

Cancer Advocacy Now!™

Legislative Advocacy for Quality Cancer Care

South Carolina Cancer Alliance
Cancer Advocacy Now!
Legislative Advocacy Training
October 19, 2006

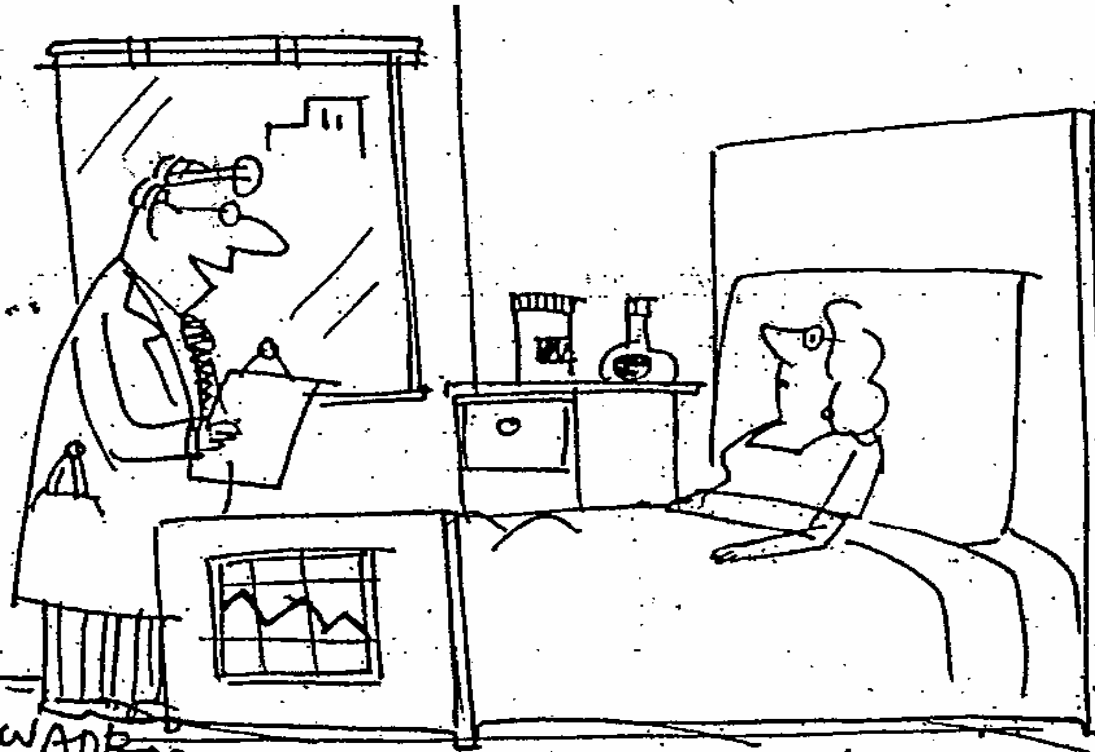
Michael Bergin, MBA
Chief Operating Officer

Introductions

- Name
- Have you been involved in legislative advocacy before?

I am from Washington and I am **HERE TO HELP!!!!**





Schwartz

"YOU'RE IN LUCK! A FAMOUS MOVIE STAR HAS YOUR DISEASE, SO THERE'S BEEN A TELETHON, AND DRUG COMPANIES ARE WORKING ON A CURE."

The Washington Time

OCTOBER 5, 2006

National Coalition for Cancer Survivorship

- Established the concept of cancer survivorship in 1986
- Oldest survivor-led advocacy organization in the U.S. Governance of/by/and for cancer survivors-- at least half of whom must have had a personal diagnosis of cancer
- Highly respected authentic voice at the Federal level, advocating for quality cancer care for all Americans
- Self Advocacy Programs: Cancer Survival Toolbox™, A Cancer Survivor's Almanac, and other publications

NCCS Founders

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

1985 NEJM "Seasons of Survival"
Fitzhugh Mullan, co-founder, NCCS
physician/survivor

My Story

Diane Bergin

- Diagnosed with Ovarian Cancer in November 1997
- Denied access to a clinical trial in 1998
- Spoke out on Capitol Hill

SPEAKING ORDER

SEN. KENNEDY

SEN. REID

Dr. Bruce Chabner
Clinical Director
MGH Cancer Center

SEN. CLELAND

Ellen Stovall
Executive Director
National Coalition for Cancer Survivorship

SEN. TORRICELLI

Diane Bergin
Patient with ovarian cancer



Coming Together To Conquer Cancer – 1 million nationwide



 **NCCS**
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

March on Washington DC in 1998

The goal – “No More Cancer”



**Results: 16% increase in funding for NIH -
opened the door to discussing access to care
issues**

Why Advocate?

- Stakes are high for cancer survivors and their loved ones
- Survivors' voices are not heard enough on quality of care issues
- Concerted action by a few well-informed advocates can make a big difference

Cancer Advocacy Now!

- The vision: An advocacy network of cancer survivors and caregivers across the country
 - Well-informed advocates with an interest in improving the quality of cancer care
- Will not focus on specific cancer types
 - Issues will be cross-cutting

Cancer Advocacy Now!

Recruitment Via Collaboration



The power of survivorship. The promise of quality care.

Cancer Advocacy Now! Communications

- E-mail updates
- Action Alerts
- E-mail newsletter
- Website: www.canceradvocacynow.org

Cancer Advocacy Now!

Training/Resources

- General
 - Workshops
 - "How To" manual
 - brochures
- Web-based
 - Talking points
 - White papers
 - Other

Cancer Advocacy Now! Internet Recruitment

The screenshot shows a Microsoft Internet Explorer browser window displaying the website for the National Coalition for Cancer Survivorship (NCCS). The browser's address bar shows the URL <http://www.canceradvocacynow.org/>. The website header features the NCCS logo and the text "NATIONAL COALITION FOR CANCER SURVIVORSHIP" above a banner image of a woman. Below the banner are four yellow buttons: "JOIN NOW", "TAKE ACTION!", "SPREAD THE WORD", and "DONATE".

The main content area is divided into three columns. The left column contains a "CANCER ADVOCACY NOW!" logo with a Capitol dome icon and a navigation menu with the following items:

- > Home
- > About Us
- > Share Your Story
- > News and Events

The middle column has a "Welcome" heading followed by a paragraph: "Cancer Advocacy Now! is a grassroots legislative advocacy network that understands that public policy decisions at the national level can affect cancer care in your community. **Cancer Advocacy Now!** works every day so that **your voice** is the voice of America's 10 million cancer survivors and the millions more who care for them. Your voice will be heard in Washington, DC and in forums where health care policy is decided."

The right column features a section titled "EVERYDAY HEROES:" with a photo of Elizabeth Biscotto and the text: "I became a 50-year cancer survivor in 2004. >> Read More of Elizabeth Biscotto's Story". Below the photo are two yellow buttons: ">> Read more stories" and ">> Tell your story".

At the bottom of the browser window, the Windows taskbar is visible, showing the Start button, several application icons, and the system tray with the time 10:54 AM.

Easy Sign Up Via The Web

The screenshot shows a Microsoft Internet Explorer browser window displaying the registration page for Cancer Advocacy Now!. The address bar shows the URL: http://www.canceradvocacynow.org/join/. The page features a navigation menu on the left with links for Home, About Us, Share Your Story, News and Events, Issues, and Contact Us. The main content area is titled "Join Now" and includes a thank-you message, a list of actions users can take (Get Educated, Tell a friend, Take Action!), and a registration form. The form fields are: *Email Address, *First Name, *Last Name, *Address 1, Address 2, *City, *State (dropdown), and *Postal Code. A "Register" button is located below the form. The Windows taskbar at the bottom shows the Start button, several application icons, and the system tray with the time 10:55 AM.


CancerAdvocacyNow.org - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print Copy Paste

Address http://www.canceradvocacynow.org/join/ Go Links >>

Google Search 3740 blocked Check AutoLink AutoFill Options

 **CANCER ADVOCACY NOW!**

> Home
> About Us
> Share Your Story
> News and Events
> Issues
> Contact Us

Join Now

Thank you for your interest in the **Cancer Advocacy Now!** network. After you register to we will update you by e-mail about activities that will help you stay informed and spread the word on the importance of quality cancer care. To officially become an advocate simply click on the registration button below.

WHAT YOU CAN DO:

- Get Educated
- Tell a friend
- Take Action!

*required

*Email Address

*First Name

*Last Name

*Address 1

Address 2

*City

*State

*Postal Code

Done Internet

Start CancerAdvocacyNow.org... 10:55 AM

Cancer Advocacy Now!

Additional Recruitment

- NCCS volunteers and donors
- Participants in conferences like CURE, Sister's Network, and others

Quality Cancer Care for All Americans



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

Comprehensive Cancer Care Improvement Act H.R. 5465

H.R. 5465 - Comprehensive Cancer Care Improvement Act (CCCCIA)

- Introduced on May 24th by Representatives Lois Capps (D-CA) and Tom Davis (R-VA)
- Endorsed by over 30 Comprehensive Cancer Centers including MD Anderson and several oncology specialty societies including ASCO



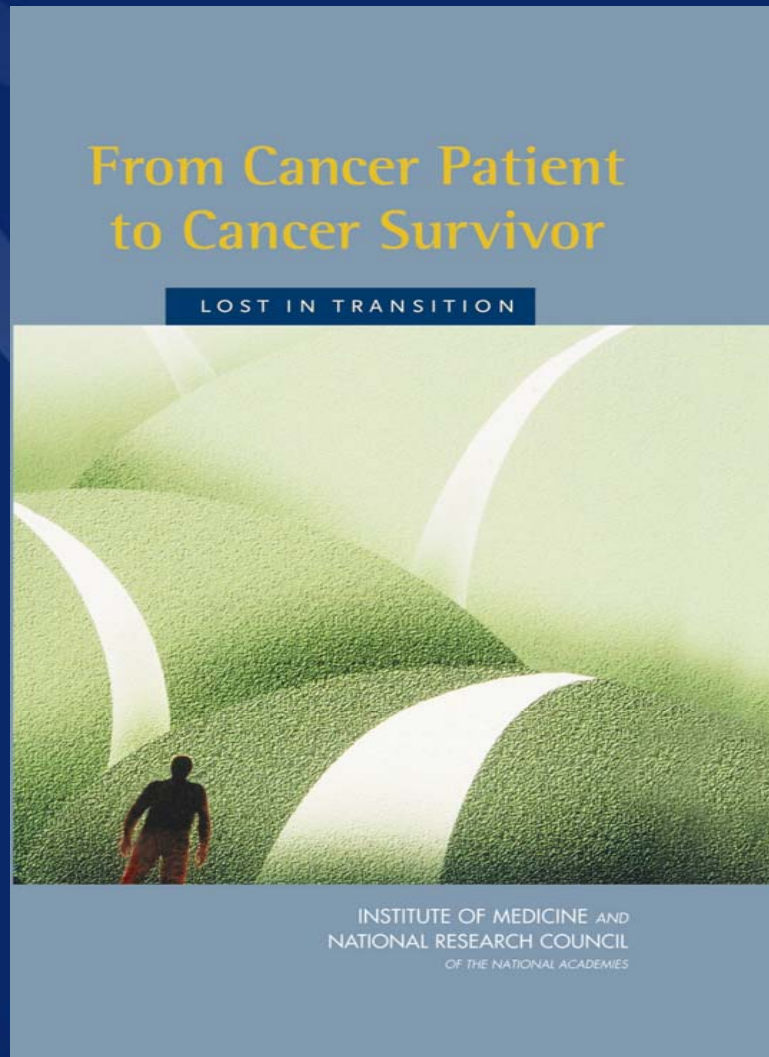
What is Comprehensive Cancer Care?

- Integrative care, which includes symptom management and palliation from the time of diagnosis onward. Treatments for nausea, fatigue, pain and depression, other psychosocial needs
- NOT limited to end-of-life care, or hospice-provided care

H.R. 5465 - Comprehensive Cancer Care Improvement Act (CCCCIA)

- Establish Medicare service for cancer care planning
- Establish a program of grants for development of model programs of comprehensive & integrated care
- Establish professional training programs emphasizing integration of primary treatment & symptom management
- Train professionals to develop & communicate treatment plans and summaries

Institute of Medicine Report

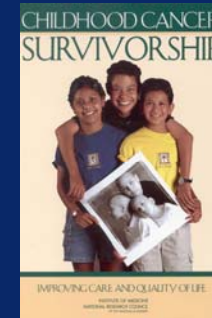


 **NCCS**
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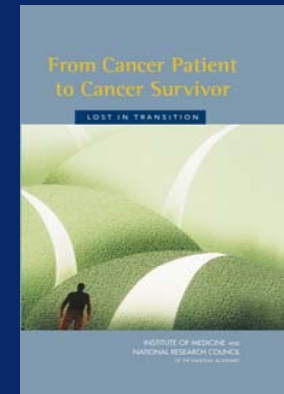
The power of survivorship. The promise of quality care.

IOM: Cancer Survivorship

- *Childhood Cancer Survivorship: Improving Care and Quality of Life (2003)*
- *Meeting the Psychosocial Needs of Women with Breast Cancer (2004)*
- *From Cancer Patient to Cancer Survivor: Lost in Transition (2005)*



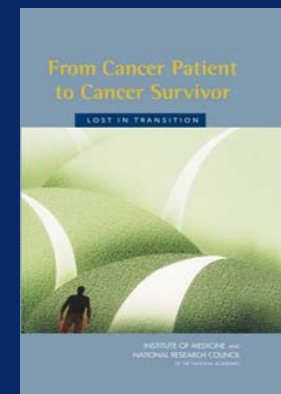
IOM Report Reveals



There is no system of post-treatment care for cancer survivors in the United States leaving more than 10 million survivors as an underserved population—many of whom are suffering disproportionately as a result.

IOM Report Shows

- Cancer is often a chronic condition, but is not treated as one.
- When treatment ends, most cancer survivors do not have a follow-up care plan or treatment summary
- Surviving cancer is something to celebrate, but it is not the end of the road. Cancer changes your life forever, and it also changes your health care needs forever



Why Quality Follow-up Care is Essential

- Cancer survivors are at a greater risk of recurrence of developing new cancers
- Cancer survivors often suffer side effects from their treatment such as organ damage
- Cancer survivors may have emotional & social issues. Some of the most common are under-treated adjustment disorders such as situational stress & depression.

Legislative Advocacy

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”

-Margaret Mead

Legislative Advocacy

- Definition of Cancer Advocacy Now!
legislative advocacy: efforts to create or change cancer care policy at the federal level
- Targets:
 - Congress
 - Administration (White House)
 - Federal agencies

Legislative Advocacy

- It's all about making "noise"
- Building relationships with policymakers over time – not a one-time effort
- Speaking up and remaining focused
- The system DOES respond

Communicating with Policymakers

- Universal elements:
 - Tell your personal story
 - Individualize your communication
 - Identify where you're from
 - Ask the person to do something
 - Thank them, if you can

Communicating with Policymakers

- Web forms / Emails
- Letters
- Telephone Calls
- Capitol Hill Visits or District Office Visits
- Town Halls & Public Forums

Locating your Policymakers

Find Your Representative at:
www.house.gov

Find Your Senators at:
www.senate.gov

Your Representative

James E. Clyburn

Energy & Water Development &
Related Agencies Committees

Transportation, Treasury and
Housing & Urban Development
Committees



 **NCCS**
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

Your Senator

Jim DeMint

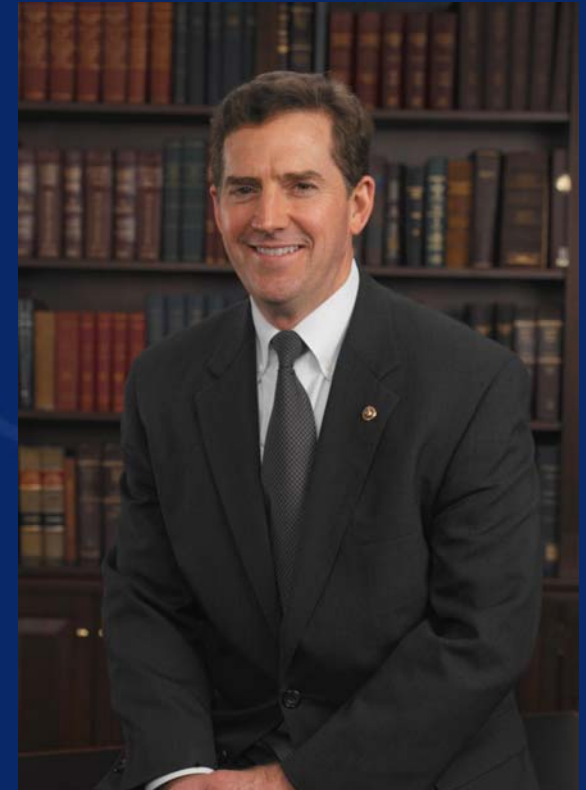
Commerce, Science & Transportation
Committee

Subcommittee on Disaster Prediction &
Prevention

Environment & Public Works Committee

The Joint Economic Committee

Special Committee on Aging



Your Senator

Lindsey Graham

Committee on Armed Services

Budget Committee

Judiciary Committee

Veterans' Affairs Committee



Our Request

- Sign Up For Cancer Advocacy Now!
& Start Receiving Information
- Recruit Friends, Family Members
- When it's time to take action - Call or Write Your Representative or Senators Re:
Access to Quality Cancer Care
 - Be Passionate & Persistent