



## 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**

3:15pm

**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

Public Policy Manager, NCCS

10:00am

### **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

11:00am

### **Break**

11:15am

### **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.

12:15pm

### **Lunch**

1:00pm

### **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  
Pubic Policy Manger, 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**