

Pioneering Survivorship

20 Years of Advocating for Quality Cancer Care



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.



The power of survivorship. The promise of quality care.

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NCCS Milestones

1986

23 leaders with expertise in cancer research, community-based cancer support programs, cancer information services and cancer advocacy gathered in Albuquerque, New Mexico and founded the National Coalition for Cancer Survivorship (NCCS). The founders adopted NCCS's charter stating, "from the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor." This definition would go on to be accepted as the standard in the cancer community.

1990

NCCS contributes language on workplace discrimination to the Americans with Disabilities Act (ADA).

1995

NCCS hosts the First National Congress on Cancer Survivorship of more than 300 experts including cancer survivors, caregivers, health care professionals, scientists, community leaders, policy experts, legislators, government officials, members of the clergy, and the media. The forum is the first-ever meeting on cancer survivorship of its kind.

NCCS launches one of the first Internet sites directing users to credible online resources on cancer treatment and survivorship - CanSearch™.

NCCS receives one of two consumer representative positions on the newly established National Cancer Policy Board (NCPB), which operates under the auspices of the Institute of Medicine. The NCPB's role is to evaluate the United States cancer program and related policy making.

1998

The March...Coming Together to Conquer Cancer™ - NCCS launches the first-ever national public awareness and grassroots organizing campaign on CNN's Larry King Live. On September 25-26, 1998, 250,000 people gather on The National Mall in Washington, DC and a million more join 200

2004

NCCS launches *Cancer Advocacy Now!*™, a grassroots legislative advocacy network that is directed at public policy issues affecting cancer survivors at the federal level. *Cancer Advocacy Now!* recruits almost 25,000 advocates from across the country by 2006.

2005

Distribution of the *Cancer Survival Toolbox*® to survivors across the country surpasses 500,000 since its introduction. *Toolboxes* have been distributed to individuals and cancer centers in all 50 states, the District of Columbia, and Puerto Rico.

1993

NCCS contributes significantly to the drafting and passage of the Rockefeller-Levin Medicare Cancer Coverage Improvement Act, which provides Medicare coverage for oral forms of existing intravenous (IV) anti-cancer drugs and gives patients an important quality of life choice in how they choose to receive cancer treatment.

NCCS founds the Cancer Leadership Council (CLC), a patient-centered forum of national advocacy organizations addressing public policy issues in cancer, by convening the 8 existing cancer patient advocacy groups. By 2005, the CLC has grown to include 31 leading patient advocacy, professional, and volunteer organizations.

1996

NCCS publishes the *Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability*, the first document to address quality cancer care from the patient's perspective (based on the First National Congress on Cancer Survivorship in 1995).

After reading NCCS's *Imperatives for Quality Cancer Care*, then NCI Director, Dr. Richard Klausner establishes the Office of Cancer Survivorship at the National Cancer Institute to encourage survivorship research.

NCCS contributes significantly to the drafting and passage of the Kassebaum-Kennedy Health Insurance Portability & Accountability Act (HIPAA) that gives patients changing jobs some measure of security regarding maintaining insurance benefits and continuity of care.

events in all 50 states calling for better funding for cancer research and access to quality cancer care for all Americans. Days later, Congress awards a 16% increase in National Cancer Institute (NCI) funding — then the largest monetary increase in funding for NCI to date.

2000

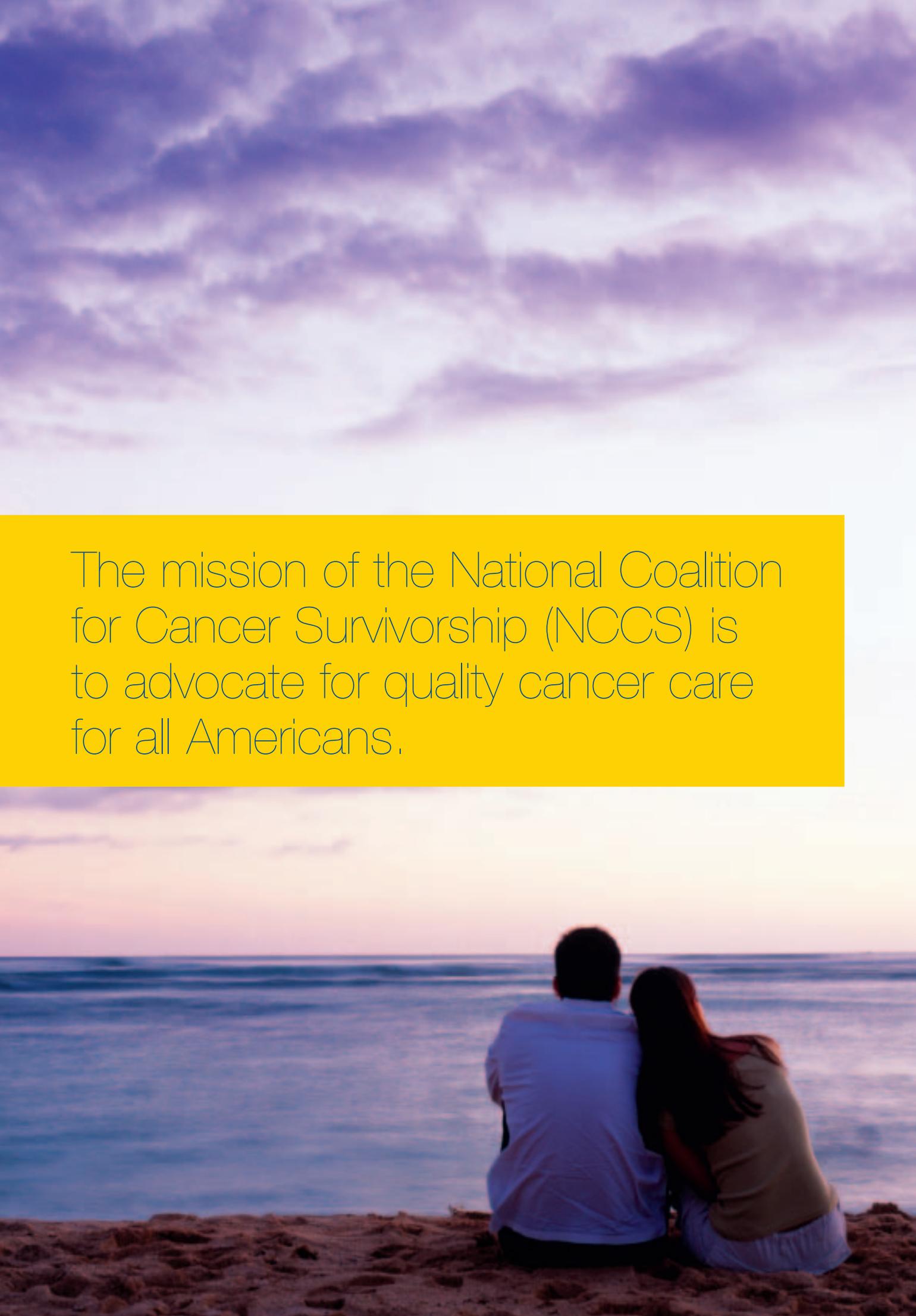
President Clinton's issuance of an executive memorandum on June 7, 2000 was directly attributable to NCCS's advocacy. This new policy guarantees Medicare beneficiaries who enroll in approved, high-quality clinical trials will have their routine patient care costs covered by Medicare.



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A couple is seen from behind, sitting on a sandy beach and looking out at the ocean. The sky is filled with soft, purple and pink clouds, suggesting a sunset or sunrise. The water is calm with gentle waves. The couple is positioned in the lower right quadrant of the frame, with the man on the left and the woman on the right. A bright yellow rectangular box is overlaid on the upper half of the image, containing text.

The mission of the National Coalition for Cancer Survivorship (NCCS) is to advocate for quality cancer care for all Americans.

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Dear Friends

The year 2006 marks two decades by the National Coalition for Cancer Survivorship (NCCS) to inform, educate and empower individuals, and to advocate on their behalf with organizations, institutions, and our nations' leaders about the complex issues facing cancer survivors. We are very proud of what we have accomplished and acutely aware of the challenges in front of us.

When NCCS was founded in 1986, *cancer survivorship* was a term of art not of science. The words *cancer survivorship* did not appear anywhere in medical or scientific literature. Today we have a burgeoning field of cancer survivorship research and an Office of Cancer Survivorship (OCS) at the National Cancer Institute (NCI), due largely to our advocacy.

Moreover, when the founders of NCCS were coming up with the words to describe someone with a diagnosis of cancer, the term "survivor" was largely relegated to someone who had remained cancer-free for five years or more. Today the generally accepted definition of survivor is the definition given to it by NCCS founders: *from the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor.*

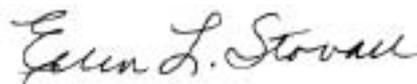
In addition, when NCCS was founded it was the first organization *created by* cancer survivors, *for* cancer survivors, and *led by* cancer survivors. Today the cancer community has grown to include hundreds of organizations whose mission includes advocacy on behalf of survivors of various cancers.

The intent of this year's annual report is not to congratulate ourselves for contributing to the birth of the survivorship movement. Rather, it is to let you know the key to NCCS's success has been the ability of its committed board and staff to always look forward – to continue a 20-year tradition to tackle some of the most difficult issues and barriers that are found in our health-care system.

For that reason, in 2005 NCCS was asked to co-edit a groundbreaking report from the Institute of Medicine (IOM), *From Cancer Patient to Cancer Survivor: Lost in Transition*. The report followed an exhaustive review of research that detailed the consequences of cancer and its treatment. And the results were troubling. The IOM's Committee on Cancer Survivorship concluded that the long-term and late effects affecting survivors are extensive. The good news is that there is much that can be done to mitigate or, in some cases, even prevent these effects. NCCS views many of the IOM recommendations as a basis for substantiating NCCS's public policy and patient education agenda moving into the next decade and beyond.

In the pages that follow, you will learn more about the work of NCCS over the past two decades and the challenges we face moving forward. From the founders to the current Board and staff, the leadership by those who have supported this organization over the last two decades has indeed laid the foundation for the important attention cancer survivorship is garnering today. And each day, we commit our work to every individual diagnosed with cancer, to their families and caregivers, to the survivorship movement, and to our very serious mission to advocate for quality cancer care for all Americans. It is our resounding hope that someday every individual who is diagnosed with cancer will live a rich and productive life that is free of pain and debilitating effects. Until such time, NCCS will invest in the power of survivorship to fulfill the promise of quality care.

Sincerely,



ELLEN L. STOVALL

President & CEO

34-Year Cancer Survivor

NCCS Founders

JULIE BECKER

CancerShare
Cincinnati, Ohio

HAROLD H. BENJAMIN

The Wellness Community
Santa Monica, Calif.

PEGGIE CAREY

Life After Cancer – Pathways, Inc.
Asheville, N.C.

HELEN CROTHERS

ACS, California Division
Oakland, Calif.

NEIL A. FIORE

Psychologist, Author
Albany, N.Y.

PATRICIA GANZ, M.D.

Oncologist
UCLA Rehabilitation Project
Los Angeles, Calif.

BARBARA HOFFMAN

Cancer Patient's Employment Right's Project
Philadelphia, Pa.

AL HIAT

Psychologist
Albuquerque, N.M.

ALICE HIAT

Psychologist
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JAN KINZLER

Oncology Nursing Society
Washington, D.C.

PAMELA LA FAYETTE

Cancer Lifeline
Seattle, Wash.

SUSAN LEIGH

University of Arizona Cancer Center
Tucson, Ariz.

EDITH LENNEBERG

People Living Through Cancer, Inc.
Albuquerque, N.M.

MICHAEL LERNER

Commonweal
Bollinas, Calif.

CATHERINE LOGAN

People Living Through Cancer, Inc.
Albuquerque, N.M.

GENA LOVE

People Living Through Cancer, Inc.
Albuquerque, N.M.

SHANNON MCGOWAN

Cancer Support Community
Point Richmond, Calif.

SHIRLEY MILLER

Affirmative Cancer Therapy
d/b/a Cancer Hot Line
Plantation, Fla.

FITZHUGH MULLAN, M.D.

Physician, Author
Garrett Park, Md.

WENDY TRABER

"Surviving," A Patient Newsletter
Stanford, Calif.

BARBARA WALIGOR-SERAFIN

Harrington Cancer Center
Amarillo, Texas

YVONNE SOGHOMONIAN

The Candlelighters Childhood
Cancer Foundation
Pittsburgh, Pa.

ESTELLE WEISSBURG

Cancer Guidance Institute
Pittsburgh, Pa.



Defining Survivorship

It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me. As with most cancer patients, the quality of my life during this period was severely compromised, and the possibility of death was always present. I was, in fact, struggling physically and mentally with the cancer, the therapy and the large-scale disruption of my life. Survival, however, was not one condition, but many. It was desperate days of nausea and depression. It was elation at the birth of a daughter in the midst of the treatment. It was the anxiety of waiting for my monthly chest film to be taken and lying awake nights feeling for lymph nodes. It was the joy of eating Chinese food for the first time after battling radiation burns of the esophagus for four months. These reflections and many others are a jumble of memories of a purgatory that was touched by sickness in all its aspects but was neither death nor cure. It was survival ...

FITZHUGH MULLAN, from his essay *Seasons of Survival: Reflections of a Physician with Cancer*, *New England Journal of Medicine*, July 1985.

On October 26, 1986, Dr. Mullan and a diverse group of leaders in the cancer field came together and founded NCCS.

The passage above was excerpted from an article written by Dr. Fitzhugh Mullan, a pediatrician serving in the U.S. Public Health Service, who first began to define what would become “cancer survivorship.” On October 26, 1986, Dr. Mullan and a diverse group of 22 nationally recognized leaders in cancer care, cancer research, cancer support, and cancer advocacy came together in Albuquerque, N.M. On this date, the National Coalition for Cancer Survivorship (NCCS) was founded with a vision to create a nationwide awareness of cancer survivorship.

The founders were expansive in their thinking and created a new language to deal with a range of issues that were separate from the biology of a cancer diagnosis. The need to create this new language occurred in the mid-1980s when large numbers of adults and children had survived their initial treatment for cancer but were left with acute, long-term, and late effects of treatment. These effects included biomedical, psychological, spiritual, economic, social, and vocational.

The phrase NCCS’s founders settled on to describe living with, through, and beyond cancer was *cancer survivorship*. In fact, the word survivorship was found nowhere in the medical literature in 1986. They also selected the term *survivor* to describe anyone with a diagnosis of cancer from the moment of diagnosis and for the remainder of life. Prior to NCCS’s founding, the term survivor was rarely used except for those whom the medical profession considered to be *cured* of their cancer, meaning without cancer for five years. NCCS’s founders extended the definition of survivor to apply to all those who support the person with cancer—family, friends, caregivers, and health professionals.

For nearly two decades, NCCS has built upon a body of work begun by its founders to establish the study of cancer survivorship as a recognized field of scientific research and to assure the application of that research into clinical practice.



In 1995, NCCS convened the First National Congress on Cancer Survivorship to formulate guidelines for specific domains of survivorship.

AUTHORED ARTICLES

“Advocacy: The Cornerstone of Cancer Survivorship.”

Written by Elizabeth J. Clark, Ph.D., and Ellen L. Stovall

Published in Cancer Practice, Volume 5, 1996

NCCS TOOLS AND PUBLICATIONS

“Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability”

White paper published by NCCS, 1996

A Cancer Survivor’s Almanac:
Charting Your Journey

Edited by Barbara Hoffman, JD

Cancer Survival Toolbox®

Developed by NCCS, the Association of Oncology Social Work, the Oncology Nursing Society, and the National Association of Social Workers.

Self-Advocacy: A Cancer Survivor’s Handbook
An NCCS Publication

Teamwork: The Cancer Patient’s Guide to
Talking With Your Doctor
Edited by Elizabeth J. Clark, Ph.D.

What Cancer Survivors Need to Know
About Health Insurance

Written by Kimberly J. Calder, M.P.S. & Karen Pollitz, M.P.P.

Working It Out: Your Employment Rights
as a Cancer Survivor

Written by Barbara Hoffman, J.D.

You Have The Right To Be Hopeful
Written by Elizabeth J. Clark, Ph.D.

Establishing Survivorship

From 1986 – 1996, there were very few self-described cancer advocacy organizations, and none focused on providing information and advocacy for what NCCS termed *cancer survivorship*. NCCS spent its first decade holding annual meetings where individual survivors from around the country assembled to attend lectures and participate in workshops exploring the issues facing cancer survivors. Experts in the nascent field of cancer survivorship research participated in these meetings and through their writings and ours, NCCS created a body of work to inform, educate, and empower individuals and organizations. In addition, NCCS began to slowly emerge as a leading voice for cancer survivors in the public policy realm.

Specifically, NCCS contributed language on workplace discrimination to the Americans with Disabilities Act (ADA) (1990). We also contributed significantly to the drafting and passage of the Rockefeller-Levin Medicare Cancer Coverage Improvement Act. This act provided Medicare coverage for oral forms of existing intravenous (IV) anti-cancer drugs and offered patients an important quality of life choice in how they chose to receive cancer treatment (1993).

Also in 1993, NCCS approached the eight existing cancer patient advocacy organizations to join efforts to ensure Medicare coverage of routine care costs associated with clinical trials be included in every piece of health-care reform legislation that was being drafted. The group succeeded, although major health-care reform did not, and NCCS went on to found the Cancer Leadership Council (CLC) with the original group of eight. The CLC, a patient-centered forum of national advocacy organizations addressing public policy issues in cancer, has grown to include 31 leading cancer patient advocacy, professional, and volunteer organizations. And NCCS remains the recognized leader of this group today.

NCCS convened the First National Congress on Cancer Survivorship in 1995 — a three-day meeting that brought 300 delegates to Washington, D.C., from around the country to participate in a series of facilitated roundtables and consensus forums. The goal was to formulate guidelines for access, advocacy, action, and accountability in three specific domains of survivorship:

- ✦ Quality cancer care
- ✦ Physiologic long-term and late effects of cancer treatment
- ✦ Psychosocial issues of cancer survivorship

This meeting also provided an opportunity for a new generation of cancer survivors to dialogue with health-care professionals, legal experts, and others to create an agenda for quality cancer care. The NCCS publication that articulated this agenda was published in 1995 and is titled, *Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability*. This document was presented to Dr. Richard Klausner, then director of the National Cancer Institute (NCI) in May 1996. Dr. Klausner's response to the findings and recommendations in this document was to establish the NCI Office of Cancer Survivorship (OCS) two months later.

The NCI Web site description of the Office of Cancer Survivorship states:

The Office of Cancer Survivorship was established in July of 1996 by the National Cancer Institute in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs.

The mission of the Office of Cancer Survivorship (OCS) is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. The Office of Cancer Survivorship conducts and supports research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families.

With the OCS in place to begin the process of building the evidence base for cancer survivorship research, NCCS began to focus its advocacy on other barriers to assuring quality cancer care for cancer survivors. It also launched plans to bring the concept of survivorship and the issues facing cancer survivors to the attention of the nation.





Just days after THE MARCH, Congress voted its largest increase to date in funding the National Cancer Institute.

On Sept. 26, 1998, more than 200,000 people gathered in Washington, D.C., and a million more gathered in communities all over the country to share hope, information, and a simple but powerful message – NO MORE CANCER. As the convener of THE MARCH ...Coming Together to Conquer CancerSM, NCCS began to realize its original vision of uniting and empowering cancer survivors. THE MARCH was the beginning of NCCS's sustained efforts to speak with one voice – the voice of patients and families, children and seniors, caregivers and researchers, educators and environmentalists, civil rights and civic leaders, and everyone who had been touched by cancer. THE MARCH exemplified NCCS's vision of the power of a community coming together to speak out on an issue – the power of survivorship.

THE MARCH brought together nearly 1,100 diverse organizations representing cancer survivors, and drew national attention with articles appearing in virtually every national newspaper in the country, as well as regional and local papers

in all 50 states. THE MARCH was featured in every national news broadcast, in radio interviews on 17,966 stations across the country, and earned a complete live day of coverage on C-SPAN. As a result of the public outcry, just days after the historic rally, Congress voted its largest increase to date in funding for the National Cancer Institute – a 16 percent increase to \$2.9 billion.

In an article published in 1996 by Dr. Elizabeth Clark, NCCS past chair, and Ellen Stovall, NCCS president and CEO, the two authors described an advocacy continuum that begins at the personal level. They called it “personal advocacy or self-advocacy.” The next piece of the continuum was “advocacy for others” and the third part was “national advocacy or public interest advocacy.” The authors asserted that skills training was a necessary part of self-advocacy and that these skills must be learned before a person can advocate for others or participate in public interest advocacy. Using this model, NCCS realized that while THE MARCH represented the last two steps of the

Launching Survivorship

advocacy continuum, there were no tools available to educate people about the first step of self-advocacy or to prepare them for the other steps.

Using information gained from a written survey of survivors, NCCS determined that the vast majority of survivors felt that they lacked basic self-advocacy skills needed when they were diagnosed. Specifically, 62 percent of respondents understood the importance of being an active partner in their own care, but only 46 percent felt they had the communication skills necessary in order to be effective when dealing with their health care team. And almost 50 percent of respondents indicated they lacked the negotiation skills necessary to effectively interact with employers, insurers, and health care providers.

In 1998, concurrent with THE MARCH, NCCS began development of the *Cancer Survival Toolbox*[®]. The *Toolbox*, created in partnership with the Association of Oncology Social Work, the Oncology Nursing Society and later the National Association of Social Workers, is a self-learning audio program that teaches cancer survivors the skills to meet the difficult challenges of a cancer diagnosis.

While designed primarily for people who have recently been diagnosed with cancer, the six basic skill sets can help anyone facing hard decisions and changes in life due to cancer. In subsequent years, NCCS released additional modules dealing with issues facing older Americans, caregivers, and its most recent module, *Living Beyond Cancer*. Since its release, NCCS has distributed nearly 600,000 free copies of the *Toolbox* to survivors, families, and caregivers in every state, the District of Columbia, and Puerto Rico.

In addition to its popularity, the *Toolbox* has received a number of prestigious awards including:

✦ **National Cancer Institute Cancer Patient Education Network (CPEN), Gold Star Award, 2000.** *This award recognizes organizations or groups that have made outstanding contributions to cancer patient education.*

✦ **Public Relations Society of America, Silver Anvil, Award of Excellence, 2000.** *The Silver Anvil Award is the highest honor a public awareness campaign can achieve. The *Toolbox* won an award in the Corporate/Nonprofit Partnership category.*

✦ **American Society of Association Executives (ASAE), Award of Excellence, 2000.** *This award recognizes associations that propel America forward with innovative educational projects.*

✦ **Women Executives in Public Relations (WEPR) Foundation Awards for Social Responsibility, 2000.** *The *Toolbox* received the coveted Crystal Obelisk, the only public relations industry award given solely for social responsibility.*

The power of survivorship was apparent, “cancer survivorship” was capturing the attention of Americans and NCCS was educating people on how to become advocates. But even though national awareness of survivorship had been achieved, NCCS knew there was much work yet to do and its focus was on the promise of quality care.



Quality Cancer Care: Declaration of Principles

- * People with cancer have the right to a system of universal health care. This access should not be precluded because of pre-existing conditions, genetic or other risk factors, or employment status.
- * Quality cancer care should be available in a health care system with standards and guidelines that are developed in consideration of treating the whole person with cancer. Health care plans must regard the cancer patient as an autonomous individual who has the right to be involved in decisions about his or her care.
- * Standards of cancer care should be driven by the quality of care, not only the cost of care, and should include participation in clinical trials and quality of life considerations.
- * Long-term survivors should have access to specialized follow-up clinics that focus on health promotion, disease prevention, rehabilitation, and identification of physiologic and psychosocial problems. Communication with the primary care physician must be maintained.
- * Systematic long-term follow-up should generate data that contribute to improvements in cancer therapies and decreases in morbidity.
- * The responsibility for appropriate long-term medical care must be shared by cancer survivors, their families, the oncology team, and primary care providers.

These principles served as the basis for the white paper which led to the establishment of the Office of Cancer Survivorship at the NCI.

- * All people diagnosed with cancer should have access to and coverage for services provided by a multidisciplinary team of care providers across the full continuum of care. Health care plans should be held accountable for timely referral to appropriate specialists when symptoms of cancer or its recurrence may be present.
- * People with cancer should be provided a range of benefits by all health care plans, that includes primary and secondary prevention, early detection, initial treatment, supportive therapies to manage pain, nausea, fatigue and infections, long-term follow-up, psychosocial services, palliative care, hospice care, and bereavement counseling.
- * People with histories of cancer have the right to continued medical follow-up with basic standards of care that include the specific needs of long-term survivors.
- * The provision of psychosocial services must be safeguarded and promoted. Persons diagnosed with cancer should receive psychosocial assessments at critical junctures along the continuum of cancer care to determine availability of needed support and their ability to seek information and to advocate on their own behalf.
- * Psychosocial research is integral to comprehensive cancer care and, as such, psychosocial outcome measures should be included in all future clinical trials. The importance of this research and its application and transfer to oncology care plans should be recognized and encouraged.
- * Cancer survivors, health care providers and other key constituency groups must work together to increase public awareness; educate consumers, professionals, and public policy makers; develop guidelines and disseminate information; advocate for increased research funding; and articulate for and promote survivors' rights.

NCCS's Commitment to Quality Cancer Care



From 1996 – 2005, NCCS put in motion a strategic plan to carry out specific goals published in its *Imperatives for Quality Cancer Care*, further defining the elements of quality cancer care. Over the last decade, NCCS has explored many opportunities to participate in forums where quality improvements in health care were being discussed. This deliberate effort to assure that the survivor's perspective would inform the considerations given to measuring and delivering quality care to people with cancer has been the hallmark of NCCS's advocacy for nearly 20 years.

The *Quality Cancer Care Declaration of Principles* were developed and adopted at the First National Congress on Cancer Survivorship on November 13, 1995. It served as the basis for the *Imperatives for Quality Cancer Care* white paper that led to the establishment of the Office of Cancer Survivorship at the NCI. In addition, these principles continue to guide NCCS's advocacy to assure that the agencies and organizations that are responsible for researching, financing, regulating, and delivering quality cancer care are accountable to people with cancer and those who care for them.

Since its founding, NCCS has relied on the best available scientific and medical evidence for its publications, patient and professional education efforts, advocacy on behalf of cancer survivors, and testimony before Congress. NCCS prides itself on being an honest broker of sound public policies that benefit cancer survivors.

Over the years, NCCS has served on a myriad of boards and committees of the most prestigious organizations involved in influencing public policy related to cancer survivorship issues and quality care. These include:

- ✦ National Cancer Advisory Board, appointed by the President of the United States
- ✦ Institute of Medicine's National Cancer Policy Forum
- ✦ Institute of Medicine's National Cancer Policy Board's Committee on Cancer Survivorship, vice-chair
- ✦ National Cancer Institute, By-Pass Budget Planning Committee
- ✦ National Committee for Quality Assurance, board of directors
- ✦ The Leapfrog Group, board of directors
- ✦ National Quality Forum, Steering Committee for Cancer Care Quality Measures
- ✦ Robert Wood Johnson Foundation's National Advisory Committee to Promote Excellence at the End of Life, vice-chair
- ✦ Robert Wood Johnson Foundation's National Advisory Committee for Pursuing Perfection: Raising the Bar for Health Care Performance

NCCS's involvement with these organizations and others not listed here supported the organization's need to improve the quality of cancer care in this country. NCCS believes that the next generation of survivorship work must be focused not just on raising awareness about survivorship but on significantly affecting and improving the quality of care.



The Mandate for Quality Cancer Care

With the likelihood that all families in the United States will have to deal with a diagnosis of cancer at some time, several reports on quality cancer care published by the Institute of Medicine's (IOM) National Research Council of the National Academy of Sciences between 1999 -2005 presented some disturbing facts. For instance, statistics showed that the care provided to cancer patients suffers from not having standards and a consistent, coordinated approach that would allow the more than 1.5 million individuals diagnosed each year and the more than 10 million survivors living today to receive optimal cancer care. This care, according to the reports, should begin with cancer prevention strategies; assure good cancer treatment; and maximize the post-treatment phase. In spite of having an identified National Cancer Program as called for in the National Cancer Act of 1971, no such system of care exists in the United States today.

The extensive research supporting the series of IOM reports consistently points to the lack of standards to assure quality care. It also indicates that the level of cancer care is different throughout the country in all settings where cancer care is delivered, including hospitals and cancer treatment centers, as well as among individual cancer specialists. Other variables in the level of care patients receive include the patient's age, sex, race, ethnicity, economic status, and amount of medical insurance.



NCCS has been involved in the development of all these reports on quality cancer care and has participated in IOM-associated workshops, seminars, and symposia dealing with this topic. All these reports and activities have findings and recommendations that are of great interest to legislators, health policy analysts, cancer researchers, federal agencies like the National Institutes of Health (NIH), National Cancer Institute (NCI), Centers for Disease Control (CDC), Food and Drug Administration (FDA), Center for Medicare and Medicaid Services (CMS), Agency for Healthcare Research and Quality (AHRQ) and others. Of particular interest to NCCS and its mission *to advocate for quality cancer care for all Americans*, is the credibility that IOM reports have with Congress, the above-mentioned federal agencies and private-sector organizations, which include physician groups and insurers.

Prior to the availability of the IOM reports, NCCS's advocacy for quality cancer care was dependent on varying levels of evidence.

As stated earlier, several of NCCS's early founders and adopters of its definition of "survivor" and "survivorship" crafted the language and gave definition to terminology frequently used today for what has become an ever-expanding field of study called *cancer survivorship research*. The principal author of much of the language of survivorship, Dr. Fitzhugh Mullan, NCCS co-founder, in 1985 wrote the following, which identified the task for the latest in this series of IOM reports issued in November 2005.

"The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards" (Mullan, 1985).

The report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, maps out the *middle ground* of cancer survivorship written about by Dr. Mullan. This is also called the extended or post-treatment phase.



IOM reports consistently point out the lack of standards and different levels of cancer care provided throughout the country.

The summary of the IOM report tells us that many cancer survivors recover with a renewed sense of life and purpose. What has often not been recognized, however, is the toll taken by cancer and its treatment, both to health, sense of security, and well-being. Acute effects of treatment may persist for years; some effects may become chronic and appear shortly after treatment or arise years later, making the road of survivorship a very rocky one for many survivors — particularly those whose access to the system of care is compromised by a lack of insurance or inadequate insurance coverage (also known as “underinsurance”).

To ensure the best possible outcomes for cancer survivors, the goals of this report are for it to:

- ✦ Raise awareness of the medical and psychosocial problems faced by cancer survivors and establish cancer survivorship as a distinct phase of the cancer trajectory during which specific clinical interventions are needed.
- ✦ Define quality health care for cancer survivors and identify strategies to achieve it.
- ✦ Improve quality of life through policies to ensure cancer survivors’ access to psychosocial services, fair employment practices, and health insurance.

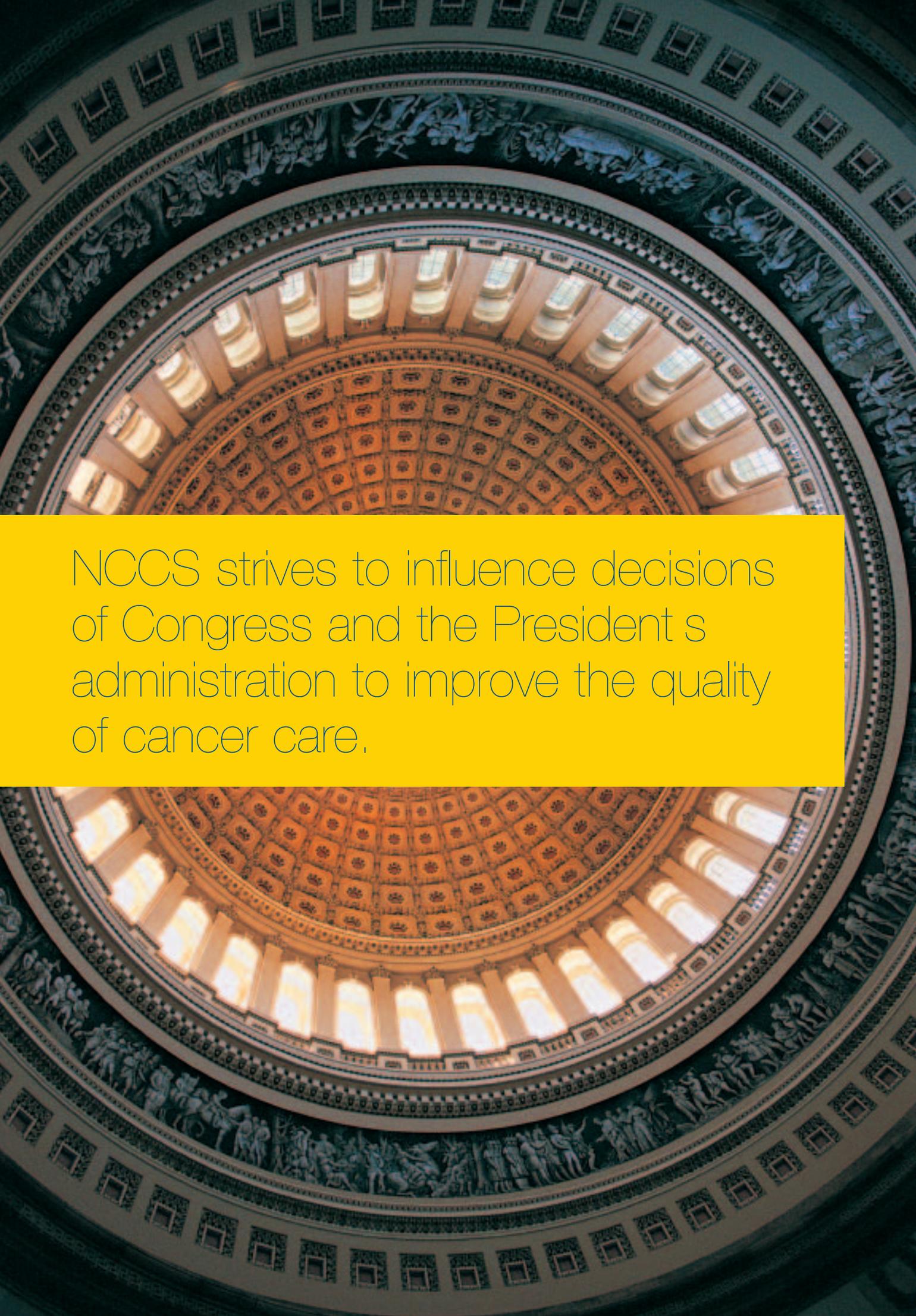
The report has 10 recommendations that correspond to the above-stated goals.

Many of these recommendations are not directly relevant to cancer survivors, but all are relevant to NCCS’s advocacy on their behalf. This is because some of them will require regulatory, financing, and legislative adjustments that currently do not favor their implementation.

The recommendations that are most meaningful to cancer survivors call for patient-centered approaches that are responsive to a survivors’ needs, promote effective communication and information sharing, encourage healthy lifestyles, and assist in helping survivors access appropriate community support. See Appendix I for NCCS’s specific activities related to the IOM recommendations.

The report finds that cancer survivors are lost to follow-up in a systematic way that causes many missed opportunities to provide appropriate follow-up care and interventions that could greatly enhance not only their quality of life, but perhaps their ultimate survival.

The IOM report helped to lay the foundation for the strategic direction of NCCS’s public policy work over the next few years.



NCCS strives to influence decisions of Congress and the President's administration to improve the quality of cancer care.

The Role of Public Policy

As a voice for cancer survivors and their caregivers in the nation's capital, NCCS strives to influence decisions of Congress and the President's administration to improve the quality of cancer care. In its advocacy, NCCS combines the passion of survivors and caregivers, borne of their experiences with cancer, with a solid base of evidence (such as the reports cited in the previous section). By persuading federal policy-makers to adopt reforms that encourage the development, delivery, and financing of quality cancer care, we hope to improve the lives of cancer survivors, their caregivers, families, and friends.

One of NCCS's major advocacy activities in 2006 and in the coming years is to seek support for and enactment of legislation to advance quality cancer care. As stated in the IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, discussed in the previous section, the system of care that has resulted in advances in cancer care has often failed to provide cancer survivors access to care that addresses the side effects of cancer and its treatment or their quality of life. Cancer survivors may not have their symptoms managed appropriately and may not have access to psychosocial services. Although these gaps in care occur across the continuum of treatment, they may be particularly acute at the end of life.

Throughout 2005, NCCS has been meeting with policy leaders to discuss a number of proposals that would advance a system of integrated cancer care. By reforming Medicare reimbursement, enhancing training of professionals who treat cancer survivors, and testing and expanding model systems of comprehensive and integrated care, NCCS believes that legislative relief could do significant more to advance a system of quality cancer care.

The reforms that are being proposed with our congressional leaders are consistent with the recommendations of *From Cancer Patient to Cancer Survivor: Lost in Transition*. Key among these are proposals that: 1) cancer survivors completing care be provided a treatment summary and follow-up plan, and 2) programs be developed to encourage interdisciplinary systems for providing integrated cancer care.

As has been the culture of NCCS since its founding, NCCS is not afraid to take on tough issues and fight for change at the federal level. Key to NCCS's success has been its ability not just to speak FOR cancer survivors but to speak WITH them. In the past this was accomplished through its annual Congress meetings and THE MARCH. Today, NCCS gains its input from and its representation of survivors through its grassroots advocacy network, *Cancer Advocacy Now!*TM





Cancer Advocacy Now! ensures that people diagnosed with cancer and their families have a voice in advocating for quality cancer care.

Cancer Advocacy Now!™

Cancer Advocacy Now! coordinates an organized, active community-based group of advocates across the country to speak out on issues affecting cancer survivors. Launched in 2004, the network ensures that people diagnosed with cancer and their families have a voice in advocating for quality cancer care. By joining *Cancer Advocacy Now!*, cancer survivors learn about issues and help to promote access to quality care and treatment. *Cancer Advocacy Now!* provides information and builds skills that enable survivors to advocate at the federal level.

Since its inception, *Cancer Advocacy Now!* has recruited over 25,000 advocates. These are people who have volunteered to be legislative advocates, to contact their legislators on

important issues, and to educate themselves on relevant issues through bi-weekly email communications. *Cancer Advocacy Now!* has already offered in-person advocacy training sessions in several cities throughout the United States, and it continues to educate cancer survivors via the Internet by providing e-mail alerts and updates on issues affecting quality cancer care.

Through *Cancer Advocacy Now!*, NCCS can harness the power of thousands of survivors and direct that energy to advocate for federal policies that benefit cancer survivors. NCCS is combining the power of survivorship with the vast potential of the Internet. It's like being able to recreate THE MARCH every day.





We will continue to make the survivor voice heard and bring about federal policies that will benefit those affected by cancer.

The Next 20 Years

NCCS will continue to make the survivor voice heard, to bring federal policies to realization that will benefit survivors and to continue empowering individuals diagnosed and living with cancer with tools and information.

We have used the “power of survivorship” in this report to mean the potential effectiveness of thousands of survivors speaking with one voice. But we recognize that the term can and does have other interpretations. As a survivor-led organization, we recognize the power of the survivorship experience

on so many levels and recognize that this experience is deeply personal and individualized.

For this reason, we felt it appropriate to include a passage from the late Natalie Davis Spingarn’s book, *The New Cancer Survivor: Living with Grace, Fighting with Spirit*, 1999. Ms. Spingarn, a past NCCS board member and cancer survivor, wrote of the power of the survivorship experience in a compelling and unique way.

I, too, have been helped by my never flagging interest in the resilience of the human spirit. This has deepened as I have seen some of my colleagues helping others voluntarily, unselfishly, others simply developing their talent for life, their ability to rely on the power of life itself. And it has swelled as I have watched them, like those who have preceded them, standing firm, learning, acknowledging the centrality of death, yet choosing life and seeking a high quality in that life; taking their stand right on the line, staying there, hanging in, even when their will to go on may seem illogical. In this way, the ordeal of the survivor becomes an experience of growth and self-realization.

NATALIE DAVIS SPINGARN

The New Cancer Survivor: Living with Grace, Fighting with Spirit



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Appendix I

From Cancer Patient to Cancer Survivor: Lost in Transition

Recommendations and NCCS Related Activities

RECOMMENDATION 1: Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care .

NCCS ACTION: Starting with defining “survivorship” in 1986, and calling for the establishment of NCI’s Office of Cancer Survivorship (1996), NCCS has worked for nearly 20 years to call attention to the experience of living with, through, and beyond cancer. NCCS has paid special attention to the need for cancer research and the cancer care delivery system to recognize this distinctive stage of post-treatment survivorship. NCCS has accomplished this through its publications, available free-of-charge to survivors, its First National Congress on Cancer Survivorship, and the publication of the *Imperatives for Quality Cancer Care*.

NCCS ensures the delivery of appropriate survivorship care through its advocacy to assure that third party payers are accountable with their reimbursement policies that impact on the services needed in post-treatment care. This is accomplished by NCCS’s ongoing work with the Centers for Medicare and Medicaid Services (CMS), the American Society of Clinical Oncology (ASCO), the National Committee for Quality Assurance (NCQA), the National Quality Forum (NQF), The Leapfrog Group, and The National Cancer Institute.

RECOMMENDATION 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principle provider(s) that coordinated oncology treatment. This service should be reimbursed by third party payers of care.

NCCS ACTION: Since the convening of the First National Congress on Cancer Survivorship (1995) and the publishing of the *Imperatives for Quality Cancer Care*, NCCS has called for the development of surveillance and follow-up care plans for cancer survivors post-treatment. NCCS has drafted legislation that calls for a treatment summary and care plan as recommended above.

In addition, in May 2006 NCCS was the primary sponsor of an Institute of Medicine National Cancer Policy Forum work-

shop on implementing cancer survivorship care planning. Other partners included the Lance Armstrong Foundation and the National Cancer Institute.

RECOMMENDATION 3: Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public and private sector efforts.

NCCS ACTION: NCCS has advocated for and worked in support of numerous guidelines related to cancer care. Representatives from NCCS have been included on guideline development panels convened by the National Comprehensive Cancer Network (NCCN); the American Society of Clinical Oncology (ASCO); the American Society of Therapeutic Radiology and Oncology (ASTRO); and the Gynecological Oncology Group (GOG).

RECOMMENDATION 4: Quality of survivorship care measures should be developed and quality assurance systems implemented to monitor and improve the care that all survivors receive.

NCCS ACTION: NCCS advocates for and participates in the development of quality measures related to cancer survivorship with public- and private-sector organizations such as the National Quality Forum (NQF), the National Committee for Quality Assurance (NCQA), and the Agency for Healthcare Research & Quality (AHRQ).

See recommendation 5 related to the Cancer Care Quality Alliance.

RECOMMENDATION 5: CMS, NCI, AHRQ, VA, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.

NCCS ACTION: In 2005, NCCS partnered with the American Society of Clinical Oncology (ASCO) to convene the Cancer Care Quality Alliance (CCQA) which aims to convene all major public and private parties dedicated to quality improvement in cancer care. The Alliance will foster collaboration among stakeholders who are committed to quality improvement and seek to eliminate unnecessary duplication in quality efforts. By fostering the implementation of practical programs to improve quality of care, the Alliance will seek to become a

national voice for quality of cancer care. The federal agencies named in this recommendation are all participants in the CCQA and will advocate for demonstration projects to test models of survivorship care.

RECOMMENDATION 6: Congress should support CDC, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.

NCCS ACTION: NCCS will collaborate and cooperate with any/all organizations that work at the state level to assure the inclusion of survivorship care in the implementation of their comprehensive cancer control plans. NCCS has met with CDC to participate in a survey and analysis of the gaps and barriers that currently impede the ability of providing survivorship services at the community level.

RECOMMENDATION 7: NCI, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.

NCCS ACTION: NCCS is frequently called upon by the National Cancer Institute, professional societies representing oncology professionals (physicians, nurses, social workers), and voluntary organizations to provide materials in support of their educational programs. NCCS initiated and partnered with the NCI in 1990 to write their first survivorship pamphlet, *Facing Forward*. NCCS's publications dealing with survivorship issues and including its award-winning *Cancer Survival Toolbox*[®] have been marketed and distributed to NCI-designated cancer centers, voluntary organizations, and at all major annual meetings of oncology professionals. In addition, NCCS has partnered with all 67 chapters of the Leukemia and Lymphoma Society (LLS) to distribute NCCS's publications to their professional support staff and to attendees of the NCCS/LLS program, *Cancer: Keys To Survivorship*.

RECOMMENDATION 8: Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to minimize discrimination and adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.

NCCS ACTION: For nearly 20 years, NCCS has been closely associated with all major national efforts to address the employment, legal, and insurance barriers for cancer survivors. One of NCCS's founders and members of its board of directors,

Barbara Hoffman, is a recognized national speaker and author on cancer survivorship issues related to employment and disability law. NCCS has written amicus briefs on cases related to workplace discrimination and cancer. We have also distributed a compilation of cases in a 1997 document edited by Barbara Hoffman, J.D., and Daniel Fiduccia, titled *Cancer on Trial: Court Rulings on Cancer Bias*. NCCS actively supported the Americans with Disabilities Act (ADA) and works with the National Partnership for Women and Families in support of fair employment practices for people with chronic illness and disabilities. Several of NCCS's publications (see page 11) address specific issues related to employment based issues facing cancer survivors.

RECOMMENDATION 9: Federal and state policymakers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payers of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

NCCS ACTION: NCCS has advocated at the federal level for nearly 20 years for health care that is universally accessible and affordable and not precluded because of pre-existing conditions, genetic or other risk factors, or employment status. NCCS participates in a variety of forums where it represents the only consumer voice for cancer issues related to health insurance access and health-care plan and benefit design.

RECOMMENDATION 10: NCI, CDC, AHRQ, CMS, VA, private voluntary organization such as ACS, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. A new research initiative focused on cancer patient follow-up is urgently needed to guide effective survivorship care.

NCCS ACTION: Since 1987, NCCS has submitted specific recommendations for survivorship research initiatives for inclusion in the NCI's By-Pass Budget. In addition, NCCS has advocated on behalf of budget increases to NIH in support of more research dollars for survivorship studies.

NCCS is a member of the American Society of Clinical Oncology's (ASCO) Survivorship Task Force, their Health Services Research Committee, Cancer Research Committee, and their Quality Advisory Group, all of which are dealing with the issues related to improving the quality of survivorship care and research.

The power
of survivorship.

The promise
of quality care.



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