Cancer Policy & Advocacy Team (CPAT) Symposium
June 25-27, 2018
Crystal City Marriott at Reagan National Airport, Arlington, VA
AGENDA

Goals for Symposium Participants:
- To gain an understanding of the most pressing public policy issues facing quality cancer care
- To develop advocacy skills in communication and meeting with policymakers
- To facilitate advocates’ ongoing engagement with NCCS in public policy advocacy to ensure the best possible care

Monday, June 25

1:00pm Registration (boxed lunches will be available)
Potomac Ballroom Foyer

1:30pm Welcome and Introductions
Potomac Ballroom

2:00pm The Survivorship Movement: Yesterday, Today, Tomorrow

NCCS was founded in 1986 as the first survivor-led organization with a “vision to create a nationwide awareness of cancer survivorship.” At the time, the concept of cancer survivorship did not exist in the scientific literature. NCCS’ founders changed the language of cancer from victim to survivor and defined someone as a survivor from diagnosis through the balance of life. In this session, one of NCCS’ founders will share the history of the survivorship movement and the role of advocacy in advancing survivorship issues, from her perspective as a four-time survivor, oncology nurse, and advocacy leader. We will discuss advances in survivorship care and gaps that remain. Finally, we will describe new projects NCCS has begun to address some of the challenges survivors face in accessing information and quality care.

Susie Leigh, RN
NCCS Founding Member

Shelley Fuld Nasso, MPP
Chief Executive Officer, NCCS

3:00pm Break
**Panel Discussion: Cancer Care Planning**

For many years, cancer patient advocates have recommended that each cancer patient receive a written plan outlining treatment choices and fostering the coordination of all elements of a patient’s care. The Institute of Medicine (now the National Academy of Medicine) has recommended a cancer care plan as an element of quality care and has defined the elements of a plan. Recent efforts to reform cancer care payment and delivery, including the Oncology Care Model, incorporate cancer care plans. In addition, the Commission on Cancer has implemented an accreditation requirement for survivorship care planning. In this session, we will review recommendations for cancer care planning, assess the implementation of cancer care planning in oncology practices, explore patient perspectives on care planning, and describe legislative efforts to increase the adoption of care planning.

Lisa Rice  
Political and External Affairs Strategist  
Patient Advocate

Elizabeth Goss, JD  
Turner & Goss, LLP

**4:15pm**

**Breakout Sessions**

**Breakout 1**

**Communications Training: Your Story in a Nutshell**  
*Potomac Ballroom*

Your cancer survivorship story or cancer experience story is a powerful tool but using it effectively requires skill and focus. How you tell your story will be different if you are sharing it with a policymaker, with the media (on or off camera), or in written form. In this interactive workshop, you will learn tips for targeting your story to the audience and practice honing your message. *We recommend this breakout for advocates new to participating in Hill days.*

Dan Weber, MMP  
Director of Communications, NCCS

Lindsay Houff, MPP  
Public Policy Manager, NCCS

**Breakout 2**

**Presentation Training: Survivorship 101**  
*Roosevelt Boardroom*

NCCS is focused on empowering CPAT members to improve survivorship care at the local level. The goal of this workshop is two-fold—to share information about what good survivorship care looks like and to prepare advocates to give a Survivorship 101 presentation to various audiences. We will review the components of a template presentation and discuss ways you can customize it
based on your unique experience. Advocates can then return to their communities and identify venues to present the information.

We recommend this breakout for advocates who are already active in their local and national cancer community.

Shelley Fuld Nasso, MPP
Chief Executive Officer, NCCS

Kelsey Nepote, MSW
Advocacy Manager, NCCS

5:30pm

Networking Reception
Crystal City Marriott
Potomac Ballroom Hallway

Tuesday, June 26

7:00am
Yoga with Jean
Outside TBD

8:00am
Breakfast
Potomac Ballroom Foyer

9:00am
State-Based Advocacy: State Cancer Plans and Coalitions
Potomac Ballroom

Comprehensive control plans are currently in all 50 states, the District of Columbia, 6 U.S. Associated Pacific Islands and Puerto Rico, and 8 tribes or tribal organizations that assess their cancer burden, prioritize proven strategies for cancer control, and create cancer plans and put them into action. The cancer coalitions are made up of stakeholders that work together to help lower the number of people affected by cancer. These coalitions receive funding from the Centers for Disease Control and Prevention (CDC) and training and technical assistance from the National Partnership, of which NCCS is a partner. Learn more about how you can get involved in your cancer coalition and use your advocacy skills at the state and local level to address cancer issues in your community.

Leslie Given, MPA
Co-Owner & Vice President, Strategic Health Concepts

Debbie Cadet, PhD, MSW
Chair, Cancer Action Coalition of Virginia

Peggy Johnson
Co-Chair, Kansas Cancer Partnership

Lindsay Houff, MPP
Communication and the Language of Cancer

NCCS has long been committed to helping patients strengthen and enhance their interactions with doctors during a challenging and complex cancer diagnosis. Studies have shown that when patients are actively engaged in their treatment experience, they are more satisfied and have better outcomes. As advocates, what can we do to facilitate improved communication between patients and their health care team? There are two ways we can help: (1) educating and empowering ourselves and other patients, and (2) demonstrating to health care providers what good communication looks like from the patient perspective. In this workshop, we will use role-play exercises to encourage communication and discussion between CPAT members and medical students from the CUPID program.

Fred Bunz, MD, PhD
Associate Professor of Radiation Oncology
Johns Hopkins University School of Medicine
CUPID Program

Sherif Abdel-Misih, MD
Assistant Professor of Surgery
The Ohio State University Wexner Medical Center
CUPID Program

Survivorship Focus Group Discussion

NCCS is embarking on two new initiatives to improve survivorship care at the local level and to provide a new resource for cancer survivors to help them navigate their care. For both projects, we will tap into the wisdom and experience of NCCS CPAT members. In this session, our CPAT Steering Committee members will help facilitate small-group discussions that will inform our next steps on these two exciting projects.

Financial Toxicity
Cancer care can result in devastating financial burdens for patients and their families, including both the out-of-pocket costs for health care as well as other costs like transportation and the loss of income for patients and caregivers. Even people with good health insurance plans can be surprised by the deductibles, copayments, and coinsurance they are expected to contribute on top of their insurance premiums. In recent years, Dr. Yousuf Zafar and colleagues coined the term “financial toxicity” to describe the negative financial effects of cancer treatment, which can be on par with the physical side effects of cancer treatment and can lead to worse outcomes. Dr. Zafar will discuss the
evidence on financial toxicity and financial distress, as well as interventions at both the policy and clinical level to reduce the financial toxicity cancer patients and survivors experience.

Yousuf Zafar, MD
Associate Professor of Medicine and Public Policy
Duke Cancer Institute

2:15pm

The State of the Cancer Care System 2018
This session will focus on two cancer care issues: the appropriate use of targeted therapies, and policy proposals to foster transparency around the cost of cancer care. New cancer therapies include “targeted” therapies and immunotherapies, for which proper targeting is important because the drugs have serious side effects and carry great financial costs to the patient. Balancing the “costs” of the drugs against their benefits is important for both the patient and the health care system. The Trump Administration recently unveiled a drug pricing blueprint that includes proposals to create greater transparency about the cost of health care. These plans assume that giving patients more information about the cost of care will empower them to be sophisticated “purchasers.” This session will focus on how patients make decisions about targeted therapies, including immunotherapies, and whether efforts to improve health care price transparency truly improve the purchasing power of cancer patients.

Shelley Fuld Nasso, MPP
Chief Executive Officer, NCCS

Elizabeth Goss, JD
Turner & Goss, LLP

3:45pm

Break

4:00pm

Staging Your Impact: Meetings with Policymakers
Meeting with a policymaker and/or or staff member can be a great way to build relationships, become a trusted source of information and advice and foster involvement in the legislative process. Such a meeting can seem intimidating at first glance, but meeting with an elected official or staffer can be easy, informative, and fun. In this session, you will learn how to prepare for and conduct meetings and how to continue the relationship. You will have a chance to practice in a mock meeting with a policymaker.

Lindsay Houff, MPP
Public Policy Manager, NCCS

Zack Marshall
Legislative Director, Congressman Yarmuth (D-KY)

5:30pm

Break
Evening Events
6:30pm  Dinner
       Crystal City Marriott
       Chesapeake Ballroom

7:00pm  Entertainment
       Chesapeake Ballroom
       Jason Dudey
       Comedian and Cancer Survivor

Wednesday, June 27

8:00am  Breakfast
       Preparing for Hill Visits
       Potomac Ballroom

9:30am  Hill Visits