. JENNINGS

"It is important for survivors to come and be heard," says President-Elect Elizabeth Johns Clark of the forthcoming Congress. Above: Clark with Chair Fitzhugh Mullan at the Albany Town Hall last summer.

Clark. "I was stirred by the commitment and thoughtfulness of the group. I still feel that way."

She sees that commitment to survivorship reflected in the forthcoming NCCS Congress program: "It's the first time that people with all types of cancer have had the opportunity to mobilize and be heard on a national level. It is important for survivors to come and participate, give NCCS their ideas and direction.

"We always assume we know what survivors need and want. This is the first time we're asking survivors themselves what they want and need on a national level."

Rowland: NCCS Needs "Clear Mandate from Survivors"

"We're in an exciting—and frightening—era of change in healthcare," says Julia Rowland, PhD. "This is a critical juncture. We have to move forward. The psychological and social areas of care are just as important as the medical side. We need to acknowledge that—not just in practice but in dollars."

That's why Rowland, who directs the psycho-oncology program at Georgetown University Medical Center, decided to help organize the

NCCS Congress.

"The capital is the perfect place to do this, where we can bring survivorship issues to the attention of members of Congress. When a constituency group says, 'we demand change,' the political leadership responds. I hope the NCCS Congress produces a clear mandate—from cancer survivors especially—that we can strive to attain in the next five years. And I would hope that that mandate represents the views of our constituency."

Rowland understands the cancer survivorship experience from a personal as well as professional perspective. Two close family members died of cancer, and another has it now.

Her professional involvement dates from 1976. Now, with Patricia Ganz, MD, of UCLA, Rowland is working on a major project. This NCI study—largest ever on breast cancer survivors in America, involving 2,000 women, 1-5 years post diagnosis—will examine the impact of treatment on sexuality and intimacy. First results will be published in spring, 1996. "This study came into being as a direct result of NCCS calling on NCI for more research into survivorship issues," Rowland says.

Rowland started the Memorial Sloan-Kettering Post Treatment Resource Program in 1987. That same year a colleague encouraged her to attend the NCCS Assembly in Albuquerque. "I've been to every Assembly since."

"NCCS helps people break through the isolation, stigma, and fear that come with diagnosis and enables people to connect with each other, to talk with each other, learn from each other," Rowland declares. "I love the central theme of the veteran helping the rookie."

Rowland sees the NCCS Congress as an extension of that commitment: "It's an important opportunity to set an agenda for priorities that need to be addressed in cancer treatment and care. And no one can do this better than survivors themselves."

“That Young Woman Was My Sister”

by Debra K. Thaler-DeMers, RN

This article is adapted from a speech delivered by the author before the Texas Conference on Managed Care on Sept. 16, 1995.

Today, there is a young man in intensive care at my cancer center, who should probably not be there.

His problems started before his diagnosis. For several weeks he had been having increasingly severe back pain. He went to see his primary care provider, who prescribed anti-inflammatory drugs.

The drugs brought no relief, so he returned to his primary care provider, who then ordered physical therapy in the form of traction. No x-ray was taken of his back. The diagnosis was back sprain.

Three months later, he was no better and his wife insisted that there must be something else going on that the physician should check for. She was told that she just needed to take better care of him at home. Again, no x-ray was taken.

The following week, he began to lose strength in his legs. His wife called an ambulance—mostly because she was frustrated with the primary care physician—and brought him to our emergency department.

An x-ray of his back showed three large tumors in the spine, pressing on and almost completely compressing his spinal cord. A medical history showed that he has been smoking since adolescence. A chest x-ray confirmed that the source of the cancer was in his right lung.

Within 24 hours, this man was a paraplegic.

Deadly Report Card?

Unknown to this man and his family, managed-care plans track the number of diagnostic tests a physician orders and sends a report card, comparing him to other physicians in the

managed care plan.

The report card does not analyze whether or not the tests were medically necessary. It just counts the number of tests and their cost. If a physician orders too many tests, he can be “deselected” from the managed care plan. That means his patients must find another physician who is on the provider’s list.

I don’t know if the x-ray of this man’s spine was not ordered because this physician was worried about his “report card” showing too many tests. I do know that had the x-ray been done, even at the time of the second office visit, I would not be assisting this family in explaining the concept of death to their 9-year-old son.

Beware the Gatekeeper

It is essential that, while we continue to attempt to control healthcare costs, we maintain the quality of care that persons with cancer need and deserve. The biggest obstacle managed care of the managed care system is the gatekeeper.

I do not argue with the need for limits to specialized care. However, there are no cancer specialists involved in setting the criteria for referrals in the majority of managed care systems. The National Cancer Institute has repeatedly urged inclusion of oncologists in the decision making process for treatment protocols adopted by managed-care plans.

One of the reasons for the improved survival rates among cancer patients is early detection. This is particularly true for colon cancer, breast cancer, and some lung cancers. It is the primary hope for controlling ovarian cancer. Primary care providers must be able to routinely screen their patients for cancer using the guidelines developed by the National Cancer Institute and the American Cancer Society.

Immediately upon diagnosis, the

person must be referred without delay to a cancer specialist for evaluation and immediate initiation of treatment. Time is of the essence.

If a patient shows symptoms but a definite diagnosis of cancer cannot be made—and it cannot be ruled out—that person also must be immediately referred to a cancer specialist for evaluation and definitive diagnosis.

Cancer treatment frequently requires an interdisciplinary approach. Once the diagnosis of cancer is established, the cancer specialist should become the gatekeeper for further referrals to specialists.

It is time consuming and costly to force the patient to return to the primary care physician for a referral form each time a visit to the oncologist or cancer specialist is needed, or for each subsequent referral to another specialist.

Paperwork Parade

Yet, there are many documented cases of patients having to return to the primary care provider for this referral form—and the primary care provider charging the managed care plan for an office visit for this needless parade of paperwork.

The cancer specialist should also be the gatekeeper for all tests, procedures and treatments. If the person is under the age of 18, or has been diagnosed with a type of cancer that occurs primarily in the pediatric population, he or she should be under the care of a pediatric oncologist.

All cancer patients must have access to trained oncology personnel and to the specialized facilities and treatments they require. The hidden cost not reflected in the analysis of healthcare spending is the cost of time and procedures performed because those personnel treating the person were not trained to detect the signs and symptoms of either the cancer itself, or the

complications of treatment.

If I am caring for a patient on a dedicated cancer floor, I know that the staff will be able to detect subtle changes in a patient that will allow us to avert a potentially life-threatening complication. By preventing such complications we can shorten the patient's stay, maintain their health and avoid costly procedures and medications. Too often, in an effort to save money, we do not look at the long range financial implications of our actions.

The Need for Monitoring

People with cancer must be monitored by cancer specialists following treatment for an indefinite time. Primary care physicians are not trained to detect late effects of treatment, which may occur up to 20 years following treatment.

In addition, some therapies cause long-term effects that must be monitored. It is cost effective for a person with cancer to consult their cancer specialist for the purpose of long-term follow-up care. In fact, consistency of care saves time and costs incurred for duplication of tests and procedures for evaluation.

One survivor of childhood leukemia was not only forced to change oncologists after his initial treatment, but also had to be transported 100 miles for his maintenance chemotherapy because the closest children's hospital with a cancer center was no longer on his healthcare provider's list of approved facilities.

What Are We Saying?

A young boy in Texas was born with a blood disease. His father had worked for more than 20 years for the same company and had just received an award for outstanding service. Shortly after a long hospitalization for the child, the father—and every other employee who had a family member undergoing medical treatment—was fired. During the time that the family was insured by an HMO, they denied coverage of home nursing care. Since the child received medications 24 hours a day, his mother was forced to stay awake all day and all night to ensure that the medications

were given. One medication had to be injected. But coverage was denied for syringes.

This was a family that was working, paying taxes and contributing to society. Eventually the only way they could obtain care for their child was for the father to collect unemployment and food stamps and receive Medicaid benefits for their child.

The HMO's profitability was raised, but at what cost to society? What mes-

**Too often,
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sage are we sending to our citizens?

The next case is very important to me. A 21-year-old woman had just graduated from college. Her employer did not provide health benefits. She awoke one day with a lump in her neck below her right ear. She called me for advice. Knowing her family history, I suggested that she consult an oncologist. Shortly thereafter, she was diagnosed with cancer.

She paid cash for all of her treatments. When she ran out of money, her oncologist refused to continue her care. She applied for Medicaid and set up an appointment at a regional cancer center.

At her first appointment she learned she had pneumonia and required hospitalization for a biopsy. Admission was scheduled for a Sunday. But admission was denied because no Medicaid beds were available. I did a little advocacy work for her and managed to gain her admission.

Hope Postponed

When she failed her first chemother-

apy protocol, she should have been offered a bone marrow transplant. But because she was a Medicaid patient, she was not informed of this option. Instead she endured two further chemotherapy protocols before being informed of the transplant option. By then, it was her only hope for survival.


Again, there was a delay. You see, this center had never performed a bone marrow transplant for her particular disease before, and Medicaid would not approve the transplant despite the center's 30-year history of successful transplants.

Again, I advocated on her behalf. But precious time was lost in the approval process and, ultimately, this young woman died.

Her death profoundly affected my life. You see, that young woman was my sister.

She is the reason I am an oncology nurse. She is the reason I travel around the country educating the public about cancer and the needs of cancer survivors. She is the reason I am here today—to implore you to maintain the quality of care for all persons in the United States, and especially for those with cancer.

Debra K. Thaler-DeMers, RN, is a certified oncology nurse and 15-year survivor of cancer of the lymphatic system. She serves on the NCCS board of directors and heads the coalition's speakers bureau.

 **Cancer
Survivors
Coalition
(NCCS)**

**Remember us
during your
workplace
campaign!**

WHAT'S NEWS

Klausner Takes Helm At NCI

When Samuel Broder, MD, stepped down as director of the National Cancer Institute (NCI), many in the cancer community held their collective breath. Dr. Broder, after all, had established and maintained close ties with the survivorship movement. Would his successor do the same?

Apparently he will. Richard D. Klausner, MD, officially took the helm at NCI on August 1, when he was sworn in by Secretary of Health and Human Services Donna Shalala. Within weeks after the ceremony, he met with NCCS Executive Director Ellen Stovall.

"Cancer survivors have a friend in Richard Klausner," says Stovall. "He brings to NCI an extraordinary scientific mind, strong leadership skills, and an inclusive attitude toward cancer survivors."

Cancer survivors and caregivers will have an opportunity to meet Dr. Klausner at the NCCS Congress in November. Dr. Klausner will speak about his plans for NCI and how he hopes to work with cancer groups.

For the past 10 years, Dr. Klausner was chief of the cell biology and metabolism branch of the National Institute of Child Health and Human Development. He is internationally



"The number you have reached is not in service."

If you tried to call NCCS recently, you may have received that discouraging message. Rest assured, NCCS has not gone out of business.

But we did change our phone system in September. In so doing, we had to also establish a new voice-mail setup. That's where the gremlins crept in. Confusion and chaos reigned for about two weeks as NCCS worked out the glitches with the phone company. During that

time, many callers could not get through and messages were lost.

The phone company eventually corrected the problem, and the system now operates normally.

Our previous phone setup was too cumbersome for the increasing monthly volume of calls, which has bolted from around 400 to about 1,000 in the past two years. The new system, which includes voicemail, will enable staff to respond more efficiently.

NCCS sincerely regrets any frustration caused by the breakdown of the answering service.

respected for his research in immunology, cell biology, and molecular biology.

Dr. Klausner graduated from Duke Medical School in Durham, NC, in 1976. He currently serves as chair of the National Committee on Science Education Standards and Assessment of the National Academy of Sciences.

NCCS to Honor Kennedy and Kassebaum

Senators Edward M. Kennedy (D-MA) and Nancy Kassebaum (R-KS) will jointly receive the NCCS 1995 National Public Leadership Award at the coalition's fall Congress.

A letter from NCCS to the pair declared: "Your strong and ongoing leadership on a variety of health issues, including health insurance reform as well as reform of the Food and Drug Administration, make you ideal recipients of the Public Leadership Award."

The award recognizes the senators for "advancing bipartisan legislation, such as your insurance reform bill, which will provide individuals with cancer with greater access to needed health care."

Boston Globe reporter Richard Knox will receive the Natalie Davis Spingarn Writer's Award for his series of articles on the tragedy at Dana-Farber Cancer

Center, where Betsy Lehman died of an overdose of chemotherapy drugs. (See "Listen to Us," page 2.)

This year's Catherine Logan Award for Service to Survivorship goes to Mary P. Lovato, founder of A Gathering of Cancer Support, a grassroots cancer support program in Santo Domingo Pueblo. The award, conferred on an individual for outstanding contributions to the survivorship movement, honors Lovato for starting the innovative program.

Three Town Halls Set for October

Two NCCS Town Hall meetings took place in September and three more are scheduled for October.

Stanford Health Systems hosted a forum in Stanford, CA, on September 16, and Faxton Hospital Regional Cancer Center hosted another on September 23 in Utica, NY.

The LowCountry Coalition for Cancer Survivorship, an NCCS regional coalition, will convene a Town Hall meeting on October 8 in Charleston, SC. For information, contact Cathy Badger, LCCS president, at 803/766-1926.

In Knoxville, TN, Thompson Cancer Survival Center will conduct a meeting

Reporters Needed

NCCS needs volunteer reporters to cover events at the First National Congress on Cancer Survivorship, Nov. 11-14, 1995, in Washington, DC.

Previous reporting/writing experience helpful but not necessary. Assignments will be made on the first day of the Congress.

If you can help, or if you have questions, please write to *Networker* editor Terrence Campbell at the NCCS office, or leave a message at 301/650-8868.

on October 21. Contact Lisa Prentice, 615/541-1957.

On October 23, Monmouth Cancer Center will host its meeting in Long Branch, NJ. Call Ruth Ann Miller at 908/870-5429.

The first NCCS Town Hall meeting took place at last fall's NCCS Ninth Annual Assembly. On June 3, Albany Medical Center hosted the first regional Town Hall meeting in Albany, NY. Another took place that same day in Burlington County, NJ.

The meetings allow survivors and caregivers to express their ideas and concerns about survivorship issues such as employment rights, insurance problems, and family matters. This information will help form the basis of future advocacy efforts by NCCS.

NCCS Urges Congress: Reform FDA

In an appearance before a House panel last summer, NCCS called on Congress to "act immediately" on basic reforms at the Food and Drug Administration.

Ellen Stovall, NCCS executive director, in testimony before the House Commerce Committee Oversight and Investigations Subcommittee urged three key changes:

- speed up the drug approval process;
- expedite the approval process for biologics; and
- allow for free flow of information on off-label drug use.

While FDA has made "some progress" in accelerating the approval process, Stovall said, "additional steps can and should be taken" to further streamline it. "This is particularly true in the case of products relating to life-threatening conditions, such as cancer ... These products should receive the highest priority," she declared.

Turning to biologics, Stovall asserted that "FDA's current system has not kept pace with developments in biotechnology."

"Many of the most promising new products used in various anticancer therapies are biologics such as interferons and interleukins, which offer new hope for previously untreatable can-

cers," she said. "Unfortunately, because of outdated regulatory requirements, biologics such as these are not available in a reasonably prompt fashion."

What is "most urgently needed," according to Stovall, "is FDA reform legislation that will provide for the free flow of accurate medical information concerning off-label uses of FDA-approved drugs." Insurers arbitrarily deny reimbursement for off-label uses of drugs, even though medical practice widely accepts many such uses.

"Thus," she concluded, "many patients have been denied the value of their insurance coverage by virtue of a reimbursement policy that has its roots in a misguided application by FDA of its authority over labeling."

With such reforms in place, she said, "Americans with cancer [will] have timely access to, and accurate information about, products that can improve the quality of their lives."

NCCS Signs Letter On Breast Implant Safety

Asserting that the Food and Drug Administration "has acquiesced, and to some degree participated, in the creation of a climate of fear surrounding breast implants," three national cancer organizations insisted that the agency publicly declare the relative safety of the devices.

In a letter delivered to the agency, the groups—the Susan G. Komen Breast Cancer Foundation, Y-ME National Breast Cancer Organization, and NCCS—noted that a number of studies have found "no association" between the devices and connective tissue disease.

"With virtually no basis in science," the letter states, "FDA precipitately restricted patient access to silicone-filled implants. This decision by FDA resulted in needless anxiety among women already having the implants."

In August, several members of Congress voiced similar protests in a hearing on the devices. At that hearing, FDA Commissioner David Kessler conceded that recent research shows that implants pose relatively little risk. But he said that questions remain

about their reliability.

The groups also called on FDA to quickly approve substitute products: "FDA could announce use of 'fast track' procedures or other means of facilitating approval of alternative products."

October: Breast Cancer Awareness Month

October 1995 marks the 10th anniversary of National Breast Cancer Awareness Month. The event promotes increased awareness of the importance of breast cancer early detection.

National Mammography Day, October 19, features numerous programs designed to encourage women to get a mammogram. Communities and organizations across the nation will offer a wide variety of other activities focusing on breast cancer awareness.

To get a free promotional kit, contact Y-ME, a sponsor of the observance, at 800/221-2141.

NCCS Advisor Wins Bentsen Award

Grace Powers Monaco, JD, a founder of Candlelighters Childhood Cancer Foundation and a member of the NCCS board of advisors, received the ninth annual Lloyd Bentsen Award in July.

Bentsen, former senator from Texas, presented the award to Monaco during a ceremony at the Candlelighters Childhood Foundation conference in Arlington, VA.

The annual award honors an individual who has made an outstanding contribution to family-centered, community based care for children and families with special healthcare needs. According to the award citation, Monaco was honored for her "relentless efforts to help all children who have suffered childhood cancer."

Monaco helped establish Candlelighters following the death, in 1970, of her daughter, who had leukemia. She founded its Ombudsman Program that year. Candlelighters provides support, education and advocacy for children with cancer.

BULLETIN BOARD

FCCS Goes Online: The Florida Coalition for Cancer Survivorship, an NCCS regional coalition, offers a computer bulletin board service (BBS) for survivors, family members, and healthcare professionals. Through the BBS, users can find cancer and health information, participate in forums on survivorship issues, and post personal stories in its repository.

Currently 560 subscribers use the service. To reach it via your computer modem, call 800/816-2744 (8N1).

Women with advanced cancer: Y-ME National Breast Cancer Organ-

ization wants to interview women with advanced cancer (of any kind) for a new booklet. The publication will provide guidance on dealing with advanced cancer on a daily basis, facing hopelessness, returning to treatment, children, decision making, work, and treatment options.

To participate, call Michelle Melin, director of patient services at Y-ME, 800/221-2141. Call weekdays between 9am and 5pm Central time.

Journal of Health Care for the Poor and Underserved: a peer-reviewed publication featuring original papers,

and letters written by and for health professionals.

Subjects include: changes in Medicare and Medicaid and how they affect healthcare providers and their clients; successful strategies for encouraging healthful lifestyles among the poor and medically underserved; recent innovations by state and local officials to provide quality healthcare to poor and underserved citizens despite federal cutbacks; and more.

Subscriptions (1 year): \$37.80 individuals, \$75.60 institutions. Contact Sage Publications, PO Box 5084, Thousand Oaks, CA 91359. Phone 805/499-0721; fax 805/499-0871.

Events

Healing Legacies: Art and Writing by Women Who Have Faced Breast Cancer, an exhibition to raise awareness about breast cancer, runs Oct. 23-November 19, 1995, at Webster University's Cecille R. Hunt Gallery, St. Louis. Presents 41 works representing 28 artists. Docent-led tours available. Sponsored by Jewish Auxiliary in cooperation with Breast Cancer Action Group of Burlington, VT. For more information, call Elaine Goodman at 314/993-0829.

National Brain Tumor Foundation Conference for Patients and Health Professionals takes place in San Francisco March 8-10, 1996. Guest speaker: Dr. David Spiegel on "Health Caring: An Equal Partnership." Sessions on treatment and research updates. Tracks designed to assist health professionals interact with patients and families. Individual patient consults available with neurosurgeons, neuro-oncologists, rehabilitation specialists, dieticians, pharmacists, and other healthcare professionals. For more information call 800/934-CURE.

Cure for Lymphoma Foundation Inaugural Benefit Dinner, "An Evening with Andrea Marcovicci," will unfold Monday, November 6, 1995 at the St. Regis Hotel in New York City. Honorary Chairman: Matthew Broderick. Silent auction, cocktails, and dinner. Tickets: \$250 each. Call 212/319-5857.

Third Annual Breast Cancer Conference, "After Breast Cancer: Communication, Sexuality and Intimacy," sponsored by Northern California Cancer Center on February 3, 1996 in San Francisco. Goal: to help women, partners, and healthcare providers understand the sexual side effects of breast cancer treatment, develop communication skills, and learn options for managing effects on sexuality.

Topics: Menopause, hormone replacement, genetic risk to children, humor and the immune system, self esteem, cultural differences. Keynote speaker: Leslie Schover, MD, Cleveland Clinic. \$75 per person; limited financial aid available. Call Pam Priest Naeve at NCCC, P.O. Box 5033, 32960 Alvarado-Niles Rd, Suite 600, Union City, CA 94587; phone 510/429-2500; fax 510/429-2550.

Wanted: Contact With Someone with the Same Diagnosis

Kathleen Rae Eldrid, RN, 10 Mt. Pleasant St, Biddeford, ME 04005; 207/282-2050. Primitive Neuroectodermal Tumor (PNET) 2 years.

Kimberly A. Stoliker, 173 Middletown Rd, Waterford, NY 12188. Inflammatory breast cancer; seeks longterm survivors who had high dose chemo and bone marrow transplant.

Joan Avant, Box 9, Dilley, TX, 78017. Metastatic breast cancer to the lung; seeking longterm survivors.

Janet Ross, 426 Garfield Ave, Troy, OH 45373. Breast cancer with metastatic pleural effusion.

Joyce Graff, 171 Clinton Rd, Brookline, MA 02146; 617/232-5946. Mother of 24-year-old son with von Hippel-Lindau disease (VHL), with retinal and kidney tumors; seeks other families with VHL.

Helen Samuels, 3535 Heron Dr S, Jacksonville Bch, FL 32250; 904/246-6325. Myocardial fibrosis; had congestive heart failure due to radiation damage.

BOOK REVIEWS

Stopping Cancer Before It Starts

Cancer Free: The Comprehensive Prevention Program by Sidney J. Winawer, MD, and Moshe Shike, MD, with Philip Bashe and Genell Subak-Sharpe. Simon & Schuster, New York; 416 pp; \$25.

Reviewed by Natalie Davis Spingarn

Prevention is probably the most seductive word in health care policy circles today, implying, at most, a one-shot investment producing a miracle vaccine, at least a simple do-it-yourself fix to avoid miserable, costly disease. After all, weren't we all brought up to believe that an ounce of prevention is worth a pound of cure? And isn't it easier and cheaper to advise people to jog and diet—above all to stop smoking—than to find ways to make them change their behavior, let alone treat them with X-rays, surgery, and complex drugs once they are sick?

Here's *Cancer Free* (what a hyped title!), a healthy person's comprehensive guide to preventing one wicked disease. If you read it carefully, you will find its authors well understand the behavioral and social quandaries involved in such questions, as one would expect of physicians associated with one of the world's preeminent cancer centers, Memorial Sloan-Kettering.

To their credit, Drs. Winawer and Shike do not guarantee that you will never contract cancer, even if you follow their primary prevention advice (most of it familiar to anyone on a stay-healthy kick): Go heavy, for example, on fruits and veggies, light on the booze and run as far and fast as you can from carcinogens (notably tobacco). They do not even claim that effective secondary prevention tests such as colonoscopy will dramatically lower health costs.

What they do claim is that "most men and women" can reduce their odds of getting cancer by half. You can

try to become one of the lucky by following their step-by-step practical guides to designing a personalized cancer prevention program. It's sort of a game plan in which you decide how to take advantage of state of the art screening in light of your own cancer risks (as judged by your heredity, prior health condition, environment, and lifestyle).

The authors make your job easier by offering a vast amount of information gleaned from experts at Sloan-Kettering, walking you through it with a multitude of clear, user-friendly charts, lists, forms, and questionnaires. The first chart tellingly shows that diet and tobacco, both "something we have the power to control," together cause 65 percent of the more than 500,000 American cancer deaths each year.

In a primary prevention section, you learn how you can develop building blocks of a cancer prevention program, identifying, modifying, or eliminating not only your lifestyle, but your environmental risks. If your family has experienced cancer (how rare is the family that has not!), you'll find the heredity and family history "building blocks" chapters particularly useful. Here you see exactly which cancers can be inherited (i.e. colorectal, breast, ovarian or prostate), and what diseases and conditions (i.e. late menopause or no children for breast cancer) may indicate a heightened risk. Then you find out how to gather the facts about your family's cancer history, draw a family tree, and estimate your risk.

This risk can be compounded by your everyday habits. With the exception of giving up tobacco and purging your home of radon and workplace of asbestos, you probably thought you were out there jogging or cutting down on scotch and stress simply to stay slim and make your heart pump longer and stronger. Not so, say the authors; you're avoiding cancer, too. Their detailed lists of what foods contain which vitamins and how much fiber, sample menus, recommended cookbooks and strategies for safe sunning

habits and giving up smoking leave little to chance.

Perhaps because the evidence is less clear, *Cancer Free* has less to say about the smaller "lifestyle" cancer risks, like excessive alcohol use, although "alcohol and tobacco together produce a synergistic effect."

Winawer and Shike's prescription: Combine their primary prevention (live healthy) advice with medical surveillance or secondary prevention. Modern screening examinations and diagnostic tests can pinpoint cancers early, when most are still localized and about 90 percent curable.

In *The Lives of a Cell*, the late Lewis Thomas, the remarkable physician-poet who headed Memorial Sloan-Kettering Cancer Center in the 1970s, wrote that diseases which, like death, still exist and cannot be hidden, "do not develop just because of carelessness about the preservation of health." Most diseases, especially the major ones, he contended, are "blind accidents that we have no idea how to prevent." So we are not likely to be good at preventing disease or preserving health until we have learned a great deal about disease mechanisms.

The world of biomedicine has turned over many times in the ensuing quarter century. We have learned enough, particularly in the exploding field of genetics, to put a book like *Cancer Free* to good use. Indeed, all of us know people who have followed the sort of advice it gives, and fallen ill with cancer anyway (and vice versa); the time has come to worry less about the inevitability of disease than how to develop ways of persuading people to use the preventive knowledge we do have, and to provide preventive tools appropriately to everyone who needs them.

Natalie Davis Spingarn is vice-chair of NCCS and former editor of the Networker. This review first appeared in the Washington Post Health magazine, August 1, 1995. Reprinted and adapted with permission.

Norman Schwarzkopf to Lead VIP Slate at NCCS Congress

(continued from page 1)

with Hillary Rodham Clinton's staff to arrange an appearance by the First Lady. Mrs. Clinton is honorary chair of the NCCS Congress.

Call to Action

The presence of such prominent national leaders promises to galvanize the event (much as Sandra Day O'Connor's appearance did at last year's Assembly).

But cancer survivors and caregivers will deliver the real highlight of the Congress themselves, as they debate survivorship issues and create an agenda for advocacy toward the year 2000.

Delegates (which includes all NCCS members present) will form working groups to discuss NCCS briefing papers on quality cancer care, long-term and late effects, psychological and social needs, and employment issues.

Taking center stage on Monday evening, Nov. 13: a general debate on "What Should Quality Cancer Care Look Like in the Year 2000?"

Following the debate, Congress delegates will vote on an NCCS Declaration that will spell out the rights and needs of cancer survivors.

Using an interactive format, Congress workshops will allow for more participation than ever before. These sessions will explore active communication, community organizing, and death and dying. A general session will also explore coping with loss and grief. Other plenaries will examine cancer prevention, long-term and late effects, and psychosocial needs. (For details on workshops see page 3.)

Other Congress highlights include:

- high-tech information fair sponsored by the National Cancer Institute;
- community programs poster display depicting successful grassroots and institutional cancer programs;

- the story of Expedition Inspiration, presented by breast cancer survivor Annette Porter;
- joint reception with the American Society of Clinical Oncology, a longstanding supporter of NCCS;
- the popular NCCS Book Fair, offering a wide selection of high quality books on cancer survivorship.

Despite the dynamic agenda, the NCCS Congress allows plenty of time for relaxing, networking, catching up with old friends, or sight-seeing in the nation's capital. All told, the NCCS First National Congress on Cancer Survivorship marks a pivotal point in our history, as the coalition launches into our 10th anniversary.

NEXT ISSUE:

Complete coverage of the First National Congress on Cancer Survivorship



National Coalition for Cancer Survivorship

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