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August 29, 1997

Mr. Jerry Mande
Office of the Vice President
Science and Technology Office
Old Executive Office Building
Washington, DC 20501

Dear Mr. Mande:

Toby Donenfeld asked that I forward this information to you in advance of your meeting with NCCS Executive Director, Ellen Stovall, which is scheduled for September 9, 1997 at 3:30 p.m.

Founded of, by, and for cancer survivors, NCCS is the largest grassroots network of individuals and organizations working on behalf of people with all types of cancer. Its mission is to lead and strengthen the survivorship movement, to empower cancer survivors, and to advocate for policy issues that affect cancer survivors' quality of life.

Over the past decade, NCCS' leadership in public policy has earned it the reputation of being a convener of cancer organizations and a broker of good policy information. In 1993, under Ellen's direction, NCCS founded the Cancer Leadership Council (CLC) to develop a consensus on health care policies as viewed from the cancer patient's perspective. In 1996, NCCS worked collaboratively with cancer survivors and their caregivers including family members and friends, health care professionals, scientists, business and community leaders, policy experts, legislators, government officials, members of the clergy and the media to define quality cancer care. This definition is described in NCCS' publication, *Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability*.

Today, NCCS is leading a public awareness and grassroots education campaign designed to make cancer a matter of national priority. The campaign is called *The March... Coming Together to Conquer Cancer* will bring together survivors, families, friends, care givers, and anyone who is willing to work together to lessen the burden of this disease.

I enclose some materials so that you may become familiar with the quality and focus of the work we do at NCCS. Please find the following items for your review in advance of your meeting with Ellen Stovall, which is scheduled for September 9, 1997 at 3:30 p.m. at your office:

1. A copy of NCCS' most recent publication, *A Cancer Survivor's Almanac: Charting Your Journey*. A comprehensive guide addressing physical, psychosocial, employment, and insurance issues those dealing with a cancer diagnosis face.

Jerry Mande
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2. A copy of NCCS' *Imperatives for Quality Cancer Care: Access, Action, Advocacy and Accountability*-- a comprehensive view of many experts within and outside the cancer community of what cancer care needs to be as we move increasingly to a national model of managed health care. NCCS has taken leadership in this area and has convened and participated in many meetings with the National Cancer Institute (NCI), the American Cancer Society (ACS), the Centers for Disease Control (CDC), the Health Care Financing Administration (HCFA), major provider groups and professional societies, the National Committee on Quality Assurance (NCQA), the Health Plan Employers Data Information Set (HEDIS), the Foundation for Accountability (FACCT), and Congressional leaders, to garner broad-based support for these imperatives. Our goal is to ensure these imperatives are incorporated into health care plans as managed care continues to enroll more and more people into their system to diagnose and treat individuals with cancer.

After thoughtful and careful review of NCCS' *Imperatives for Quality Cancer Care* last December, National Cancer Institute Director, Dr. Richard Klausner, announced his intention to create a new office within the Division of Cancer Treatment known as the Office of Cancer Survivorship (OCS). In a Rose Garden ceremony, President Clinton announced November 1, 1997 as the official opening day of this office.

3. Materials about the NCCS Ribbon of Hope™; general information about NCCS including our most recent, as well as some past issues, of our newsletter, *The Networker*; some press clippings; a list of some of our accomplishments; and our 1995 Annual Report.

Again, thank you for your interest in NCCS. I know Ellen is looking forward to your meeting.

Sincerely,

A handwritten signature in cursive script that reads "Donna Doneski".

Donna Doneski
Assistant to the Director

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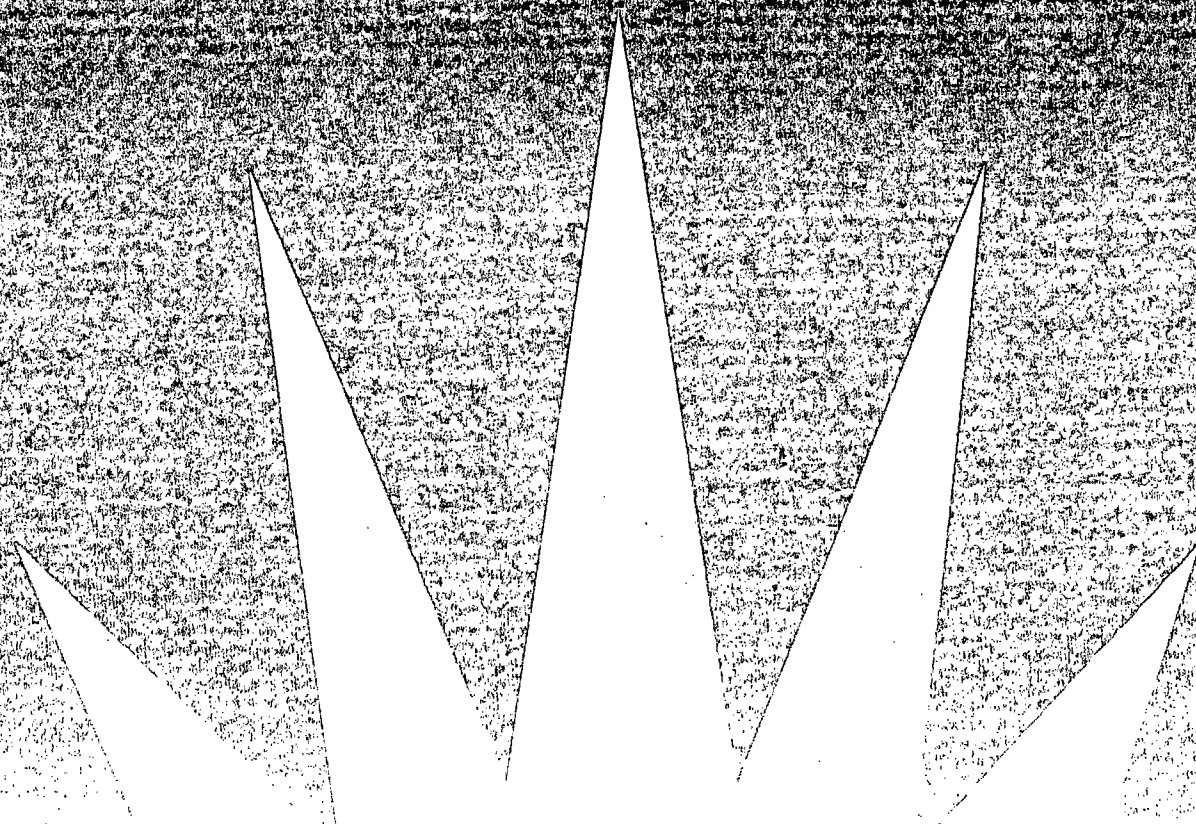
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IMPERATIVES FOR QUALITY CANCER CARE:

ACCESS, ADVOCACY, ACTION,
AND ACCOUNTABILITY

A large, stylized sunburst graphic composed of several white triangular rays pointing upwards, set against a dark, textured background.

*Adopted at the First National Congress on Cancer Survivorship
November 13, 1995*

JOIN NCCS ANNUAL MEMBERSHIP

Name _____
Street _____
City _____ State _____ Zip _____
Daytime Phone (____) _____
Organization (if any) _____

I (circle one) do/do not want to receive research surveys.

INDIVIDUAL

- ☐ \$35 – Regular (Those unable to pay may join for the amount they can afford.)
☐ \$65 – Sustaining
☐ \$100 – Physician-friend

ORGANIZATIONS

- ☐ \$65 – budgets less than \$150,000
☐ \$125 – budgets of \$150,000 – \$1 million
☐ \$250 – budgets more than \$1 million

INSTITUTIONS

- ☐ \$200 – budgets less than \$1 million
☐ \$350 – budgets more than \$1 million

☐ I would like to make an additional donation of
\$500 \$250 \$100 \$50 other: \$ _____

In honor/memory of: _____

Please send acknowledgment to: _____

PAYMENT INFORMATION

Membership	\$ _____
Donation	\$ _____
Publications	\$ _____
Total	\$ _____

Please charge my _____ Visa _____ Mastercard

Card# _____

Expiration Date _____

Signature _____

Billing Name (print) _____

Please make checks payable to NCCS. Mail to: NCCS,
1010 Wayne Avenue, Suite 505, Silver Spring, MD 20910

NCCS is a 501(c)(3), tax-exempt organization.

ABOUT NCCS MEMBERSHIP

Thousands of individuals and more than 350 cancer-related organizations and institutions support NCCS' work through memberships and donations.

NCCS members include:

- * Cancer survivors — people of all ages — diagnosed recently or years ago
- * Friends and loved ones
- * Healthcare providers
- * Support, survivorship, and professional organizations and agencies
- * Research and medical centers

As an individual or organization, you can benefit from, participate in, or contribute to NCCS' work. Your membership or contribution will support critical NCCS services to and advocacy for cancer survivors. Members also receive the NCCS quarterly *Networker*, policy alerts, NCCS publication discounts, and advance notice of special events.

NCCS AND CANCER SURVIVORS STILL
FACE ENORMOUS CHALLENGES.

IN THE FUTURE, NCCS MUST:

- * Raise awareness of cancer as the #1 public health issue
- * Fight for universal access to quality healthcare and promote health insurance reform
- * Expand our national network of organizations and resources to assist the growing number of survivors in need
- * Ensure that our *Imperatives for Quality Cancer Care* become the standards of care for every person diagnosed with cancer in the nation

*In the presence of hope,
anything is possible.*

— Ellen Stovall
25-year cancer survivor,
NCCS Executive Director

National Coalition for
Cancer Survivorship
1010 Wayne Avenue, Suite 505
Silver Spring, MD 20910
phone: 301-650-8868
fax: 301-565-9670
web site: <http://www.access.digex.net/~mkragen/cansrch.html>



NATIONAL COALITION FOR CANCER SURVIVORSHIP

*A mission I'm proud
to be a part of.*

— General H. Norman Schwarzkopf
U.S. Army (retired) and cancer survivor

N C C S

N C C S

YOU ARE NOT ALONE

Life after a cancer diagnosis is a concern and a reality for more than 7 million American cancer survivors.

Each day cancer survivors, their families, their friends, and care givers face the challenge of living with, through, and beyond cancer.

CANCER TURNS LIVES UPSIDE DOWN.

Suddenly everything you took for granted has changed. Your body. Your relationships. Your finances. Your job. Your life.

WE KNOW. WE'VE BEEN THERE.

Founded 10 years ago of, by, and for cancer survivors, the National Coalition for Cancer Survivorship (NCCS) has grown into the largest network of independent organizations and individuals working in the area of cancer support and information.

NCCS has become a respected voice for people with all types of cancer.

THE NATIONAL COALITION FOR
CANCER SURVIVORSHIP (NCCS)
ACTS AS A CLEARINGHOUSE AND
HELPS CANCER SURVIVORS,
THEIR FAMILIES, AND FRIENDS:

- Find local support groups
- Start a group where none exist
- Learn health insurance options
- Prevent employment bias
- Obtain healthcare news
- Speak out on cancer policy

PLUS, NCCS:

- Testifies before Congress and other national, state, and local policymakers on the survivorship experience
- Produces the *Networker*, our quarterly newsletter, and other publications on survivorship issues
- Convenes NCCS Town Hall Meetings on cancer-related issues throughout the U.S.
- Maintains CanSearch™, a cancer survivor's guide to Internet information that can be accessed through any search engine or at <http://www.access.digex.net/~mkragen/cansearch.html>

*From the time of discovery
and for the balance of life,
an individual
diagnosed with cancer
is a survivor.*

– NCCS Charter

NCCS MAJOR ACCOMPLISHMENTS TO DATE:

- Changed how cancer is perceived in this country; once called "victims," thanks to NCCS, people with cancer are now more frequently known as "survivors"
- Ensured cancer survivors are covered by the landmark Family and Medical Leave Act and Americans with Disabilities Act
- Developed *Imperatives for Quality Cancer Care*, which set standards for medical care for cancer survivors
- Inspired the National Cancer Institute to establish its new Office of Cancer Survivorship
- Provided urgently needed information to thousands of cancer survivors and their supporters
- Produced publications written from the survivor's point of view, which have provided information and inspiration to thousands more

NCCS PUBLICATIONS: SELECTED FAVORITES

- ☐ *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*, single copy FREE
- ☐ *Working It Out: Your Employment Rights as a Cancer Survivor*, single copy FREE
- ☐ *What Cancer Survivors Need to Know About Health Insurance*, single copy FREE
- ☐ *A Cancer Survivor's Almanac: Charting Your Journey*; 325 pages, \$18.95 + \$4.00 shipping/handling. New edition of NCCS' most popular publication. Filled with timely advice. Written by 13 of the country's leading cancer survivorship experts. Provides essential up-to-date practical information and an expanded resource section.
- ☐ *You Have the Right to Be Hopeful* by Elizabeth J. Clark, PhD., NCCS President; 28 pages, \$5.00. Examines cancer and the benefits of hope. Learn why "There is no such thing as false hope."

Please make checks payable to NCCS and mail with this completed form to: NCCS, 1010 Wayne Avenue, Suite 505, Silver Spring, MD 20910.

- ☐ Please send NCCS' complete publication/video catalogue (includes quantity discounts).
- ☐ Please send the NCCS general information packet.

(For membership information, please see reverse)



NCCS VISION, MISSION & GOALS

VISION

NCCS's vision is that all cancer survivors and all those affected by cancer in their lifetime, will know as much as possible about their options for living the best quality of life following a diagnosis, and that they all will have equal opportunity to access treatment and support.

MISSION

The mission of the National Coalition for Cancer Survivorship (NCCS) is to lead and strengthen the survivorship movement, to empower cancer survivors, and to advocate for policy issues that affect cancer survivors' quality of life.

GOALS

NCCS's goals are to identify and address the needs of long-term cancer survivors, and to advocate for change in health care delivery and policy to maximize survivors' access to optimal treatment and support.



**National
Coalition for
Cancer
Survivorship**

1010 Wayne Avenue
Silver Spring, MD 20910
301-650-8868
FAX 301-565-9670

1996 HIGHLIGHTS

A handful of visionary cancer survivors founded the National Coalition for Cancer Survivorship (NCCS) in 1986. Since then, NCCS has become the largest network of organizations and individuals serving people with all types of cancer. Thousands have benefitted from NCCS referrals, education, and advocacy.

In 1996, NCCS empowered survivors with information, spoke out on vital survivorship issues before our nation's leaders, expanded public awareness of cancer survivorship, and played a leadership role in the survivorship movement.

Empowered cancer survivors with information

- **Handled over 10,000 requests**--more than 900 phone calls a month--for information and guidance on employment and insurance issues, treatment options, and support and information resources.
- **Expanded our internet site**--NCCS' Cansearch enables users to leapfrog to hundreds of cancer information sites. Address: <http://www.access/digex.net/~mkragen/cansearch.html>
- **Developed major action plan: *Imperatives for Quality Cancer Care***, a strategy addressing quality cancer care, long-term consequences of cancer treatment, and psychosocial care for people with cancer.
- **Published *A Cancer Survivor's Almanac: Charting Your Journey***--NCCS' most comprehensive publication provides essential, practical information on nearly every aspect of the cancer experience.

Spoke out on vital survivorship issues

- **Helped create the Office of Cancer Survivorship at the National Cancer Institute.** The Office studies longterm and late effects as well as psychosocial effects of cancer. NCCS serves on the Office's advisory board.
- **Voiced survivors' needs at Congressional insurance reform hearings** leading to new law protecting insurance coverage for people who lose or change jobs.
- **Helped develop important bipartisan legislation**, introduced by Senators Jay Rockefeller (D-WV) and Connie Mack (R-FL), for Medicare coverage of clinical trials.
- **Urged improvements of FDA regulatory process**--sparked FDA renewed commitment to broader availability of cancer diagnostics, treatments, and new technologies.
- **Received appointment to the National Cancer Advisory Board** when President Clinton named NCCS Executive Director Ellen Stovall to that top-level panel.

- Received Special Recognition Award from the American Society of Clinical Oncology (ASCO) for "exemplary contributions" to the field of oncology and to people with cancer.

"For bringing cancer survivorship to the health care debate ... for giving new meaning to the words cancer survivorship, ... the American Society of Clinical Oncology (ASCO) presents the National Coalition for Cancer Survivorship with ASCO's Special Recognition Award."

—John H. Glick, MD
President of ASCO
May, 1996

Expanded public awareness

- Built awareness of survivorship issues with the NCCS Ribbon of Hope™--President Clinton signed the Ribbon in the Oval Office, as did Hillary Clinton during our First National Congress on Cancer Survivorship. Other notable leaders who signed in 1996 include Elizabeth Dole and Gen. H. Norman Schwarzkopf. Signed by thousands of cancer survivors and their supporters throughout the year, the Ribbon's rays formed a large radiant sun when displayed at NCCS' 10th Anniversary Assembly.
- Released television announcement featuring Gen. H. Norman Schwarzkopf urging people with cancer not to go it alone, but join with fellow survivors to battle cancer.

Played a leadership role in the survivorship movement

- Convened, led, and joined collaborative efforts among major cancer organizations on a wide range of vital issues.
- Continued successful NCCS Town Hall Meetings™ program where thousands of survivors, caregivers, and community leaders in 11 cities across the country met to discuss cancer-related issues.
- Spearheaded formation of model cancer survivorship programs to reach minority populations through grants to successful grassroots minority outreach cancer support programs that can serve as prototypes for other communities.
- Celebrated 10th anniversary and showcased successful cancer peer support, information access, and networking programs at NCCS' 10th Anniversary Conference "Of, By, and For Cancer Survivors," in Albuquerque.

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President Clinton signs NCCS Ribbon of Hope



THE WHITE HOUSE

President Bill Clinton signs the NCCS Ribbon of Hope™ and calls it "a symbol of the progress we have made and the progress still to come." Survivorship leaders present include (far right) NCCS President Betsy Clark and NCCS director Ellen Stovall (next to Clark). Also on hand (l-r): Jane Reese-Coulbourne, executive vice president, National Breast Cancer Coalition; cancer survivor Olda Mondragon; cancer survivor Erin Schraibman; Harold Varmus, MD, director, National Cancer Institute; Dorothy Bankhead, cancer survivor; Richard Klausner, MD, chief of the National Cancer Institute; Fran Visco, head of the National Breast Cancer Coalition; Stephen Joseph, MD, Assistant Secretary of Defense for Health Affairs; Susan Blumenthal, MD, director, Office of Women's Health, Dept. of Health and Human Services; and Patrick Garbe, cancer survivor.

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NCCS spotlights 4 groups as models for the cancer community

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Learning from Lerner

Michael Lerner talks about complementary therapies, and the story of Bill's cat

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New gains for survivors

The President announces big gains for survivors, and appoints NCCS' Stovall to national cancer post. And Gen. Schwarzkopf's PSA on NCCS hits television airwaves.

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"A fighting chance"

Ellen Stovall on the tools needed to make a real difference in dealing with cancer

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Plus: reviews, resources, and more

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Special report: the cancer bill

A bipartisan bill calling for Medicare coverage of clinical trials makes its way through the Senate.

A 4-page package on the bill's provisions, why we need it, and a meeting between advocates and Senate staff.

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Speaking up on talk radio

It's showtime. With a huge audience and an entertaining format, talk radio makes a terrific forum for cancer advocates. Here's how to prepare to make airwaves.

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The new insurance law

The Kennedy-Kassebaum act makes it easier for workers to protect their insurance coverage in a job hop

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How to choose a peer-support group

Veteran survivor and advocate Catherine Logan-Carrillo offers practical advice on where to look and what to look for. An excerpt from the new NCCS Almanac

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NCCS debuts *Cancer On Trial*

A new NCCS publication looks at how the courts are handling cancer-discrimination cases

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Healing mind and spirit at the kitchen table

Award-winning author Arthur Frank reviews *Kitchen Table Wisdom*, and physician-survivor Wendy Harpham heralds a video on talking to kids about cancer

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PLUS: stories on grassroots groups, *Advocacy Update*, and a listing of resources on our Bulletin Board