Engaging in Public Policy Advocacy: Changing Cancer Care in the US

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National Coalition for Cancer survivorship
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Agenda

• What is Public Policy and Why is it Important to Cancer Survivors?
• Advocacy vs. Lobbying and Why You Can (and Should) Lobby
• Media Advocacy
• Meeting with Policymakers
• Group Exercise
About NCCS

- Our mission is to advocate for **quality cancer care** for all people touched by cancer
- We represent **cancer survivors** in **public policy efforts** to improve cancer treatments and enhance access to **quality cancer care**
- **Our goal** is to foster a cancer care system that is **evidence-based**, **quality-driven**, **patient-focused** and affordable and accessible to all
- We **convene** cancer advocates, industry, payers, professional societies, academia and providers
- We champion **cancer care planning**, at diagnosis and at major transition points during treatment and survivorship
NCCS’ definition of a survivor is from the time of diagnosis through the balance of life. NCCS expanded its definition to include family, friends, and caregivers.
Public policy is government action on a public issue. Federal, state and even local governments make decisions that have an impact on cancer survivors.

Everyone who is diagnosed with cancer is impacted by public policy.
What is Public Policy and How Does it Impact Cancer Care?

The federal government:

• Funds for research on the prevention, cause, diagnosis, and treatment of cancer;

• Funds public health programs that provide education, screening, and access to care.

• Reviews and approves cancer treatments and tests;

• Determines what medical services and treatments are paid for by Medicare, which covers more than half of cancer patients and influences coverage provided by private insurance companies.
The Federal Government

- **Executive Branch**
  - The President
  - Departments/Agencies (HHS, CDC, NIH, etc.)

- **Legislative Branch**
  - U.S. House of Representatives
  - U.S. Senate

- **Judicial Branch**
  - U.S. Supreme Court
Executive Branch: Agencies

- United States Department of Health & Human Services
- National Cancer Institute
- Centers for Medicare & Medicaid Services
- Centers for Disease Control and Prevention
- U.S. Food and Drug Administration
Legislative Branch: House of Representatives

- Population based
- Elected for 2-year term
- All 435 seek election at same time
- Qualifications:
  - U.S. citizen for at least 7 years
  - At least 25 years old
  - Resident of the district

- [www.house.gov](http://www.house.gov)
Legislative Branch: Senate

• Each state has two Senators
• Elected for 6-year term
• Staggered elections - 1/3 every two years
• Qualifications:
  • U.S. Citizen for at least 9 years
  • At least 30 years old
  • Resident of the state

• [www.senate.gov](http://www.senate.gov)
U.S. Senate Leadership

President of the Senate
VP Joe Biden

Majority Leader
Mitch McConnell (R-KY)

Minority Leader
Harry Reid (D-NV)

Majority Whip
John Coryn (R-TX)

Minority Whip
Richard Durban (D-IL)
114th Congress

• U.S. House of Representatives
  • 435 Representatives
    • 247 Republicans
    • 186 Democrats
    • 2 Vacancies (PA and HI)

• U.S. Senate
  • 100 Senators
    • 54 Republicans
    • 44 Democrats
    • 2 Independents
Where Does it All Begin?

1. Members get ideas for legislation
2. Legislation drafted with assistance from staff and legislative counsel
3. Bills introduced – referred to committees
How a Bill Becomes a Law

1. Introduction / committee assignment
2. Executive agency comments
3. Committee* hearings
   - Expert testimony
   - Advocacy organizations
4. Committee* mark-up
   - Amendments
5. Committee* votes and issues report
6. Referral to full chamber for floor vote

*or subcommittee

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Key House Committees

• **Ways & Means**
  Medicare, Medicaid, Social Security

• **Energy & Commerce**
  Other Health Programs

• **Appropriations**
  Labor, HHS, Education Subcommittee (NIH, CDC)
Key Senate Committees

• Finance
  Medicare, Medicaid, Social Security

• Health, Education, Labor & Pensions (HELP)
  Other Health Programs

• Appropriations
  Labor, HHS, Education Subcommittee (NIH, CDC)
NCCS Policy Priorities

• Delivery and payment reforms that provide cancer survivors access to cancer care planning services and coordinated care

• Implementation of the Affordable Care Act so that it best serves the needs of cancer survivors

• Resources to support an efficient and effective cancer drug review process at the Food and Drug Administration (FDA) that takes into consideration the needs of patients
NCCS Policy Priority

... to ensure that every cancer patient has access to **cancer care planning and coordination services**
Planning Actively for Cancer Treatment (PACT) Act H.R. 2846

- Creates a Medicare service for cancer care planning and coordination
- Encourages doctor-patient discussions and shared decision-making
- Available to patients at diagnosis and at major transition points in care
- Written plan that explains diagnosis, treatment, and expected symptoms
- Survivorship care plan at completion of active treatment
What is Care Coordination?

Care coordination involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care...

...the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and...used to provide safe, appropriate, and effective care to the patient.

—AHRQ (Agency for Healthcare Research and Quality)
Recommendation 1

- The cancer care team should:

  - Communicate and personalize this information for their patients at key decision points along the continuum of cancer care, using decision aids when available.

  - Collaborate with their patients to develop a care plan that reflects their patients’ needs, values, and preferences, and considers palliative care needs and psychosocial support across the cancer care continuum.

- CMS and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to discuss this information with their patients and document their discussions in each patient’s care plan.
Adoption of Cancer Care Planning: Delivery & Payment Reforms

Our Goal
• Engaged patients, shared decision-making
• Cancer care planning, at diagnosis and at major transition points during treatment and survivorship

Payment
• Legislation – establish a Medicare benefit
• Regulation (CMS)
• Alternative payment models (CMMI’s OCM)
• Private Payers

Patient
• Prepare patients to be engaged partner
• “Take Charge of Your Cancer Care” tools

Providers
• Standards & Guidelines
• Journey Forward Survivorship Planning Tools

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# Take Charge of Your Cancer Care

**Complete this worksheet** and use it to help you prepare for your doctor's visit and discuss your wishes with your physician and your family.

## What information do I need to help me make a decision about treatment?
- Will I be able to work? Take care of my family? Travel? Be around young children?

## What information do you use to make treatment recommendations for me?
- What are your realistic goals for my treatment?
- What are the chances that I can be cured?

## What are my chances of a long-term response with good quality of life?
- Are there clinical trials available to me?
- How will I feel during treatment?

## Essential questions to ask your doctor

- What are your realistic goals for my treatment?
- What are the chances that I can be cured?
- What are my chances of a long-term response with good quality of life?
- Are there clinical trials available to me?
- How will I feel during treatment?
- Will I be able to work? Take care of my family? Travel? Be around young children?
- What help will I need in managing the side effects of treatment?
- When and for how long?
- Should I consider a second opinion regarding my diagnosis and treatment?
- Are there different approaches to treating my kind of cancer?

## Cancer Care Plans

- [canceradvocacy.org/careplans](canceradvocacy.org/careplans)
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Commission on Cancer’s Continuum of Care Standards

3.3 Survivorship Care Plan: Cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated and presented at least annually to the cancer committee and documented in minutes.
Journey Forward

Survivorship Library
For professionals & patients
- Symptom management
- What to expect
- What to watch for
- Surveillance guidelines

My Care Plan
For patients
- Psycho-social assessment
- Care team coordination & follow-up
- Treatment summary (abridged)

Survivorship Care Plan

Survivorship Care Plan Builder
For professionals
- Psycho-social assessment
- Treatment summary
- Follow-up care
- Data import from EHRs via cancer registry software

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Adoption of Cancer Care Planning: Delivery & Payment Reforms
Delivery & Payment Reforms Are Essential to Quality Improvement

- NCCS considers changing the conversation between doctor and patient as the essential foundation of delivery reform
- Payment reforms must be aligned to improve communication, treatment decision-making, symptom management, and coordination of care
NCCS Principles for Patient-Centered Payment Reform

- Reward **quality of services**, not just quantity
- Require **shared decision-making and a cancer care planning process**, including advance care planning
- Promote **evidence-based care** by encouraging adherence to guidelines, quality measures, and standards of care
- Include **consideration of clinical trial options**, where appropriate, in the care planning discussion
NCCS Principles for Patient-Centered Payment Reform

- Communicate patient cost-sharing responsibilities as part of the care planning process
- Include protections against underutilization or overutilization
- Incorporate outcome, process, and patient-reported outcome measures, developed with input from patients
- Ensure that therapeutic innovations will be rapidly incorporated into the standard of care
- Reimburse for coordination of care, from screening through survivorship
Oncology Care Model

- Payment model piloted by Centers for Medicare and Medicaid Innovation (CMMI)
- Nearly 200 oncology practices and 17 insurance companies participating
- Financial and performance accountability for episodes of care surrounding chemotherapy administration to Medicare beneficiaries
- The practices will provide enhanced services such as care coordination, care planning, and navigation
"I am not a researcher. I am not an oncologist. I am not a geneticist. I am a Vice President of the United States. But I've been on the other end of the need."

National Cancer Moonshot Initiative

- President Obama announced during 2016 State of the Union address and asked Vice President Joe Biden to lead the effort.
- Task Force and Blue Ribbon Panel convened.
- Moonshot Summit held June 29 in Washington, DC, with additional meetings held across the country.
National Cancer Moonshot Initiative

- White House Cancer Moonshot Task Force charged to develop recommendations to:
  - Accelerate our understanding of cancer and its prevention, early detection, treatment, and cure
  - Improve patient access and care
  - Support greater access to new research, data, and computational capabilities
  - Encourage development of cancer treatments
  - Identify and address any unnecessary regulatory barriers and consider ways to expedite administrative reforms
  - Ensure optimal investment of federal resources
  - Identify opportunities to develop public–private partnerships and increase coordination of the federal government’s efforts with the private sector, as appropriate
National Cancer Moonshot Initiative

- Convened a Blue Ribbon Panel, whose report will be released in September. Working groups include:
  - Expanding Clinical Trials
  - Enhanced Data Sharing
  - Cancer Immunology and Prevention
  - Implementation Sciences
  - Pediatric Cancer
  - Precision Prevention and Early Detection
  - Tumor Evolution and Progression
Advocacy vs. Lobbying

- **Advocacy**  
  Educates and may urge support for an issue of cause

- **Lobbying**  
  Urges support for specific legislation
What You Can Do as a 501c3

• Legislative Activities - You CAN Lobby, subject to limits
  • Direct Lobbying – contacting an elected official about a specific issue
  • Grassroots Lobbying – encouraging the general public to contact an elected official about a specific issue

• Testifying at a Congressional hearing, or responding to a request for information is NOT lobbying
What You Can Do as a 501c3

• Electoral Politics
  • You CANNOT participate in partisan political activities, or support or oppose candidates for office
  • You CAN engage in nonpartisan electoral activities like candidate questionnaires
What You Can Do as a 501c3

• Executive Branch Advocacy
  • Commenting on regulations
  • Requesting enforcement of existing laws
  • Advocating for or against executive orders
  • Trying to influence administrative decisions on policy and program implementation

• As long as intent is not to influence legislation, this is NOT considered lobbying
BolderAdvocacy.org - Alliance for Justice

Celebrating 50 Years of Voting Rights – and Working For More
Posted by Isaiah Castilla on August 6, 2015

In commemoration of the VRA’s passage, we want to lift up organizations working to mobilize and turnout voters in the 2016 election. Voter mobilization and civic engagement are some of the safest and most effective ways for nonprofits to work in elections. To help organizations navigate the changing landscape, Bolder Advocacy provides resources, trainings, and technical assistance on the legal rules for election-related activities.
Media Advocacy
Media Advocacy – What? Why?

- Get on the public agenda
- Shape public opinion
- Foster debate
- Mobilize constituents and allies
- Launch or energize a project
- Influence decision makers
Media Types

- Cable or community television
- Public and college radio
- Newsletters of groups, institutions, etc.
- Direct mail
- Social media
- Listservs
- Billboards
PLANNING ACTIVELY FOR CANCER TREATMENT (PACT) ACT OF 2015

BY Shane Smithson | Posted: Tuesday, July 07, 2015 03:34 PM

Local Residents Meet with the Office of Representative in Washington, DC: Bipartisan Bilinear Improve Cancer Care is Introduced in House by Representatives Capps and Boustany

Planning Actively for Cancer Treatment (PACT) Act (H.R. 2846)
would enhance care of millions of Medicare patients

Washington, DC – Shane Smithson from St. Louis County traveled to Washington, DC on June 25 and 26, 2015 to ask Congress to improve quality cancer care. The group, advocates of the National Coalition for Cancer Survivorship (NCCS), Missouri, 2nd District, called on representatives to co-sponsor the Planning Actively for Cancer Treatment (PACT) Act (H.R. 2846), which would significantly improve the quality and coordination of care for Medicare patients with cancer. This bill is the top public policy priority of NCCS.
NCCS CEO Applauds Oncology Care Model

By Shelley Fuld Nasso

The recent announcement by the Innovation Center at the Center for Medicare and Medicaid Services regarding the launch of an Oncology Care Model is an important step toward patient-centered cancer care.

In 2013, the Institute of Medicine released its report, “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis.” According to the IOM, the American cancer care system is in crisis due to three failings: it is often not patient-centered, does not provide well-coordinated care, and does not always encourage evidence-based treatment decisions. One of the IOM’s recommendations is that CMS and other payers should design and evaluate innovative payment models to improve care delivery.

Although only a step in the payment and delivery reform process, the OCM holds significant promise of boosting patient satisfaction and improving the overall quality of care. Participation in the Oncology Care Model, or OCM, is voluntary for oncology practices. Those volunteering practices will be required to refine their care processes to focus on the needs of patients who are undergoing chemotherapy.
Cancer ‘moonshot’: Improve quality of life too

By Shelley Fuld Nasso

One of the emotional high points of President Obama’s final State of the Union address came when he announced he is putting Vice Joe President Biden “in charge of Mission Control” of a new “moonshot” to cure cancer “once and for all.” In response, members of Congress – seemingly from both sides of the partisan aisle – erupted in applause.

And why not? Who in that chamber and beyond wouldn’t want to end cancer – especially if this “moonshot” results in a well-financed, urgent cancer research and development effort that can go beyond what we have now? And who among them – even the most implacable administration antagonists – wouldn’t want to pay this modest tribute to the vice president whose son, Beau, succumbed to brain cancer last year?
Media Opportunities: Events
Site Visits with Elected Officials

- Determine appropriate policy maker
- Gauge interest of official
- Identify ideal site
- Follow up with scheduler
- Coordinate between parties involved
- Invite community
- Distribute media advisory; follow-up
- Prepare site and speakers
- Distribute press release; follow up
News/Press Conference

• Determine newsworthiness, news hook, message and messengers
• Develop media contact list
• Draft and send media advisory
• Make follow-up calls to reporters
• Prep media packet and other materials
• Send press release
• Make follow up calls to reporters
Use Your Media Coverage

• Share with Members of Congress
• Show other advocates to obtain their support
• Share with donors
• Use to pitch other stories
Social Media
Examples

• Communication-focused:
  • Blogs and Microblogs (blogger, Tumblr)
  • Social Networks (Facebook, Twitter, LinkedIn)
  • Online Advocacy & Fundraising ( Causes, Kickstarter, Twibbon)

• Multimedia-focused:
  • Photosharing (Flickr, Instagram)
  • Videosharing (YouTube, Vimeo)
  • Livecasting (Youstream, Periscope)

• Others:
  • Reviews/Opinions, Entertainment (Yelp!, Pinterest)
Does Congress Use Social Media?

As of May 13, 2013:

• All 100 Senators and 90% of Representatives are on Twitter

• 64% of staff surveyed think Facebook is an important tool for understanding constituents’ views and opinions

• 42% of staff surveyed think Twitter is also important

Congressional Management Foundation, “Perceptions and Use of Social Media on Capitol Hill”
Why Does Congress Use Social Media?

• Members can control their message
• Makes Members more responsive to their constituents
• Enables Members to reach new people
• Enables Members to have more meaningful interactions with constituents
• Eliminates media as the moderator/gatekeeper
How This Benefits Your Organization/Cause

- Direct connections with elected officials & your members
  - Opportunities to make new connections
- Opportunities for rapid response
- Direct connections with constituents or other opinion leaders
- Free visibility to a wide audience to elevate your issues and priorities
How You Can Amplify

• Spread the message
  • Show your subject matter expertise, and become a resource to others
  • Build a coalition with local constituents, activists and media
  • Micro-target communications
  • Add to conversations, move them in a desired direction
  • Highlight facts and stories
How You Can Amplify

• Drive Action
  • Broadcasts calls to action
  • Inform supporters quickly
  • Facilitate “virtual lobbying” (petitioning, email outreach, etc.)
  • Help prepare followers with good information for their own conversation
  • Highlight overlooked issues
Meeting with Policymakers
How to Write a Better Letter to Congress

1. Be Specific – the “ask” must be measurable
2. Keep it short – seven to 10 sentences
3. Personalize and establish standing
4. Connect to the larger group
5. Augment other advocacy efforts

Source: http://www.congressfoundation.org/news/blog/1116-how-to-write-a-better-letter-to-congress
Structure of a Congressional Office

- Constituents
  - Member of Congress
    - Chief of Staff
      - Scheduler
      - Legislative Director
      - Communications Dir.
  - Staff Assistant
  - Legislative Assistant
  - Legislative Corr.

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For Cancer Survivorship
Schedule a Meeting

- Email request to scheduler
- Follow-up with scheduler
- Member unavailable? Meet with staff
- Thank the scheduler and send confirmation to staffer
Preparing for the Meeting

- Determine “ask”
- Review issues and develop talking points
- Localize the issue
- Know the Member
- Prep leave-behind materials
- Set meeting agenda and attendee roles
- Confirm logistics with scheduler / staff 48 hrs prior
Legislative Visit Do’s and Don’ts

• Do’s
  • Be punctual and dress neatly
  • Allow time to get through security
  • Introduce yourself with a handshake, a smile, your full name, and where you are from in their district
  • Share your story, make it personal
  • Know the name/number of the bill and be able to present a short summary about it with a couple of facts.
  • Be courteous and friendly to everyone in the office
  • Ask the Representative’s position and why
  • Follow up with a “thank you” by email

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Legislative Visit Do’s and Don’ts

• Don’ts
  • Don’t overload the Congressional visit with too many issues or too much paper
  • Don’t expect your Representative, or their staff, to be a specialist on the issue
  • Don’t be afraid to say, “I don’t know,” to a question asked of you – you can follow up with a response
  • Don’t be offended if a legislator is unable to meet and requests that you meet with his/her staff
  • Don’t confront, threaten, pressure, or beg
After the Meeting

• Tweet to thank the member for meeting
• Send thank you – include responses to questions
• Follow-up with staff on action items
• Share meeting notes internally
• Following Member action, thank Member and staff
Maintaining Long-term Relationships

• Sign up for legislator’s email updates and follow on social media
• Check in with staff regularly
• Serve as a resource on cancer issues
• Invite to local cancer community events in hometown
• Thank for co-sponsoring legislation
• Schedule in-district meetings
• Attend town hall meetings
Meeting in the District

The PACT Act: How To Visit Congressional District Offices

Advocating for legislation doesn’t only happen in Washington, D.C., but back home in the district as well, especially during district work days when Congress is not in session. All senators and representatives in Congress have offices in their state or home district where constituents can meet with their representatives. Many Members of Congress also often host local events like town halls or coffee conversations. These are excellent opportunities to speak with the Member or their staff about why the PACT Act is so important.

Below are step-by-step instructions on how to advocate for PACT Act with your Members of Congress.

Click here for a printable PDF of these instructions.

Step 1: Legislative Schedule and Finding Your Members

Face-to-Face with Congress: Before, During, and After Meetings with Legislators

• Key Findings
  • 93% of House Schedulers surveyed indicated requests for meetings with lawmakers should be made 2-4 weeks in advance;
  • 71% of participating House Chiefs of Staff expressed "no preference" for meeting location (Washington, D.C., versus the district);
  • 94% of the House Chiefs of Staff felt a "1-2 page issue summary" left behind after a meeting is somewhat or very helpful, while only 18% said the same of a "5 page or greater length" document

NCCS Cancer Policy & Advocacy Team (CPAT)
NCCS Cancer Policy & Advocacy Team (CPAT)

- Advocate engagement, training, and action program focused on improving cancer care
- **Symposium** in Washington, DC in June with two days of training and a Hill Day
- Webinars and conference calls to share key policy issues, advocacy best practices
- Online forum
- Email updates with advocacy opportunities

To Join CPAT, email cpat@canceradvocacy.org
Group Exercise