

Hill Day Preparation

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► Comprehensive Cancer Survivorship Act

- 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)





The Ask:

Will you cosponsor the Comprehensive Cancer Survivorship Act when it is introduced?



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?

- Coverage cancer care planning and communication
- Survivorship transition tools
- Alternative payment model
- Survivorship navigation
- Survivorship care demonstration program
- Employment assistance program
- Adult cancer survivorship study
- Survivorship progress report
- Easing transition to primary care for children with cancer
- Childhood cancer demonstration model and standard of care
- Medicaid coverage of fertility preservation

- ▶ **We are highlighting three key provisions**
 - Cancer care planning and communication
 - Employment assistance program
 - Adult cancer survivorship study

▶ The Meeting

- Brief introductions (name, city, connection to cancer, NCCCS advocate)
- State the purpose of the meeting – to advocate for the Comprehensive Cancer Survivorship Act
- Share your story
- Make the ask: Will you cosponsor the CCSA once it is introduced?
- Take a photo



DOs for Hill Meetings



- Be prepared
- Be on time
- Be flexible
- Be respectful
- Be concise
- Share the spotlight
- Be responsive
- Be appreciative
- Use social media
- Follow up

DON'Ts for Hill Meetings

- Overload the Hill visit with other issues
- Expect your legislator or staffer to be an expert on the issue
- Be afraid to say “I don’t know”
- Be offended if your legislator is unable to meet with you
- Confront, threaten, or pressure

Telling Your Story

NCCCS' Telling Your Story Worksheet can help you identify the key pieces of your story while also keeping your story concise and compelling.



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

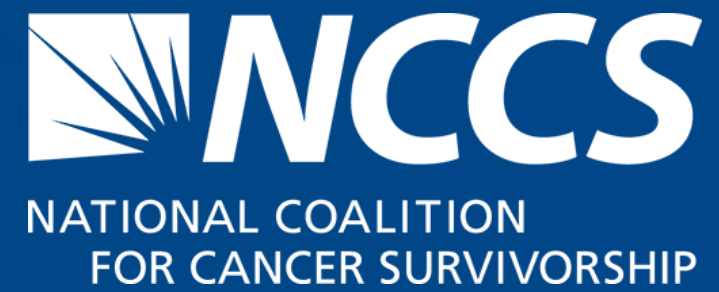
People have been telling stories since human beings first sat around campfires. We are hard-wired to take in new information through stories.

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.

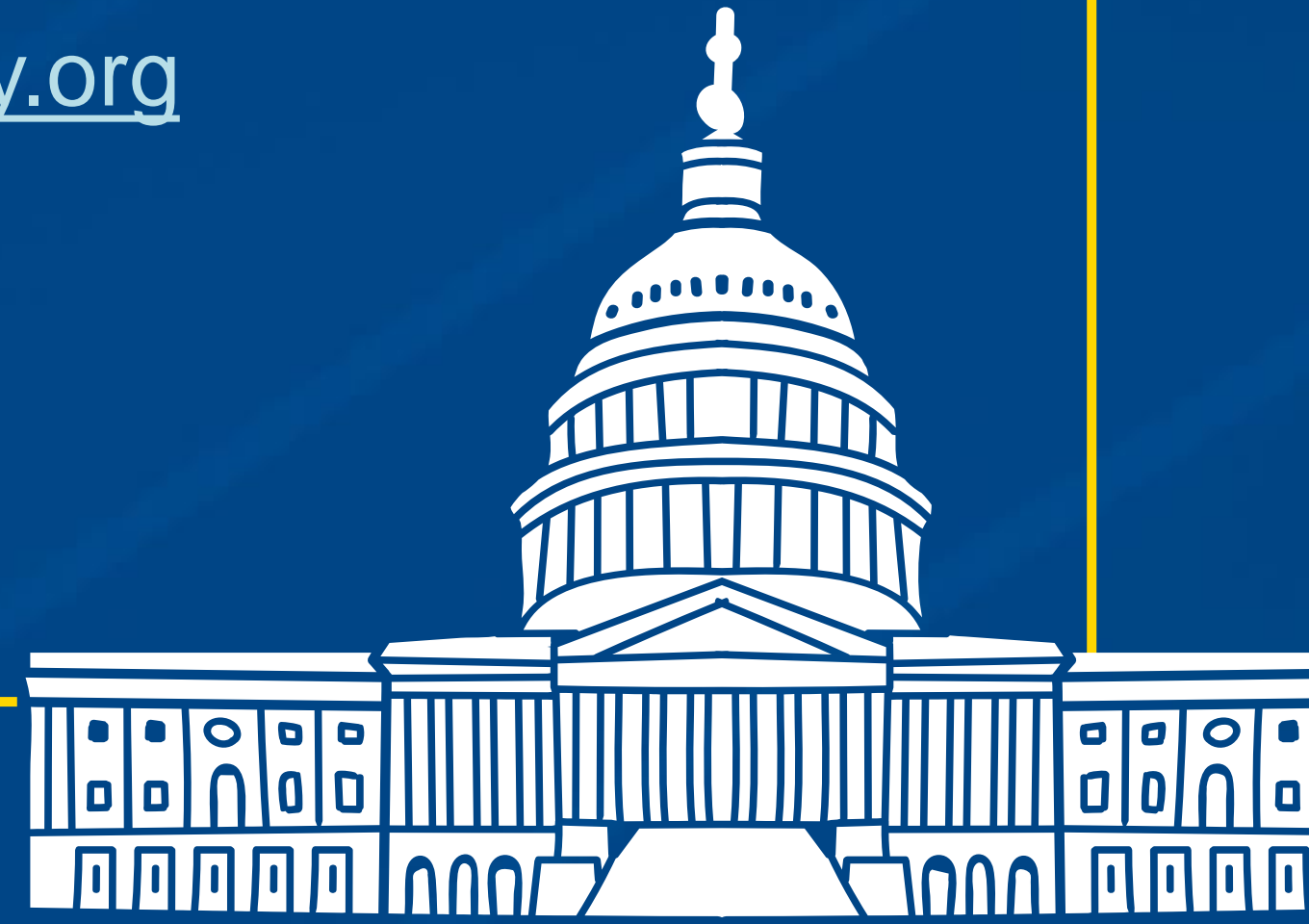
1. Hi. I'm [name] from [place].
If meeting with a member of Congress, identify yourself as living in their district.

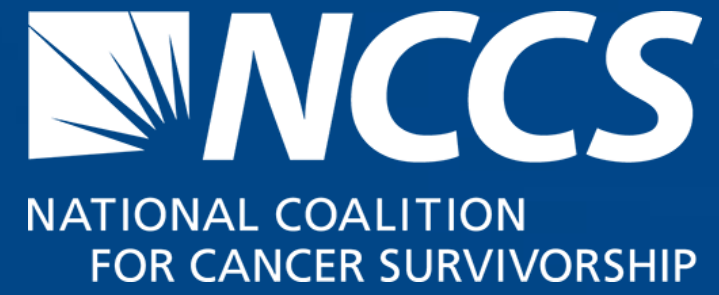
2. My life changed when [describe your diagnosis or a loved one's].
Example: I had to undergo multiple surgeries and rounds of chemotherapy, which took a physical and mental toll on me. Despite having a good relationship with my doctors, it was difficult to coordinate my care between them, leading to 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.



Questions?

Email hsmoot@canceradvocacy.org



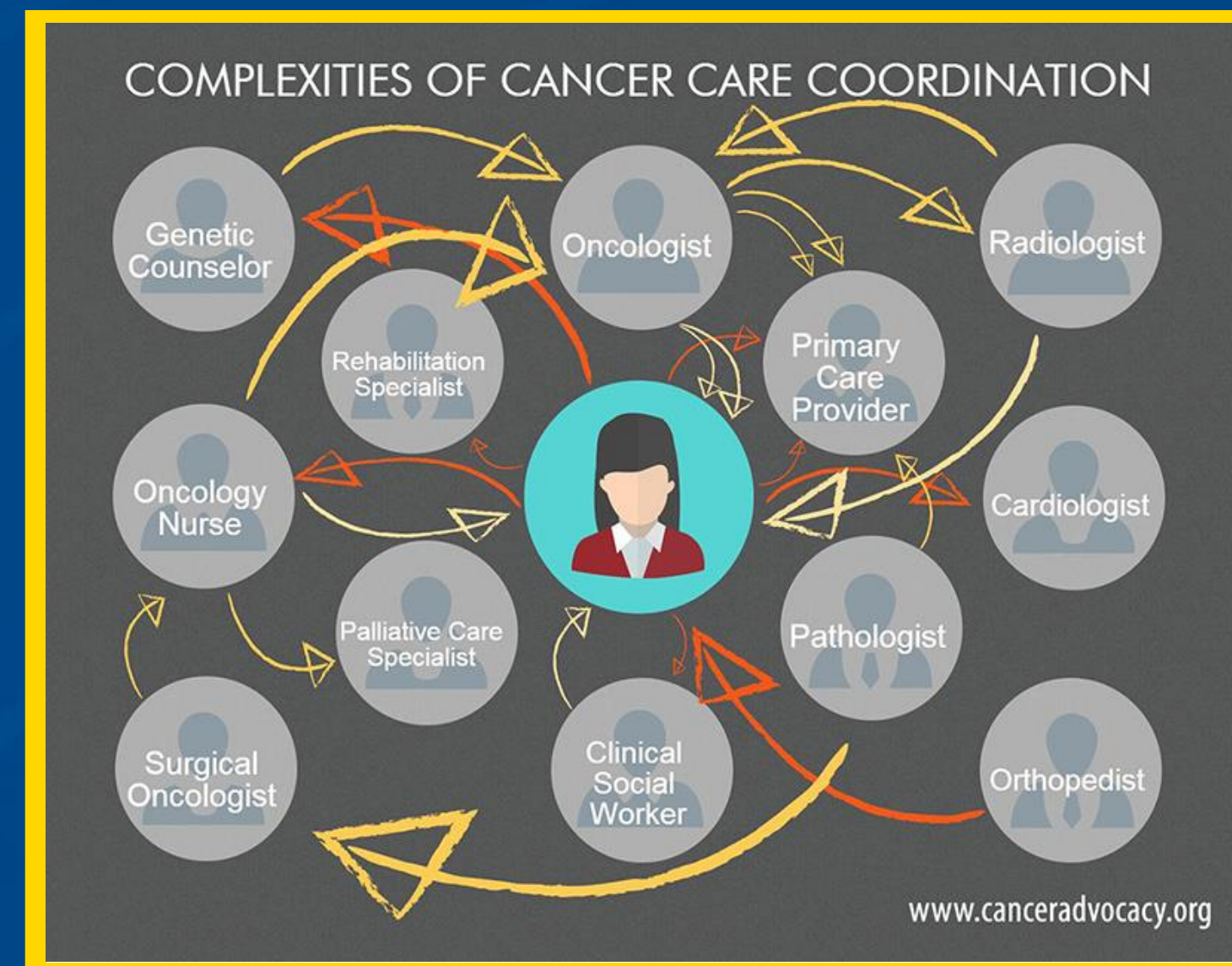


Backup Slides



► 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.



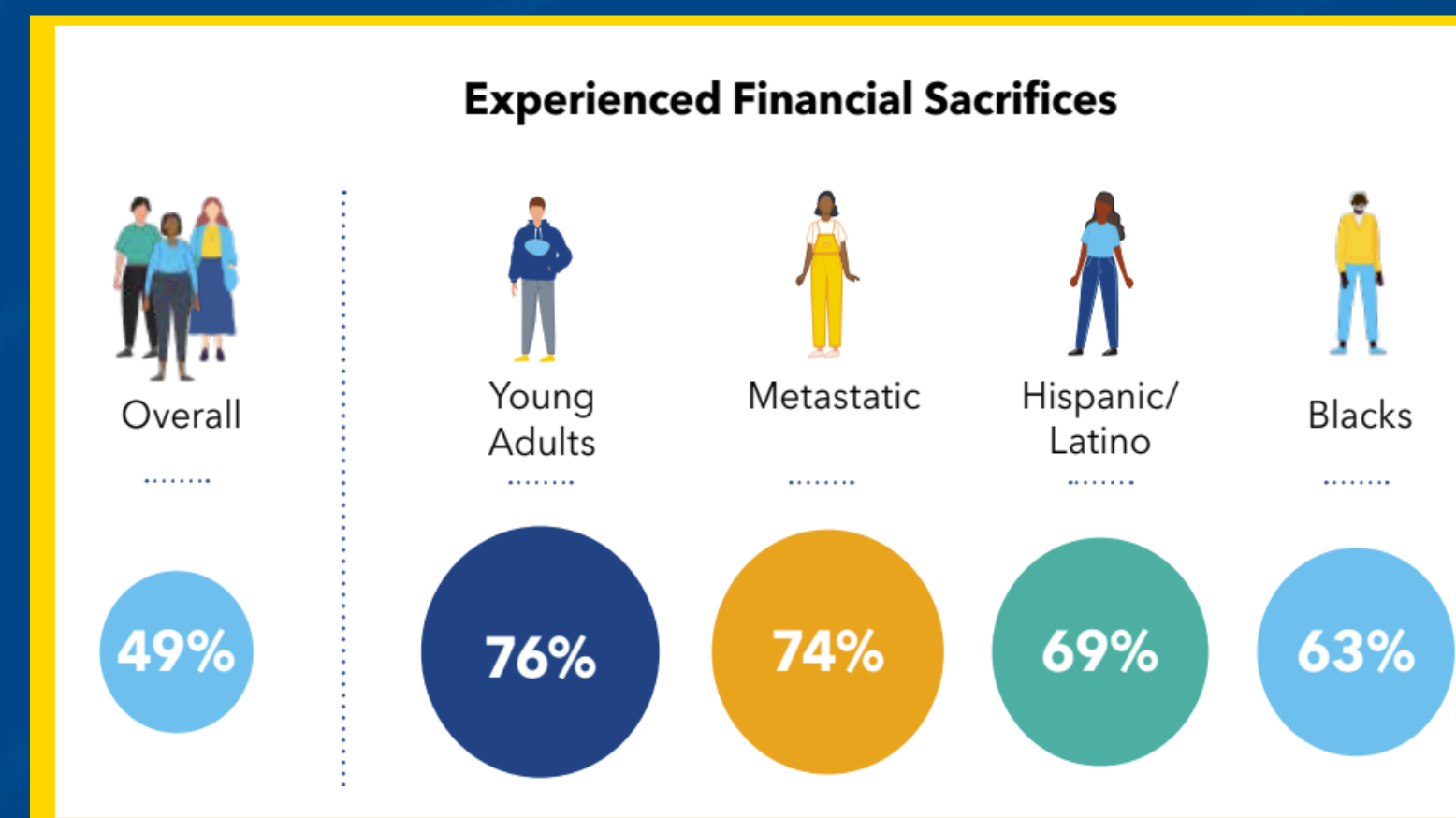
Majority of cancer patients say they discussed what to expect post-treatment with their provider (62%), but far fewer got information about exercise and nutrition (39%), long-term side effects (39%), or mental health support (24%). Only 17% report getting a post-treatment survivorship plan.

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.

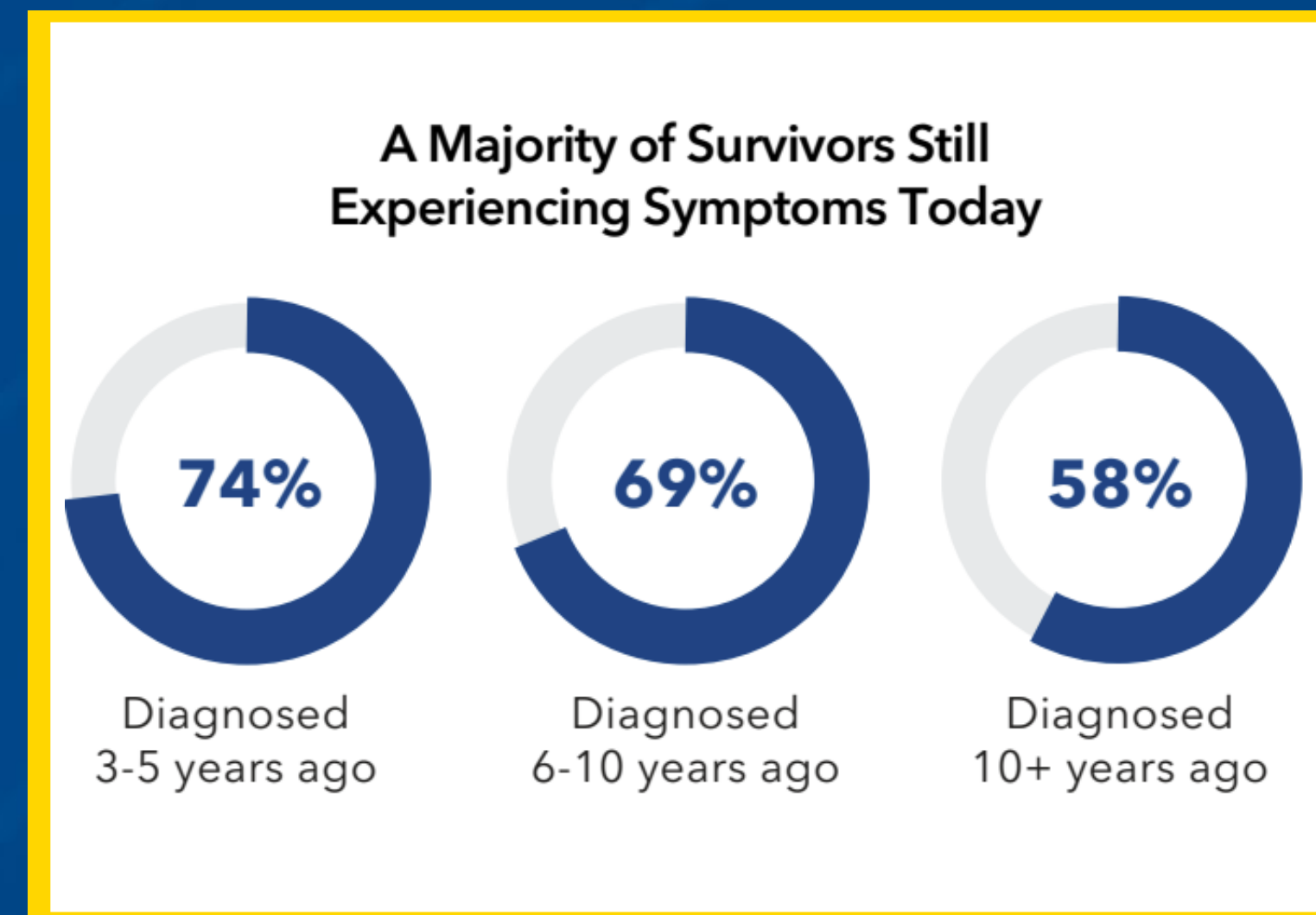


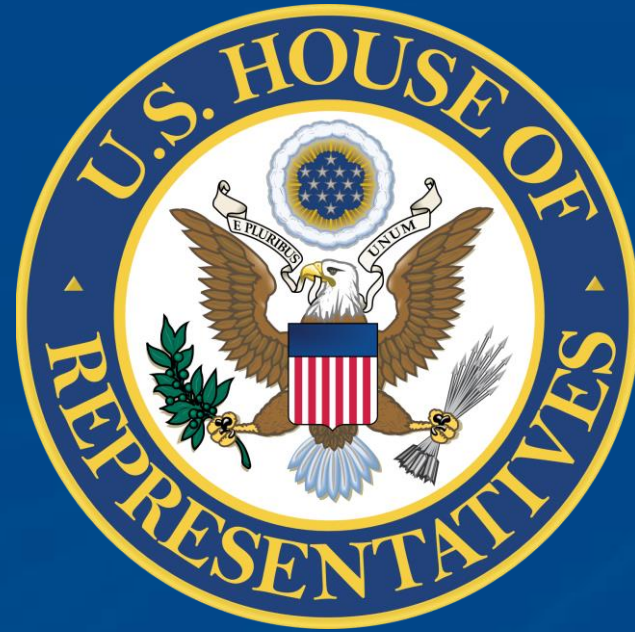
Adult Cancer Survivorship Study

- 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.





- **1 representative per district**
- **# based on population**
- **435 voting members**
- **6 non-voting members (e.g. DC, PR, Guam, etc.)**
- **2-year terms***



- **2 senators per state**
- **100 total**
- **6-year terms**
- **1/3 of seats up for election every two years**

*Puerto Rico's resident commissioner serves a 4-year term.

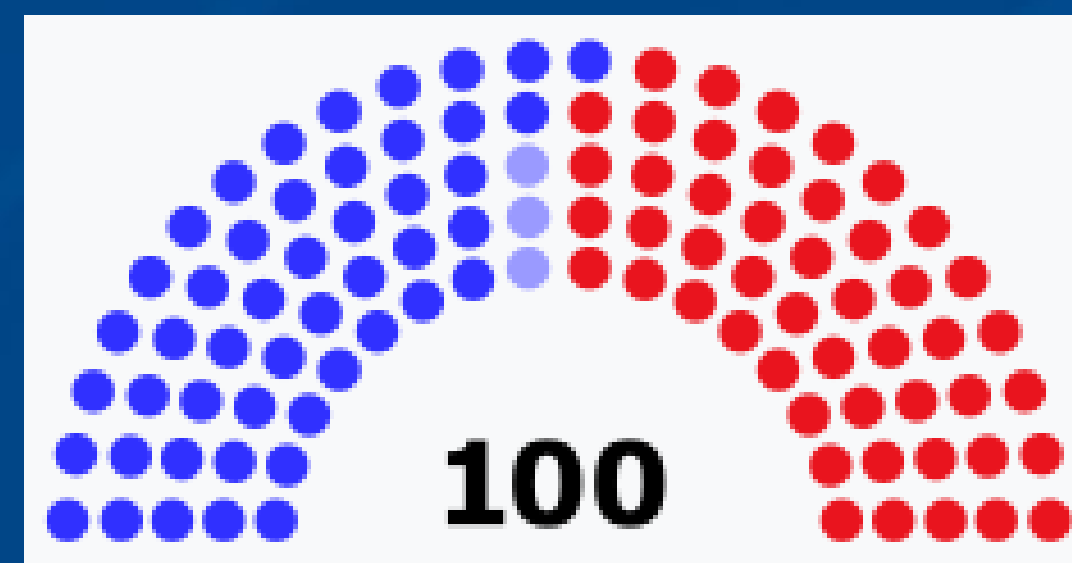
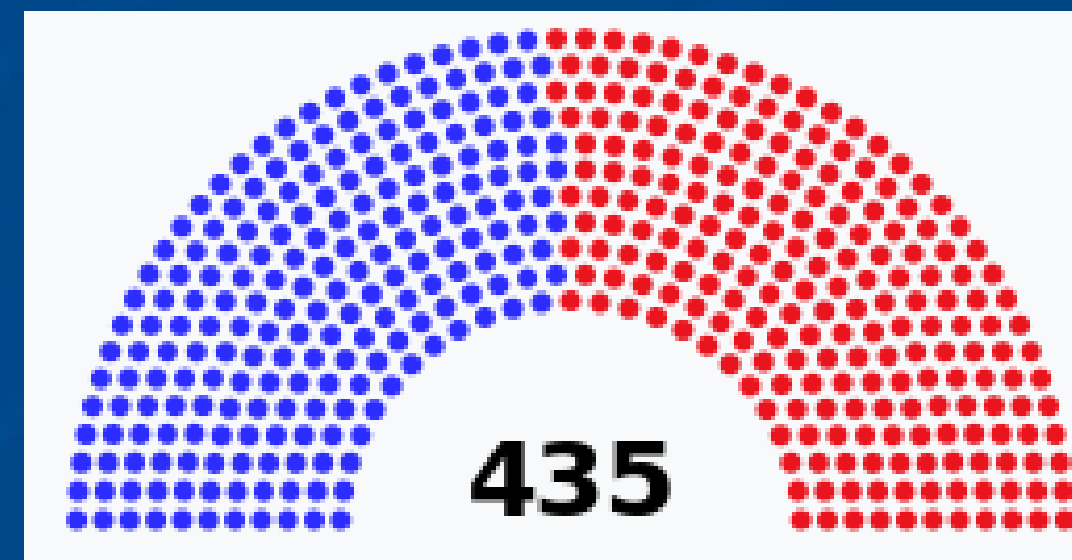
▶ 118th Congress

House of Representatives

- 435 representatives
 - 222 Republicans
 - 213 Democrats
 - 0 vacant seats
 - 6 non-voting members (e.g. PR, DC, Guam)

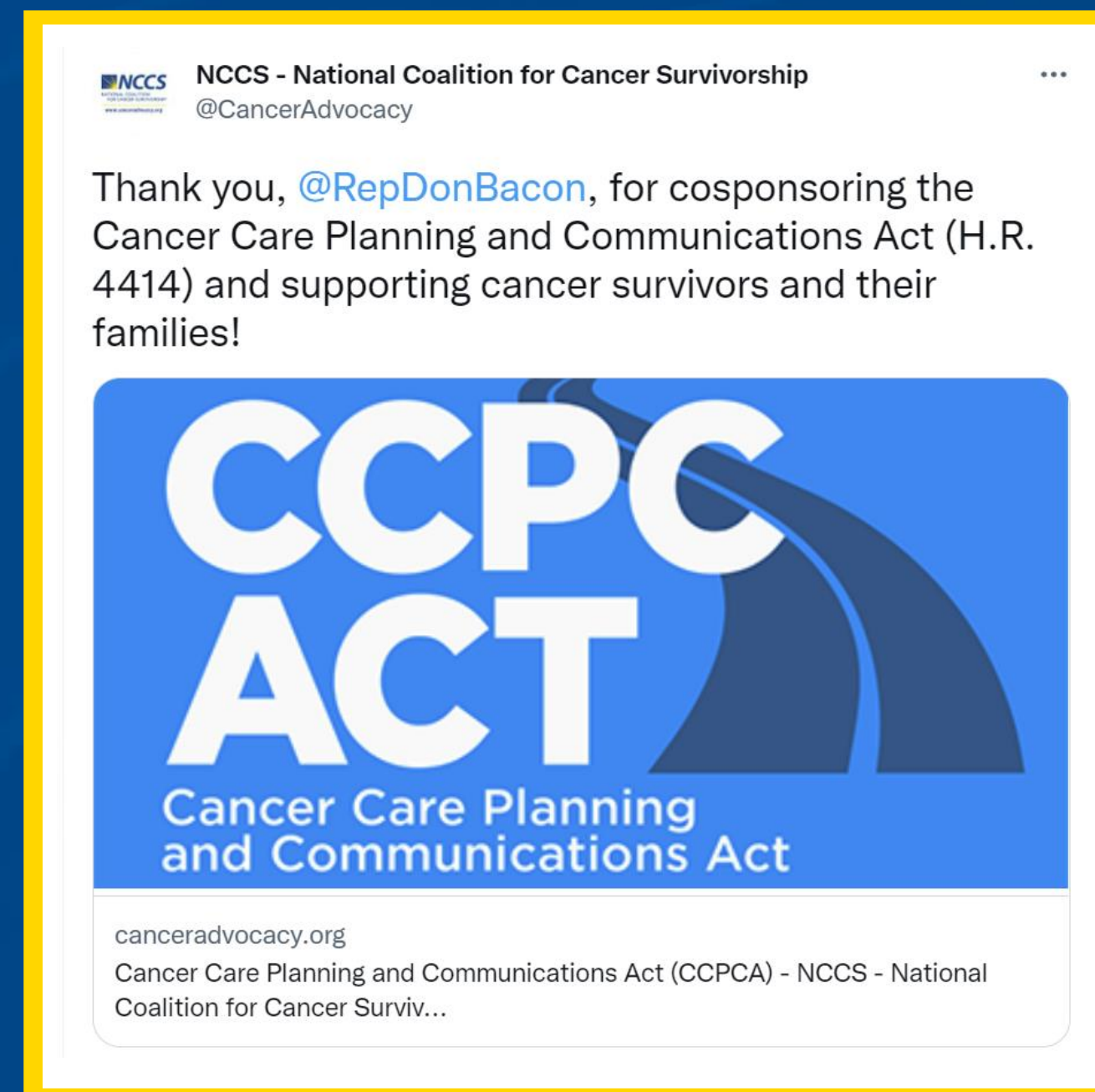
Senate

- 100 senators
 - 48 Democrats
 - 3 Independents (caucus with Ds)
 - 49 Republicans
 - VP Harris casts tie-breaking votes



▶ After the 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



▶ After the Meeting

- Reach out to local media to share about your experience
- Watch Media Training Webinar and download template press release

DAILY TIMES

8th-grade students at Media-Providence Friends...



Yvonne McLean Florence of Drexel Hill, cancer survivor and advocate for others suffering with cancer, was chosen to share her experiences with members of Congress on Hill Day in Washington D.C. to raise awareness about the importance of the Comprehensive Cancer Survivorship Act and the impact it will have on the lives of cancer survivors and their families. (COURTESY PHOTO)

Drexel Hill advocate participates in cancer policy and advocacy team

Cancer survivor/advocate Yvonne McLean Florence of Drexel Hill was chosen by the National Coalition for Cancer Survivorship (NCCS) to participate in their annual Hill Day on June 22 on Capitol Hill in Washington.

► **Maintaining Relationships – Stay Engaged!**

- Subscribe to the legislator's email list and follow on social media
- Don't be afraid to check in with staff regularly
- Serve as a resource on cancer issues
- Invite your member to local cancer community events in your hometown
- Thank them for co-sponsoring legislation
- Schedule in-district meetings
- Attend town hall meetings