

The Comprehensive Cancer Survivorship Act

Shelley Fuld Nasso, CEO

Haley Smoot, Director of Public Policy



► Background

- Bipartisan legislation first introduced December 2022
- Introduced by Representatives Debbie Wasserman Schultz (D-FL), Brian Fitzpatrick (R-PA), and Mark DeSaulnier (D-CA) and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD)
- Seeking additional cosponsors in the House
- Seeking Senate Republican to lead and introduce bill in the Senate



▶ What Does the CCSA Do?

- Addresses the health of cancer survivors throughout the entire continuum of care – from diagnosis to active treatment and post-treatment
- Aims to close many of the gaps survivors face to improve survivorship, treatment, and transition for all cancer survivors.



Comprehensive Cancer Survivorship Act

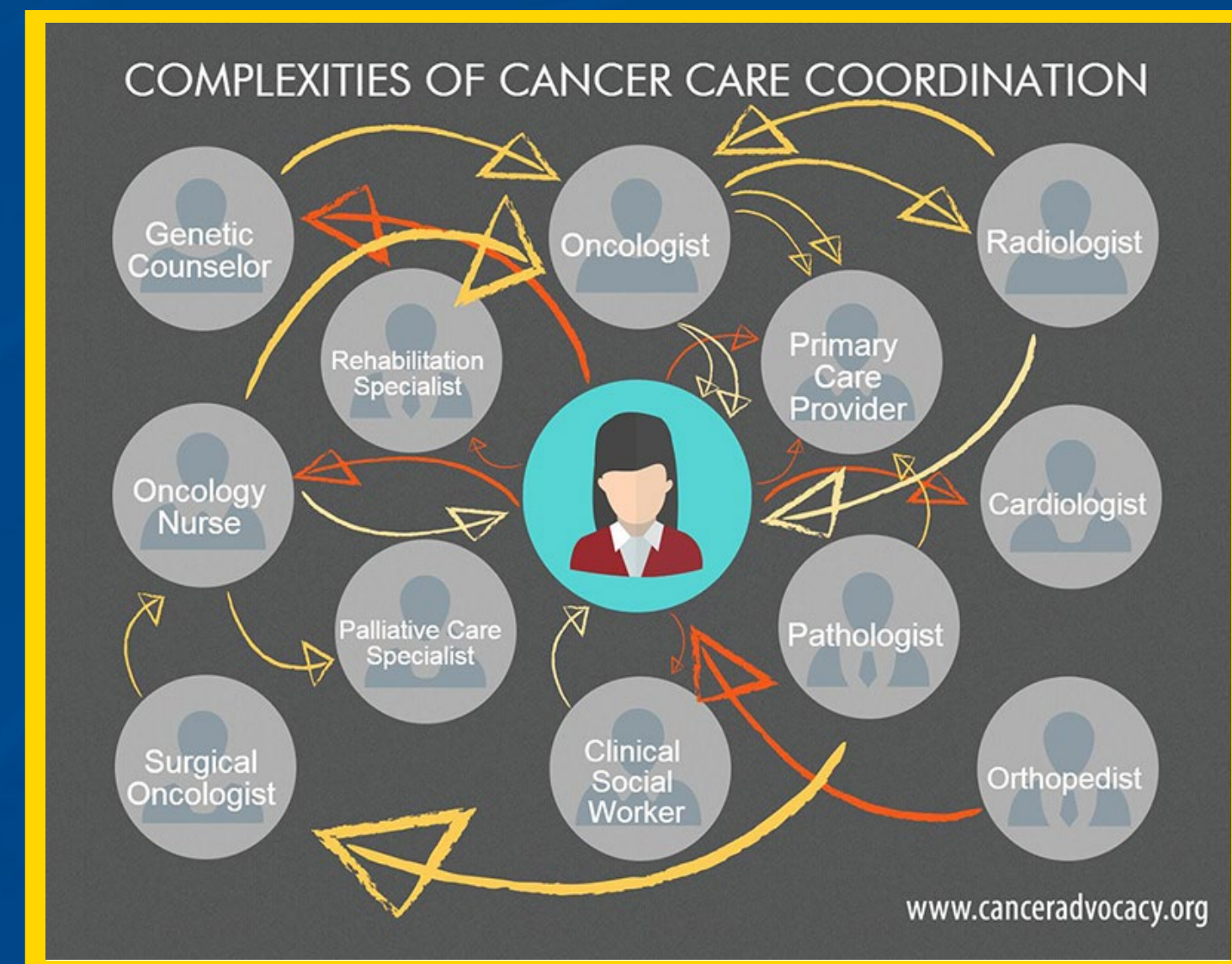
Providing a lifeline to survivors and their families
by addressing the entire survivorship continuum of care

What's in the CCSA?

- Cancer care planning and communication
- Survivor education and resource tools
- Alternative payment model
- Survivorship navigation
- Survivorship care demonstration program
- Employment assistance program
- Adult cancer survivorship study
- Support for childhood cancer survivors
- Fertility preservation for Medicaid beneficiaries

► Cancer Care Planning and Communication

- Creates Medicare service and payment for care planning and coordination services to help improve coordination of care and transition to primary care.
- Cancer care planning has been identified as an element of quality cancer care.
- In the NCCS 2020 State of Survivorship Survey, only 17% of survivors said they received a care plan.
- Without a written plan, survivors are left to navigate their cancer diagnosis without clear direction.



► Cancer Care Planning and Communication

- Will help cancer patients by supplying them a tangible plan or roadmap.
- Will promote shared decision-making between patients and their cancer care teams so patients are not left in the dark.
- Will empower patients with information necessary to help manage and coordinate their care.
- Will help providers deliver the right care at the right time, better coordinate a patient's care, and use resources effectively.



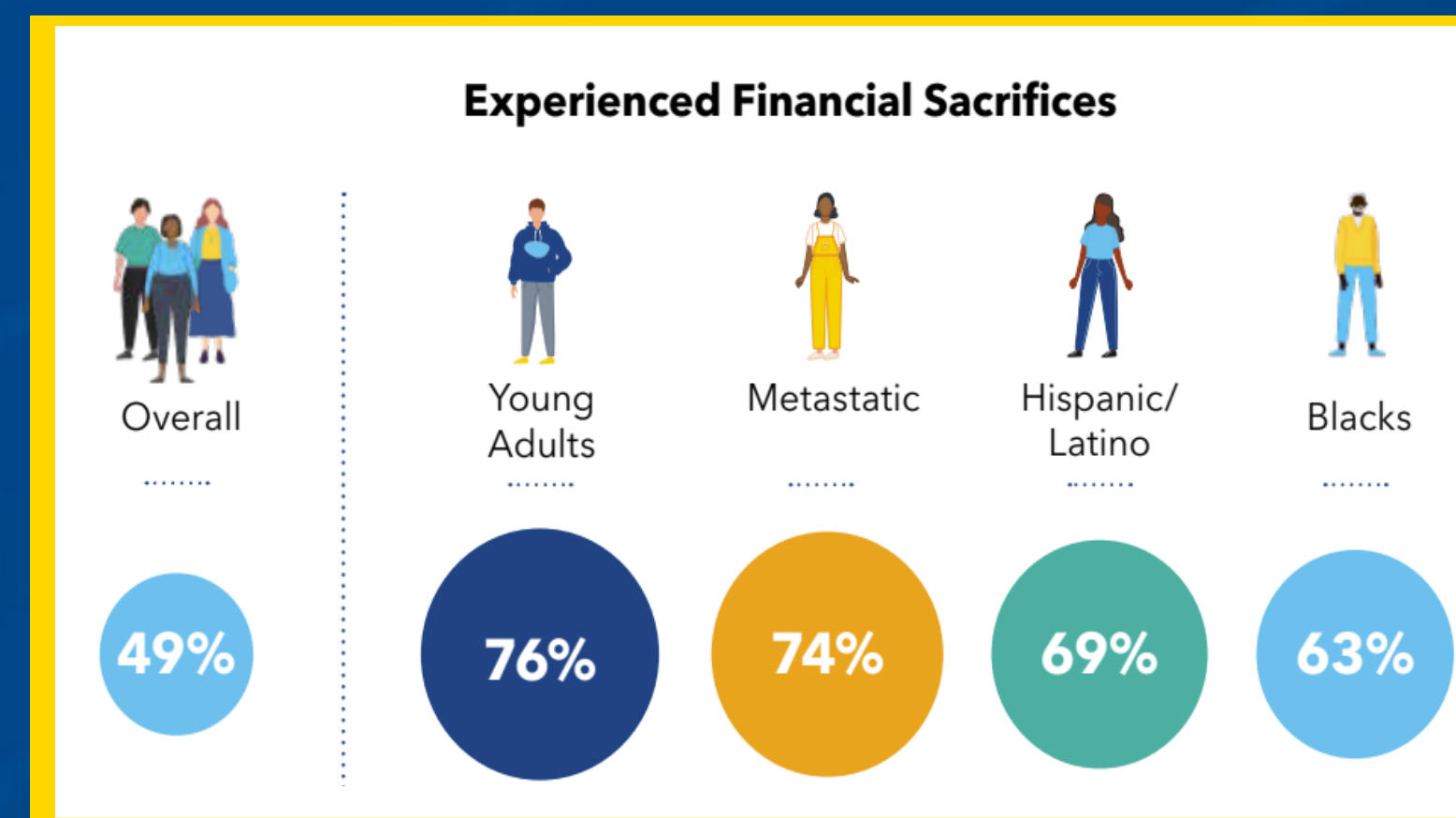
Majority of cancer patients say they discussed what to expect post-treatment with their provider (62%), but far fewer got information about exercise and nutrition (39%), long-term side effects (39%), or mental health support (24%). Only 17% report getting a post-treatment survivorship plan.

Employment Assistance

- Provides education and assistance to survivors and their families and caregivers experiencing barriers to employment as a result of a cancer diagnosis.
- Includes transportation, childcare, nutritional, physical activity, psychosocial, and financial assistance and career and training services.
- Applies to cancer survivors who remain employed during treatment, who must reduce their working hours while in treatment, and who reenter employment after treatment, as well as their families and caregivers.

► Employment Assistance

- Many survivors experience financial toxicity because of lost wages and out-of-pocket costs associated with parking and travel for doctor appointments.
- Survivors have higher “patient time costs” (time spent receiving care which could be used for other purposes) than those without a cancer history.
- Targeted assistance can help cancer survivors facing employment challenges remain employed and financially stable.

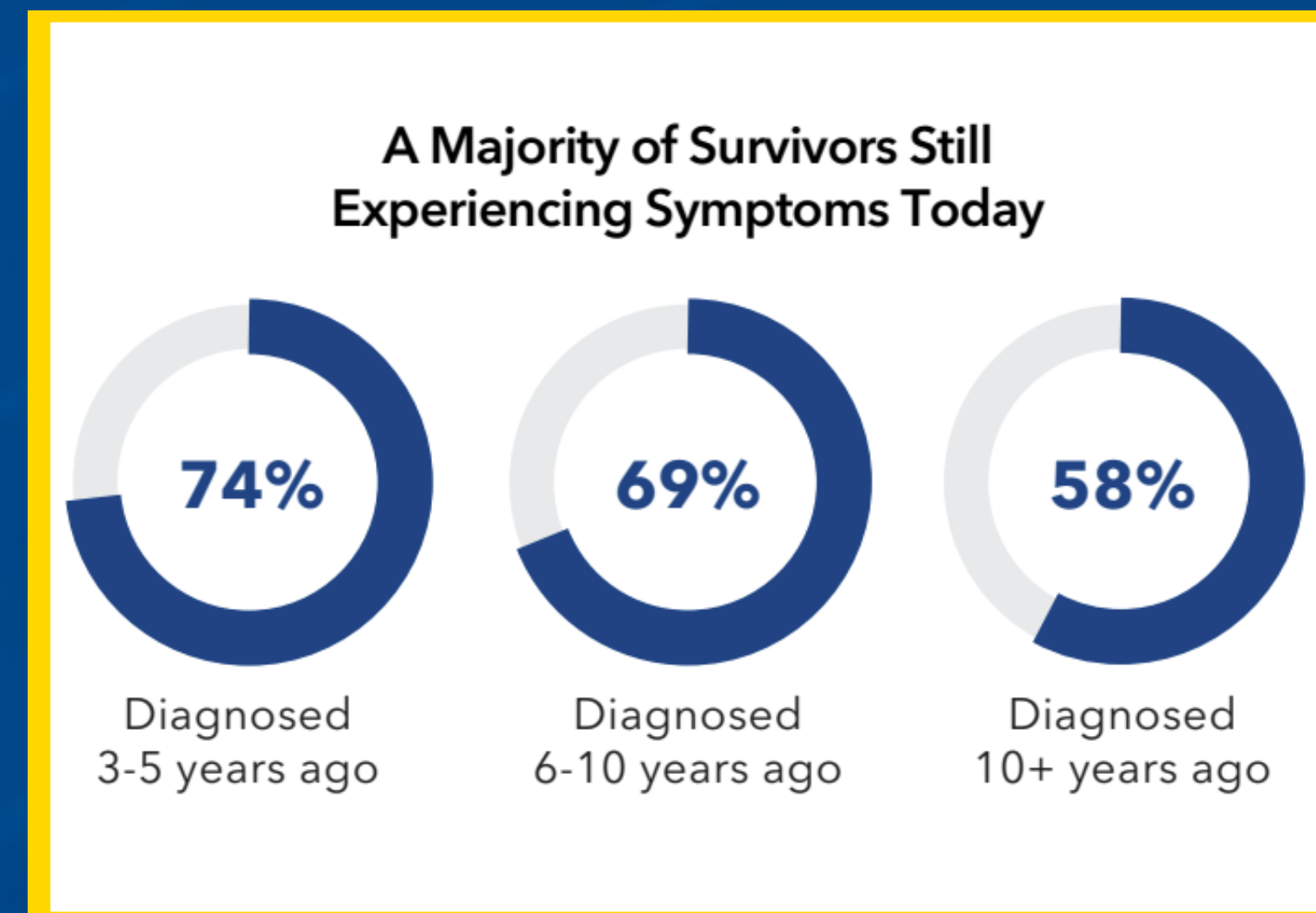


Adult Cancer Survivorship Study

- Requires an analysis to assess the benefits of creating an adult version of the Childhood Cancer Survivor Study.
- The study would collect information about late and long-term effects of cancer to:
 - Help better understand these effects
 - Improve treatments and interventions to increase survival, minimize harmful health effects, and improve quality of life

▶ **Adult Cancer Survivorship Study**

- Survivors are at risk of developing future health problems due to their cancer treatment, often decades after completing treatment.
- This study would provide important data and insights to help survivors and their health care providers make informed decisions about their care.
- It would also help ensure future cancer survivors have access to the best possible care.



▶ The Meeting

- **Brief introductions**
 - Share your name, city, connection to cancer, and that you're an NCCS advocate
- **State the purpose of the meeting**
 - Share that you're advocating for the Comprehensive Cancer Survivorship Act
- **Share your story**
- **Make the ask (OR thank them if they are a cosponsor)**
 - House: Will you cosponsor the CCSA?
 - Senate: Will you cosponsor this legislation once it's introduced in the Senate?



Comprehensive Cancer Survivorship Act Telling Your Story: A Step-by-Step Worksheet

People have been telling stories since human beings first sat around campfires. We are hard-wired to take in new information through stories.

Statistics reach people in the head. Stories hit people in the heart. Sharing your personal experience is a powerful way to establish a connection and drive your listener to action. Your audience (e.g. elected officials, donors, the media, other volunteers) may disagree with your facts or arguments, but they cannot argue with your unique personal experience.

The steps below are based on research in effective storytelling, but you should tailor them to your own circumstances.

1. Hi. I'm [name] from [place].

If meeting with a member of Congress, identify yourself as living in their district.

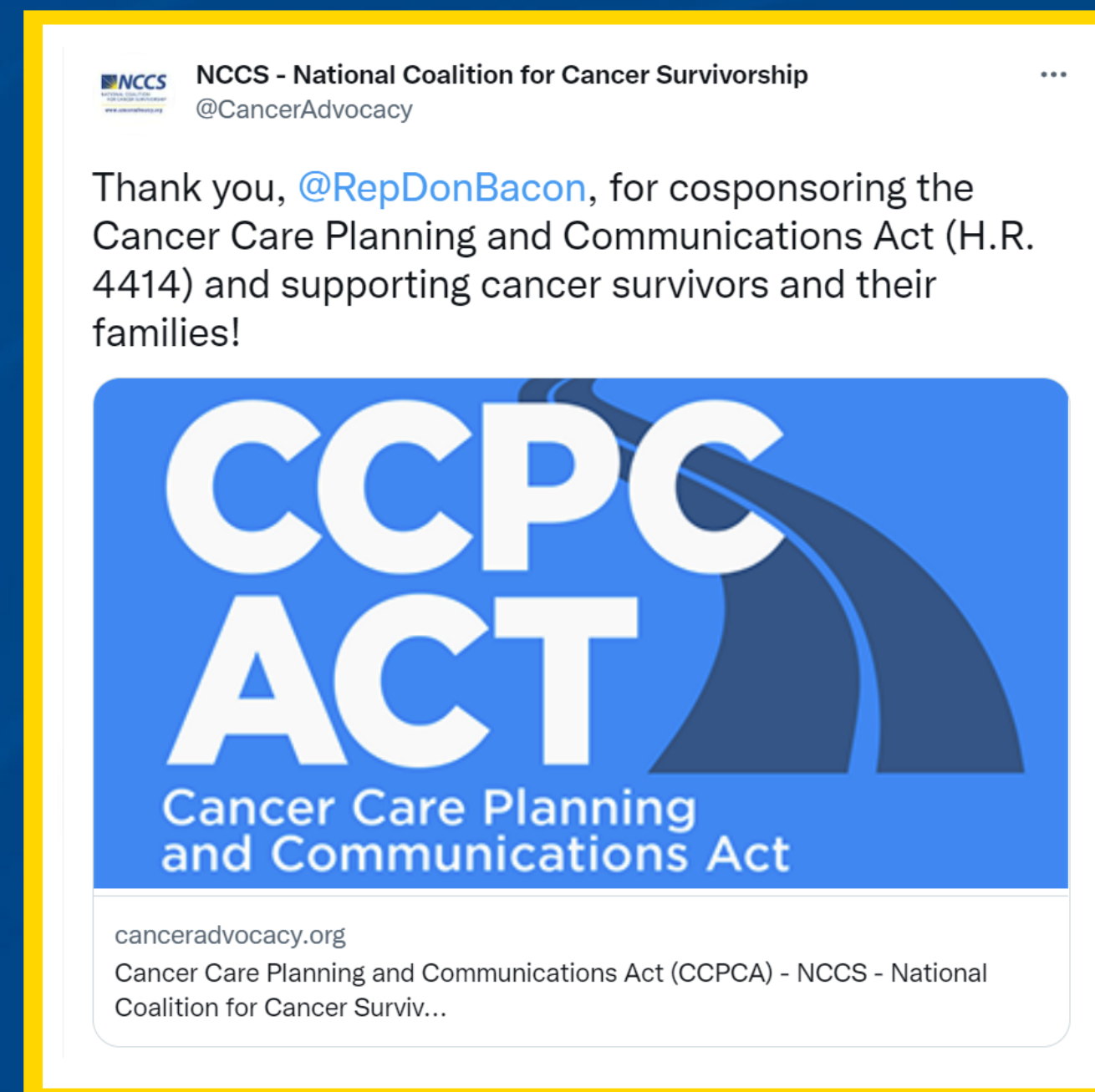
2. My life changed when [describe your diagnosis or a loved one's].

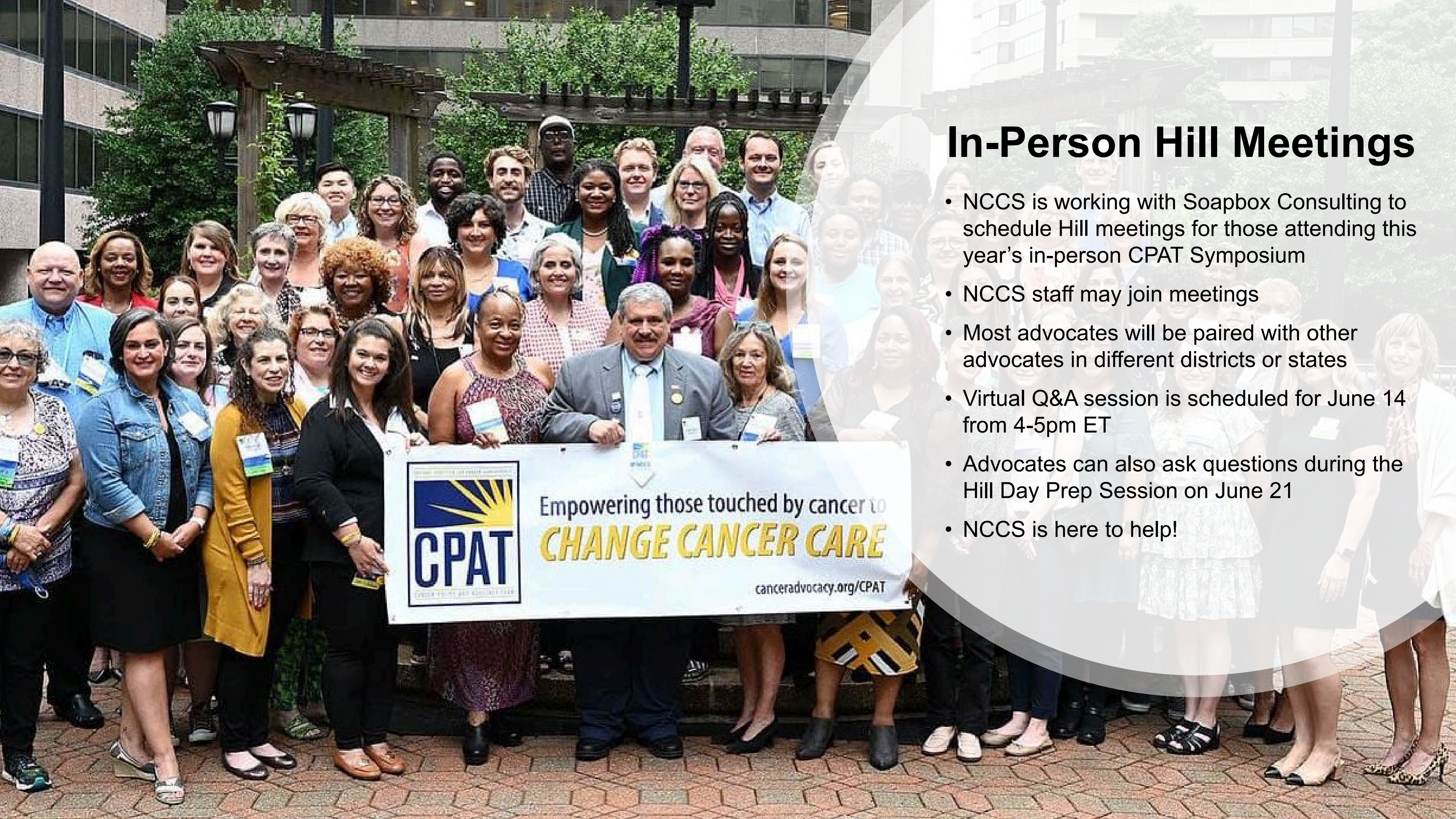
Example: I had to undergo multiple surgeries and rounds of chemotherapy, which took a physical and mental toll on me. Despite having a good relationship with my doctors, it was difficult to coordinate my care between them, leading to confusion and frustration.

Example: As my father's primary caregiver when he was diagnosed with cancer, I had to navigate a complex health care system that I knew little about. I was constantly worried about whether I was making the right decisions for his care and felt like I had to advocate for him at every turn.

▶ After Your Meeting

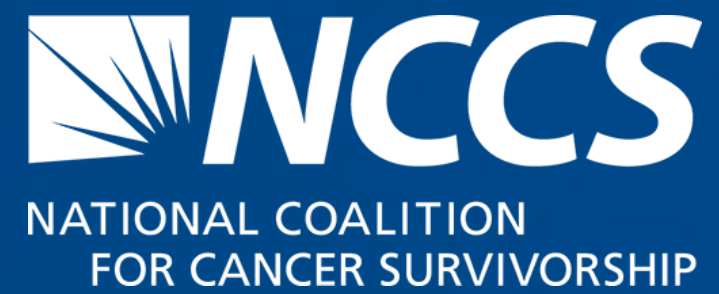
- Tweet to thank your legislator for the meeting and restate the ask
- Send thank you emails with responses to any outstanding questions
- Follow up with Hill and NCCS staff on action items, if any
- If your member takes action, thank them and their staff





In-Person Hill Meetings

- NCCS is working with Soapbox Consulting to schedule Hill meetings for those attending this year's in-person CPAT Symposium
- NCCS staff may join meetings
- Most advocates will be paired with other advocates in different districts or states
- Virtual Q&A session is scheduled for June 14 from 4-5pm ET
- Advocates can also ask questions during the Hill Day Prep Session on June 21
- NCCS is here to help!



Questions?

Email hsmoot@canceradvocacy.org

