NCCS

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

*The power of survivorship. The promise of quality care.*

# 2009 Annual Report

## We Speak

*For all cancers. For quality care. As survivors.*

# Table of contents

Message from the President & CEO ..... 3

Organization Background ..... 4

Mission, Vision and Goals ..... 5

2009 Activities at a Glance

- Advocacy & Public Policy ..... 7
- Programs ..... 9
- Outreach & Event ..... 12

Financial Overview

- Corporate sponsor policy ..... 15
- Financial statements ..... 15

Acknowledgement of 2009 Donors and Sponsors ..... 18

Acknowledgement of 2009 Board and Staff ..... 20

# Message from the President & CEO

Dear Friends,

In many ways, nothing can be more powerful than voices united, speaking out. As cancer survivors, we stand 12 million strong, united in our fight in living with, through and beyond a cancer diagnosis. At the National Coalition for Cancer Survivorship (NCCS), we work diligently to ensure the voice of cancer survivors is being heard around the world to improve the quality of cancer care for all.

With this collective voice, we continue to advocate for public policies that protect the rights of cancer survivors and provide improved care for all people affected by cancer. NCCS has been hard at work ensuring all survivors have a voice at the table when it comes to cancer and healthcare policy discussions. In 2009, NCCS took the lead in sharing resources and expertise with key stakeholders to elevate survivor care as a top policy priority and advocate for the adoption of reforms that encourage the development, delivery, and financing of quality cancer care.

NCCS is also working to ensure cancer survivors have the tools needed to take charge of the quality of care they receive. Tools like our first-ever cancer specific program, *Living with Multiple Myeloma*, for the award-winning Cancer Survival Toolbox®; Journey Forward, a software program oncologists and other health care professionals can use to easily build post-treatment summaries and follow-up care plans; and an online community that connects cancer survivors and their family members, caregivers and friends. Through these resources, cancer survivors learn to be their own advocates, empowered to stand up for their rights and help drive their care.

With each passing year, our voices become stronger as we work toward a shared vision: access to the best quality care for all people affected by cancer. The voice of a cancer survivor is the strongest tool we have, and together we are transforming the cancer landscape.

A special thank you to our advocates, individual donors, sponsors, Board of Directors and dedicated NCCS Staff - without their support none of this positive work would be possible.

Sincerely,

Thomas P. Sellers, MPA
President and CEO
12-Year Cancer Survivor

# Organization background

The National Coalition for Cancer Survivorship (NCCS) is the oldest survivor-led cancer advocacy organization in the country, advocating for quality cancer care for all people touched by cancer and empowering cancer survivors. Incorporated in 1987, the founders of NCCS set out to establish an organization that would change the parlance from cancer "victim" to cancer "survivor," envisioning an organization that would deal with the full spectrum of survivorship issues related to living with, through, and beyond a cancer diagnosis. NCCS's definition of a survivor, from the time of diagnosis and for the balance of life is now the norm for the cancer community and beyond. NCCS has expanded its definition of survivor to include family, friends, and caregivers.

*NCCS set out to establish an organization that would change the parlance from cancer 'victim' to cancer 'survivor'.*

Founded in Albuquerque, New Mexico, NCCS's diverse leadership included some of the most recognized experts on employment and disability law, health care consumerism, and psychosocial and behavioral research. Consequently, NCCS quickly developed a reputation as the "go to" organization for how to deal with the physiological, psychosocial, economic, and spiritual issues that accompany a cancer diagnosis. The informed patient was — and still is — at the heart of NCCS's agenda. NCCS began its work by contributing to the literature. NCCS's first publication dealt with doctor/patient communications, followed by publications on survivors' rights and how to be an informed and knowledgeable health care consumer.

In 1992, NCCS relocated its offices to Washington, D.C. to be closer to the organizations and institutions that play a role in educating government agencies and policymakers about the need for quality cancer care throughout the survivorship continuum — beginning at the moment of diagnosis and continuing for the remainder of life. NCCS understands that while better therapies for treating cancer now exist, a patient's ability to access those treatments is not guaranteed. That is why NCCS continues to advocate for survivors' rights and to represent the patient/survivor perspective at the highest levels of policy making — so those facing a diagnosis of cancer today have access to quality cancer care.

# Mission, Vision & Goals

### Mission

To advocate for quality cancer care for all people touched by cancer.

### Vision

To be an advocacy organization that reflects the needs of all cancer survivors to effect policy change at the national level.

### Goals

NCCS represents the millions of Americans who share a common experience - the survivorship experience - living with, through and beyond a cancer diagnosis. That experience has value and can be a transforming, positive force.

NCCS also knows that cancer survivors and those who care for them face many challenges. To help meet those challenges, NCCS:

- Advocates for changes in how the nation researches, regulates, finances and delivers quality cancer care.
- Empowers cancer survivors through its publications and programs, which provide tools for self-advocacy.
- Convenes other cancer organizations to address nationwide public policy issues affecting cancer survivors.

*NCCS advocates for quality cancer care for all people touched by cancer.*

# Remembering Our Friend, Dan Waeger

***"Life will never be the way it was before, but we cannot surrender to the disease."*** – Dan Waeger

It is with deep sadness that the National Coalition for Cancer Survivorship (NCCS) conveys the news of the death of our friend and colleague Dan Waeger in early 2009. Dan's survivorship spanned nearly four years with Stage IV lung cancer. Those four years were characterized by many highs and lows, but with a never-faltering "can do" attitude and a telegenic smile.

The NCCS staff and hundreds of others have been touched by 26-year-old Dan's gregarious spirit and exemplary journey of survivorship. Dan epitomized cancer survivorship and embraced the core mission of NCCS. He further devoted much of his time to sharing his cancer experience with fellow survivors. He used his experience as a survivor to increase awareness of the challenges that both he and others facing a cancer diagnosis, deal with on a daily basis.

Dan joined NCCS as development manager in 2006 - a little more than a year after his diagnosis. Having been diagnosed while in college, Dan founded the National Collegiate Cancer Foundation to provide services and support to young adults diagnosed with cancer. The Foundation has provided thousands of dollars in financial support to young adults pursuing a higher education throughout their cancer treatment and beyond.

We will remember Dan for his winning sense of humor, infectious smile, his strong sense of responsibility and motivational inspiration to reach beyond ourselves to make a difference.

# 2009 Activities at a Glance

## NCCS ADVOCACY & PUBLIC POLICY

### 2009 NCCS Cancer Policy Roundtables

The Cancer Policy Roundtable is an innovative biannual healthcare policy forum involving representatives from the patient community including advocates, researchers, regulators, clinicians, academics and a diverse community of biotechnology and pharmaceutical companies that support NCCS's mission of advocating for quality cancer care for all Americans.

The first Cancer Policy Roundtable, held in March, reviewed several issues relating to the delivery of quality cancer care to all Americans. The speakers and participants considered proposals to improve health insurance coverage and affordability and assessed the impact of healthcare reform on the delivery of patient-centered cancer care. The meeting also considered the challenges facing the Food and Drug Administration, its accomplishments in review of new cancer therapies, and the consequences of a potential new regulatory system for review of follow-on biologics.

During the October meeting, participants evaluated whether the reform packages and proposed changes to them will foster the delivery of high quality cancer care and eliminate disparities in access to care. The Roundtable panels focused on a wide range of issues, with special attention to the potential impact of healthcare reform on all facets of cancer care.

### Brookings Institute: Cancer Data Infrastructure and Applications

NCCS worked with the American College of Surgeons, the National Comprehensive Cancer Network (NCCN) and the Brookings Institution to develop a framework and infrastructure for the collection of data at the physician/patient level in clinical practices around the country. NCCS was the only patient group represented at this meeting and contributed information on the vision for implementation of care planning for patients at the beginning and end of treatment.

## 2009 ACTIVITIES AT A GLANCE

### Breaking the Mold: New Options to Enhance Care & Empower Patients with Advanced Illnesses

Dr. Richard Payne and Ellen Stovall represented NCCS at a planning meeting hosted by the Institute of Medicine, which brought together leading clinicians, academics, payers, service providers, policymakers, consumers, professional organizations, and patient advocacy groups to share their perspectives on issues affecting care available to patients with life-limiting illnesses.

### Markle Foundation: Connecting for Health

NCCS successfully advocated for inclusion of care planning in the Connecting for Health's recommendations for "meaningful use." Connecting for Health has been very influential in the last several years in the development of policy and technical standards for implementation of health information technology. Connecting for Health has provided input to the Department of Health and Human Services National Coordinator for Health IT on the definition of "meaningful use" for Stimulus HIT funding.

### Alliance for Quality Psychosocial Care

NCCS staff served as co-chair for the Alliance for Quality Psychosocial Care, a coalition of 30 cancer and psychosocial professional organizations formed to implement recommendations of the 2008 Institute of Medicine Report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.* Key recommendations of the report call for adoption of psychosocial assessment, referral for services and follow-up from referrals as standard of care for cancer care.

### Consumer Purchase Disclosure Project

In July 2009, NCCS staff participated in a Disclosure Project forum, Shared Decision-Making, which addressed the tools and skills patients need to be effective participants in their medical decision-making. NCCS is a member of the Consumer Purchaser Disclosure Project, a group of leading employer, consumer, and labor organizations working toward a common goal to ensure that all Americans have access to publicly reported healthcare performance information.

### National Quality Forum Measure Prioritization Advisory Committee

At the request of the Department of Health and Human Services (HHS) Secretary, Kathleen Sebelius and the National Quality Forum's (NQF) President,

## 2009 ACTIVITIES AT A GLANCE

Dr. Janet Corrigan, Ellen Stovall was nominated to co-chair – with Dr. George Isham (CEO, Health Partners) – a national advisory committee to guide the strategy for identifying priorities for healthcare performance measurement. The committee will engage a series of activities to identify gaps in endorsed measures, and provide guidance on priorities for a measure development agenda. Construction of the agenda is responsive to direction from HHS, which has contracted with NQF to lead the formulation of a national strategy and priorities for healthcare performance measurement.

### The Comprehensive Cancer Care Improvement Act

NCCS continued to advocate at the federal level for systemic changes in how the nation researches, regulates, finances and delivers quality cancer care through the reintroduction of the Comprehensive Cancer Care Improvement Act (CCCIA). NCCS worked closely with Representatives Lois Capps (D-CA) and Charles Boustany (R-LA), lead co-sponsors of the bill, to reintroduce this critical piece of legislation, followed by support from Senator Mary Landrieu (D-LA), who introduced the Senate version.

The CCCIA is designed to foster the coordination of cancer care and put processes in place to assure informed decision-making and improved communication between doctor and patient from the moment of diagnosis through the balance of life. It encourages doctors to provide a detailed plan for patients before they begin treatment, discuss outcomes once treatment is completed, and develop a follow-up plan for the months and years after treatment. The legislation establishes a new Medicare service for cancer care planning.

## NCCS PROGRAMS

### Cancer Survival Toolbox®: Living with Multiple Myeloma

In early 2009, NCCS launched its first cancer-specific program for its award-winning Cancer Survival Toolbox. *Living with Multiple Myeloma* is a new stand-alone audio program that offers the opportunity to listen to conversations between patients and their caregivers and learn how they get solutions to real problems when dealing with multiple myeloma. Specifically, this program addresses:

## 2009 ACTIVITIES AT A GLANCE

- Multiple myeloma diagnosis and basic treatment options
- Side effects and symptom management
- Coping with change
- Information for caregivers

The goal of this program is to provide a person diagnosed with multiple myeloma—as well as caregivers, family, and friends—practical tools for use in daily life while dealing with a cancer diagnosis and treatment. *Living with Multiple Myeloma*, which was written by cancer survivors and healthcare professionals, can be helpful both to individuals newly diagnosed with multiple myeloma, as well as to anyone at any other stage of this illness.

### Cancer Survival Toolbox® Wins Two National Health Awards

The Toolbox was honored with two National Health Information Awards in 2009. The general Toolbox received the highest award in the Consumer Decision-Making Information class for Total Health Information Program, while the new multiple myeloma program won the highest award given in the Patient Education Information class for Other/Miscellaneous Material.

### Journey Forward

Journey Forward – a combined effort of NCCS, WellPoint, Inc., the UCLA Cancer Survivorship Center and Genentech – launched in February 2009 in five pilot states for survivors of breast and colon cancers and will later include plans for survivors of other cancer types throughout the country.

The program promotes the use of treatment summaries and follow-up plans that give clear steps for care and monitoring after active cancer treatment. Journey Forward's custom-made Survivorship Care Plan Builder is available for use by any oncologist. In addition, Journey Forward offers an electronic Medical History Builder where patients can record their health history in a format that makes changes easy and avoids the need to fill out medical history forms repeatedly.

Through NCCS efforts, Journey Forward is now in discussions with researchers at the United States Department of Veterans Affairs (VA) about the potential for partnering with the VA on use and evaluation of Journey Forward electronic tools and materials within the VA. Journey Forward is developing a generic survivorship care plan template to be available next year, and the

project is also developing a "plug-in" that would integrate Journey Forward's survivorship care plan capability into hospital system electronic medical record systems.

In October 2009, the Journey Forward program won the BlueWorks® award, which honors health care innovation that improves the quality and value of health care for consumers. BlueWorks is a unique partnership between the Blue Cross and Blue Shield Association and the Harvard Medical School Department of Health Care Policy.

### Cancerversary

NCCS launched the Cancerversary program, a new online community created for survivors and their loved ones to share, inspire and empower. At www.cancerversary.org, cancer survivors and their friends, family, caregivers and healthcare providers can create a personalized web page to acknowledge their cancerversary, honor someone else's cancer experience or pay tribute to someone they've lost.

Many survivors commemorate a significant date or time from their cancer journey – even if they don't have a name for it. This might be a celebration or a time of quiet reflection, but it's always about survivorship.

### Oral Adherence Partnership with National Association of Social Workers (NASW)

NCCS entered into a partnership with NASW to develop a training and informational online program around oral drug adherence. The goal of the new program is to improve the atmosphere for patients' adherence to oral drug therapies. The online module is expected to launch in March 2010.

### Survivorship Teleconference Workshop Series

Each spring, NCCS partners with CancerCare, the National Cancer Institute's Office of Cancer Survivorship and Office of Communications and Education, the Lance Armstrong Foundation, the Intercultural Cancer Council, and Living Beyond Breast Cancer to produce a three-part teleconference series on key survivorship issues. The 2009 Seventh Annual Cancer Survivorship Series: "Liv-

ing With, Through and Beyond Cancer" topics included:

- Managing the Stress of Survivorship
- The Importance of Nutrition and Physical Activity
- Survivors Too: Family, Friends and Loved Ones - Managing the Fatigue of Caregiving

More than 8,000 people participated in the teleconference, giving the 2009 series the largest number of participants to date, including people from all 50 states as well as international listeners.

## NCCS OUTREACH & EVENTS

### Amgen Breakaway from Cancer

NCCS partnered with Amgen and other leading cancer organizations on the Breakaway from Cancer™ initiative to empower and support people affected by cancer. A complementary component of the Amgen Tour of California, the Breakaway from Cancer initiative was created to increase awareness of the important resources available to cancer survivors and their families, from prevention and diagnosis through treatment and survivorship. NCCS provides resources and information to attendees in eight cities throughout California.

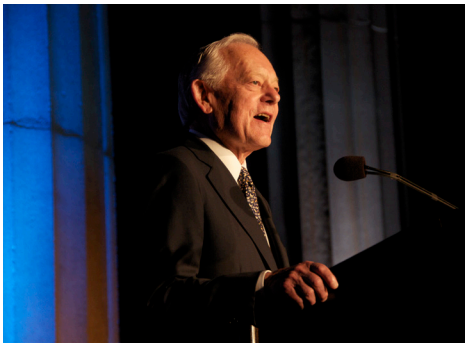
The initiative featured two charity bike rides open to the public in northern and southern California. The Amgen Tour of California ran a 750-mile course from Sacramento to Escondido.

## 2009 ACTIVITIES AT A GLANCE

### NCCS Rays of Hope Gala

Each year, NCCS honors organizations and individuals who have made significant contributions to cancer survivorship by hosting the Rays of Hope Awards Gala in Washington, D.C.

Awardees included Golden Globe and Emmy Award winner Mariska Hargitay of Law & Order SVU, and Doug Ulman, founder of the Ulman Cancer Fund for Young Adults and president of the Lance Armstrong Foundation. Bob Schieffer, CBS News Chief Washington Correspondent, moderator of Face the Nation, and cancer survivor, emceed the event.



### Kaleidoscope

NCCS partnered with 10 other cancer advocacy groups to support Kaleidoscope, a holiday entertainment variety special that combines the beauty of skating, the excitement of song and the brave message of survivorship to raise awareness of the key issues surrounding women and cancer. The show featured the return to the ice of legendary figure skaters Scott Hamilton and Dorothy Hamill, and a performance by cancer survivor Olivia Newton-John.

## 2009 ACTIVITIES AT A GLANCE

### American Society for Clinical Oncology (ASCO) Tribute

NCCS and the ASCO Cancer Foundation honored Dr. Richard Schilsky, ASCO's 45th President on May 30. The ASCO Foundation and NCCS Tribute event brought together a broad coalition of healthcare professionals, non-profit partners, industry representatives, and national business leaders for an evening to pay tribute to Dr. Schilsky's impressive career in gastrointestinal malignancies and cancer pharmacology.

Established in 2000, this annual event has become a wonderful opportunity for attendees, ASCO leadership, ASCO past-presidents and others to pay tribute to the accomplishments and dedication of the ASCO outgoing president. Participation in this event provides supporters the opportunity to interact with ASCO leadership and leaders in the cancer community. Proceeds from the event benefit the important work of both NCCS and the ASCO Cancer Foundation.

### 2009 EIF REVLON Run/Walk for Women

NCCS was chosen as a beneficiary of the annual EIF Revlon Run/Walk for Women - a 5K run/walk fundraiser in New York City to raise awareness for women's cancers research, treatment, counseling and outreach programs. With the help of runners, walkers, volunteers and donors, NCCS distributed its programs, resources and general information to thousands of event participants.

# Financial Overview

## CORPORATE SPONSOR POLICY

The National Coalition for Cancer Survivorship (NCCS) is a national 501(c)(3) advocacy organization representing cancer survivors and their families. NCCS partners with corporations on events, programs and educational materials to better serve the cancer survivor community. In these instances, NCCS thoroughly vets all partnerships to ensure its ability to remain an independent, credible and transparent organization. For more information on the NCCS corporate sponsor policy, please contact NCCS at info@canceradvocacy.org.

## FINANCIAL PICTURE

**Statements of Financial Position**
*Year ending December 31, 2009 and 2008*

| ASSETS | 2009 | 2008 |
|---|---|---|
| **Current assets** | | |
| Cash and cash equivalents | 1,346,681 | 523,708 |
| Marketable securities | 1,505,810 | 1,468,535 |
| **Accounts receivable** | | |
| Special events | 140,256 | 140,256 |
| Others | 26,387 | 122,962 |
| **Inventory** | 229,414 | 70,807 |
| **Prepaid expenses** | 98,448 | 431,936 |
| **TOTAL CURRENT ASSETS** | **3,346,996** | **2,758,204** |
| **Other assets** | | |
| Furniture ($305,846) and equipment ($244,200) depreciation | 105,382 | 146,752 |
| Deposits | 18,038 | 18,038 |
| **TOTAL ASSETS** | **$3,470,416** | **$2,922,994** |

## FINANCIAL OVERVIEW

**Statements of Financial Position**
*Year ending December 31, 2009 and 2008* **(continued)**

| LIABILITIES AND NET ASSETS | 2009 | 2008 |
|---|---|---|
| **Current liabilities** | | |
| Accounts payable | 202,769 | 183,502 |
| Deferred revenue | 350,807 | 570,626 |
| Accrued salaries and benefits | 1,231 | 11,882 |
| Accrued vacation | 48,796 | 59,133 |
| TOTAL CURRENT LIABILITIES | $603,603 | $825,143 |
| **Net assets** | | |
| Unrestricted | | |
| Board designated | 1,700,201 | 1,541,811 |
| Other | 230,484 | 297,853 |
| Total unrestricted | 1,930,685 | 1,839,664 |
| Temporarily restricted | 936,128 | 258,187 |
| TOTAL NET ASSETS | $2,866,813 | $2,097,851 |
| TOTAL LIABILITIES AND NET ASSETS | $3,470,416 | $2,922,994 |

## FINANCIAL OVERVIEW

**Statements of Activities and Changes in Net Assets**
*Year ending December 31, 2009 and 2008 with summarized financial information for the year ending December 31, 2009*

| | Unrestricted | Temporarily Restricted | 2009 Total | 2008 Total |
|---|---|---|---|---|
| **Revenue** | | | | |
| Contributions | 1,127,754 | 1,459,008 | 2,586,762 | 1,896,391 |
| Publications and merchandise | 28,954 | - | 28,954 | 19,106 |
| Special events | 1,810,950 | - | 1,810,950 | 2,188,100 |
| Cost of direct benefits to donors | (76,270) | - | (76,270) | (99,072) |
| Interest and dividend income | 56,959 | - | 56,959 | 83,630 |
| **TOTAL REVENUE** | **$2,948,347** | **$1,459,008** | **$4,407,355** | **$4,088,155** |
| **Net assets related from restrictions** | | | | |
| Satisfaction of program restrictions | 781,067 | (781,067) | - | - |
| **TOTAL REVENUE AND ASSETS** | **$3,729,414** | **$677,941** | **$4,401,355** | **$4,088,155** |
| **Expenses** | | | | |
| Program services | 2,721,045 | - | 2,721,045 | 3,275,019 |
| Management and general | 156,976 | - | 156,976 | 234,849 |
| Fundraising | 846,954 | - | 846,954 | 804,946 |
| **TOTAL EXPENSES** | **$3,724,975** | **-** | **$3,724,975** | **$4,314,814** |
| **Change in net assets before other gains and (losses)** | 4,439 | 677,941 | 682,380 | (266,659) |
| **Other gains and (losses)** | | | | |
| Realized gain/loss on investments | (13,362) | - | (13,362) | (28,269) |
| Unrealized gain/loss on investments | 99,944 | - | 99,944 | (165,280) |
| **CHANGE IN NET ASSETS** | **$91,021** | **$677,941** | **$768,962** | **($420,208)** |
| **NET ASSETS, BEGINNING OF YEAR** | **$1,839,664** | **$258,187** | **$2,097,851** | **$2,518,059** |
| **NET ASSETS, END OF YEAR** | **$1,930,685** | **$936,128** | **$2,866,813** | **$2,097,851** |

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