

Comprehensive Cancer Survivorship Act

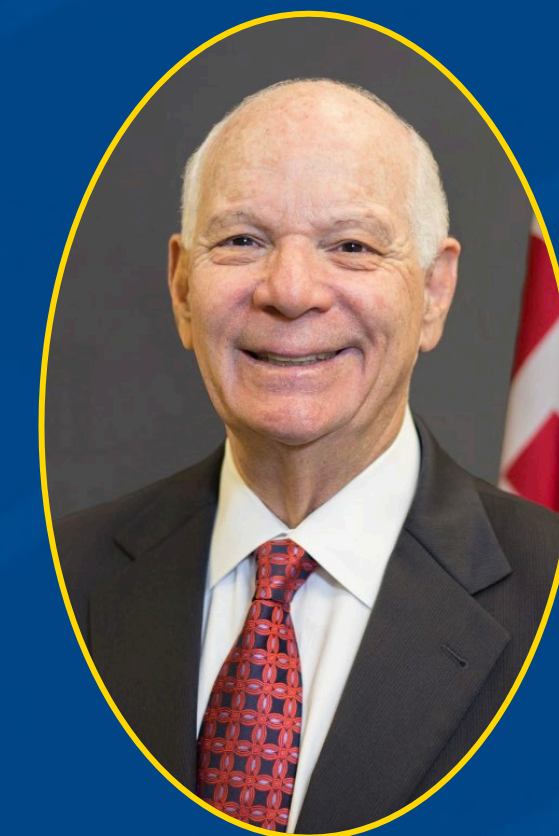
Meeting with Members of Congress at Home



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► Comprehensive Cancer Survivorship Act (CCSA)

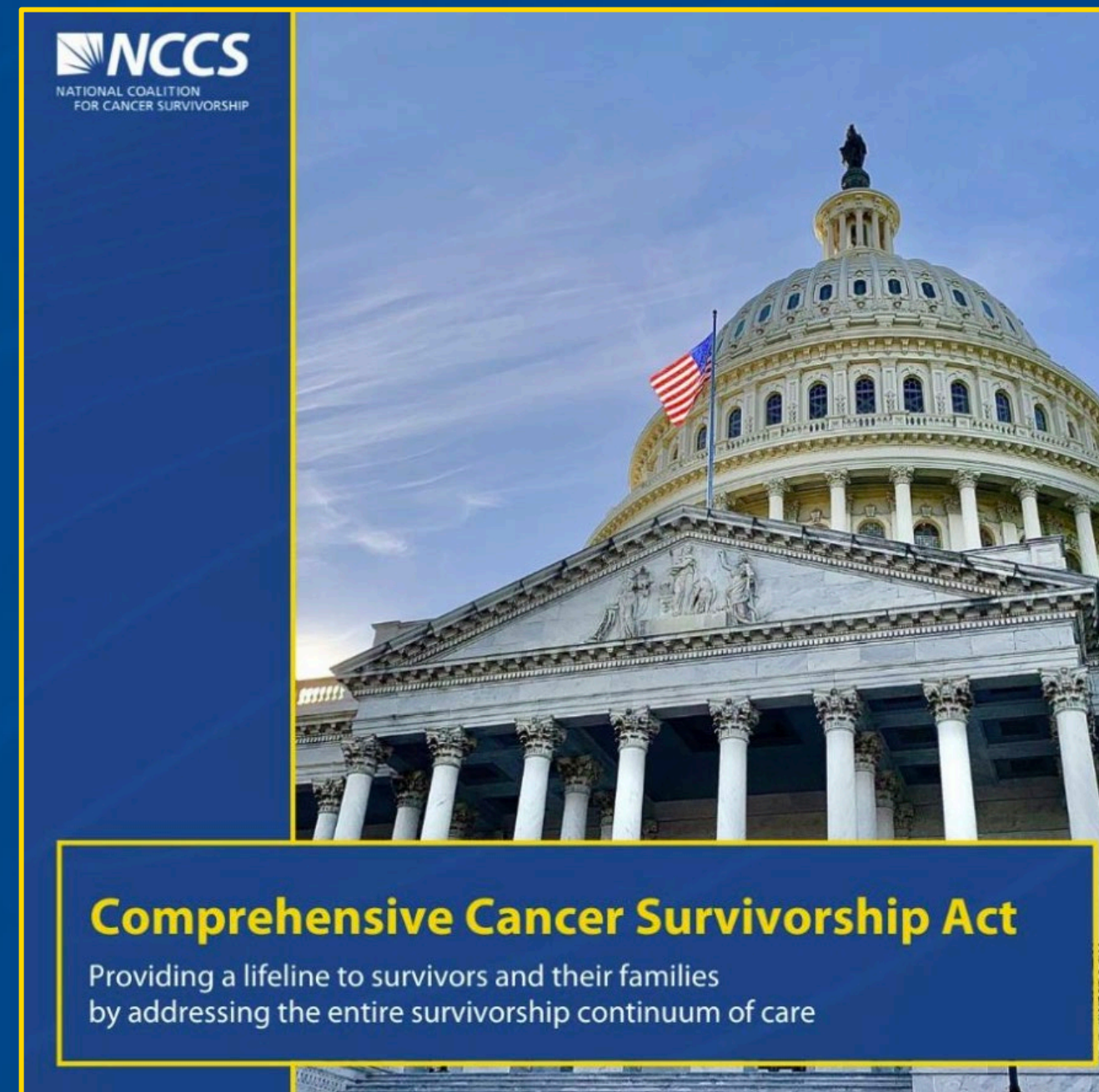
Bipartisan legislation introduced by Representatives Debbie Wasserman Schultz (D-FL), Brian Fitzpatrick (R-PA), Mark DeSaulnier (D-CA) and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD)



▶ What Does the CCSA Do?

This legislation addresses the entire continuum of care – from diagnosis to active treatment and post-treatment – to improve survivorship, treatment, and transition for all survivors. CCSA intends to:

- Provide coverage for care planning services to address transition to primary care
- Develop navigation services for survivorship
- Establish employment assistance grants for survivors, caregivers, and their families
- Provide education and awareness through resources for survivors and health care providers
- Ensure coverage for fertility preservation services
- Require study of the existing reimbursement landscape and development of an alternative payment model, among many other things



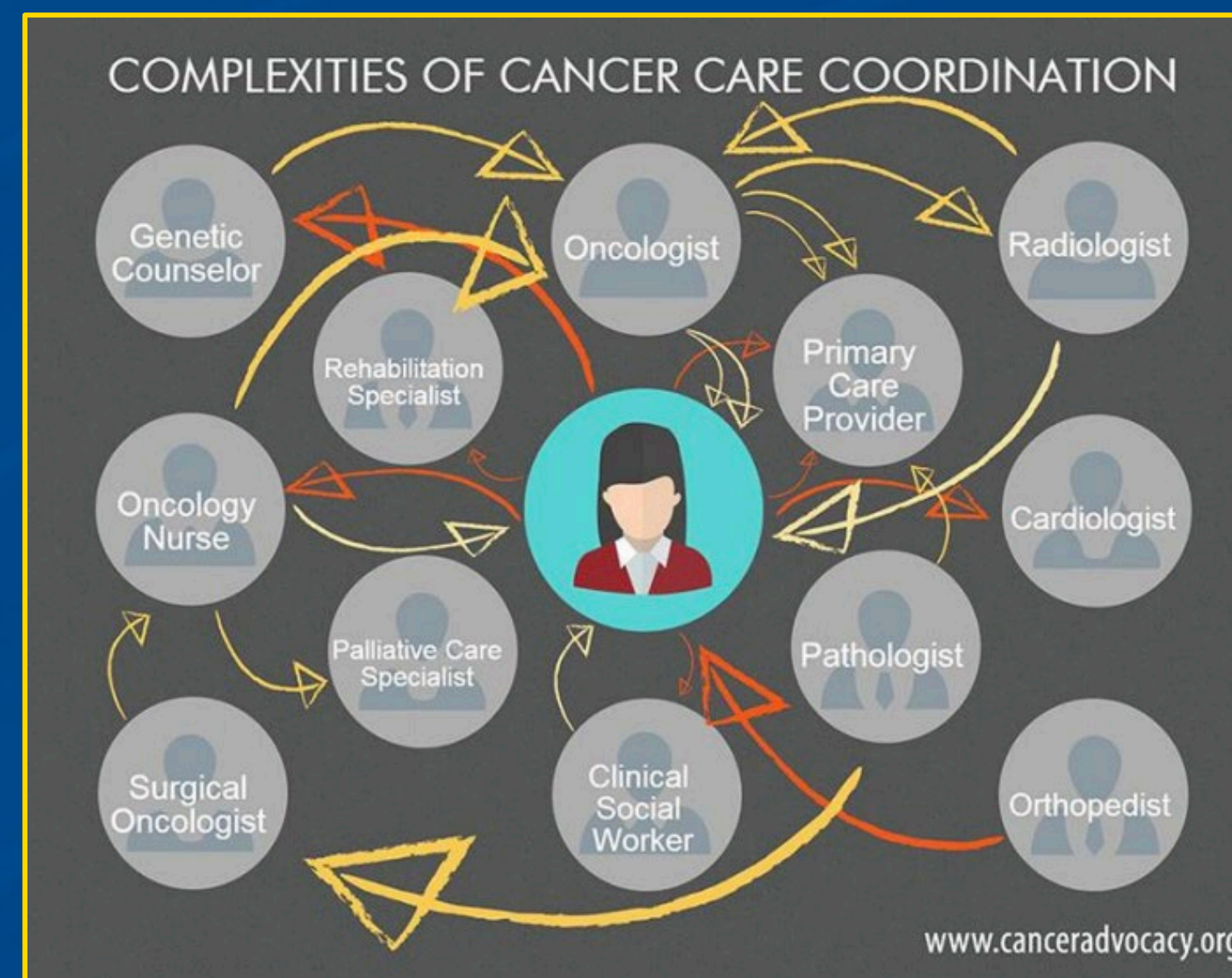
NCCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

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

► Cancer Care Planning and Communication

Creates a Medicare service and payment for cancer care planning and coordination services to help improve cancer survivors' coordination of care and transition to primary care.

- Without a written plan, survivors are left to navigate their cancer diagnosis without clear direction.
- Will promote shared decision-making between patients and their cancer care teams.
- Will empower patients with the information necessary to help manage and coordinate their care and allow providers to deliver the proper care at the right time, better coordinate a patient's care, and use resources effectively.

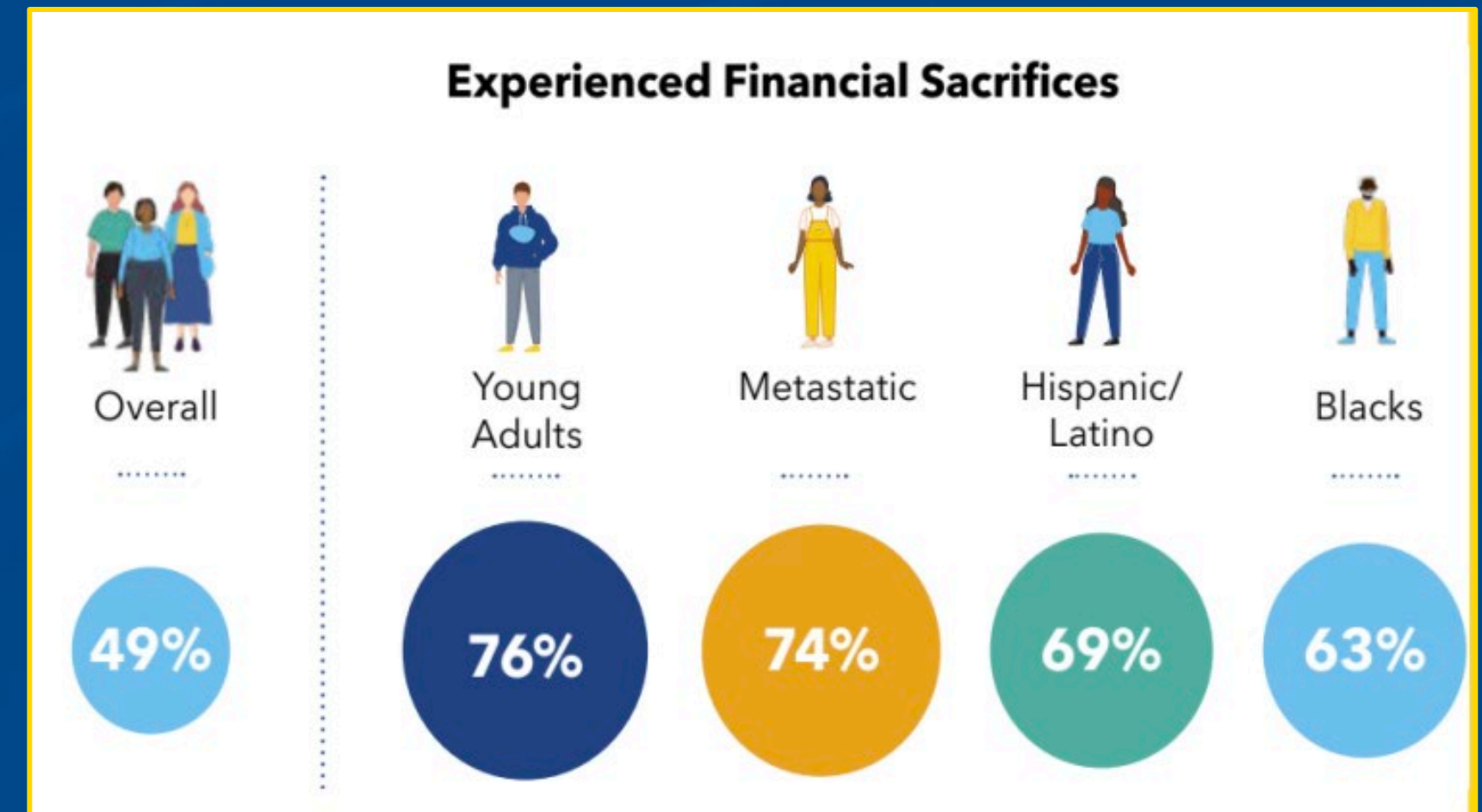


► Employment Assistance Program

Establishes a grant program to provide education and targeted assistance to cancer survivors, their families, and caregivers experiencing barriers to employment due to a cancer diagnosis.

Many survivors experience financial toxicity because of lost wages and out-of-pocket costs associated with parking and travel for doctor appointments.

The bill provides targeted assistance like career and training services and transportation, financial, and psychosocial support, which can help cancer survivors facing employment challenges remain employed and financially stable.

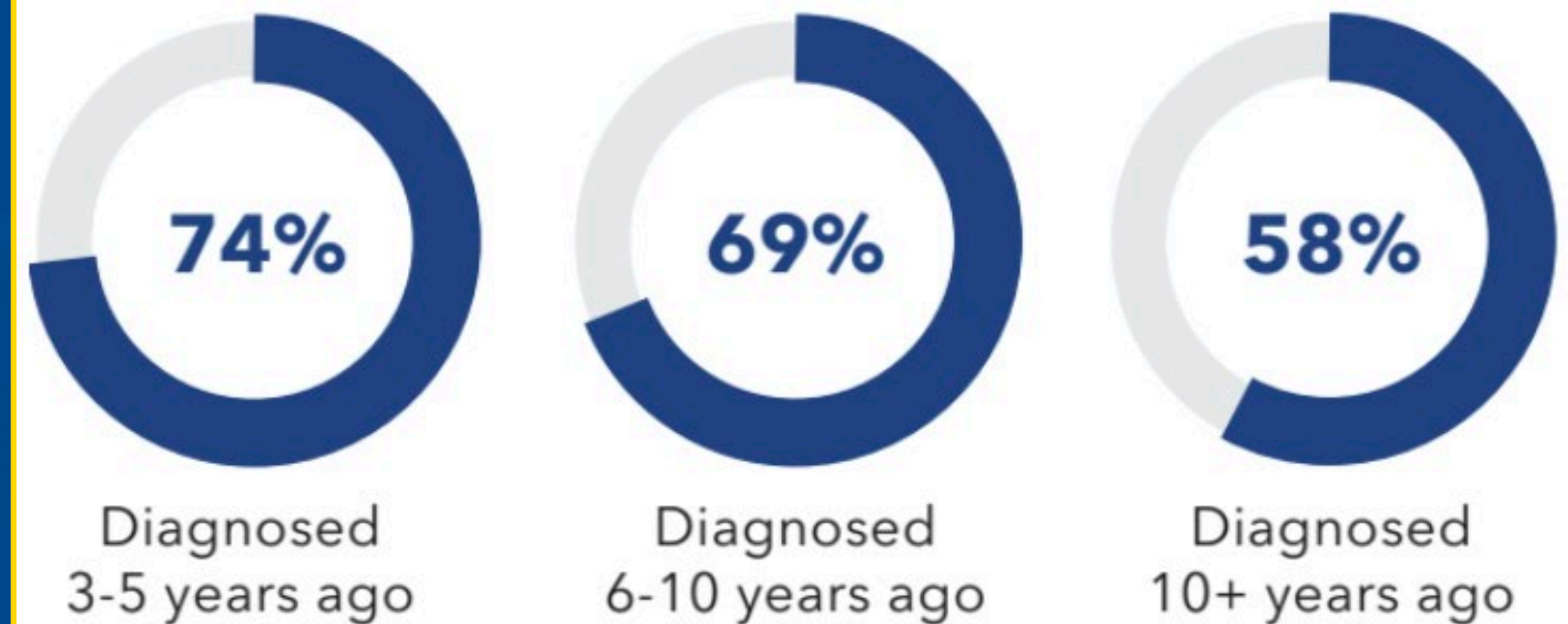


▶ Adult Cancer Survivorship Study

Requires an analysis assessing the benefits of creating an adult version of the Childhood Survivor Study, which would collect information about late and long-term effects of cancer.

- The study would provide important data and insights to help survivors and their health care providers make informed decisions about their care.
- Would improve treatments and interventions to increase survival, minimize harmful health effects, and improve quality of life, ensuring future cancer survivors have access to the best possible care.

A Majority of Survivors Still Experiencing Symptoms Today



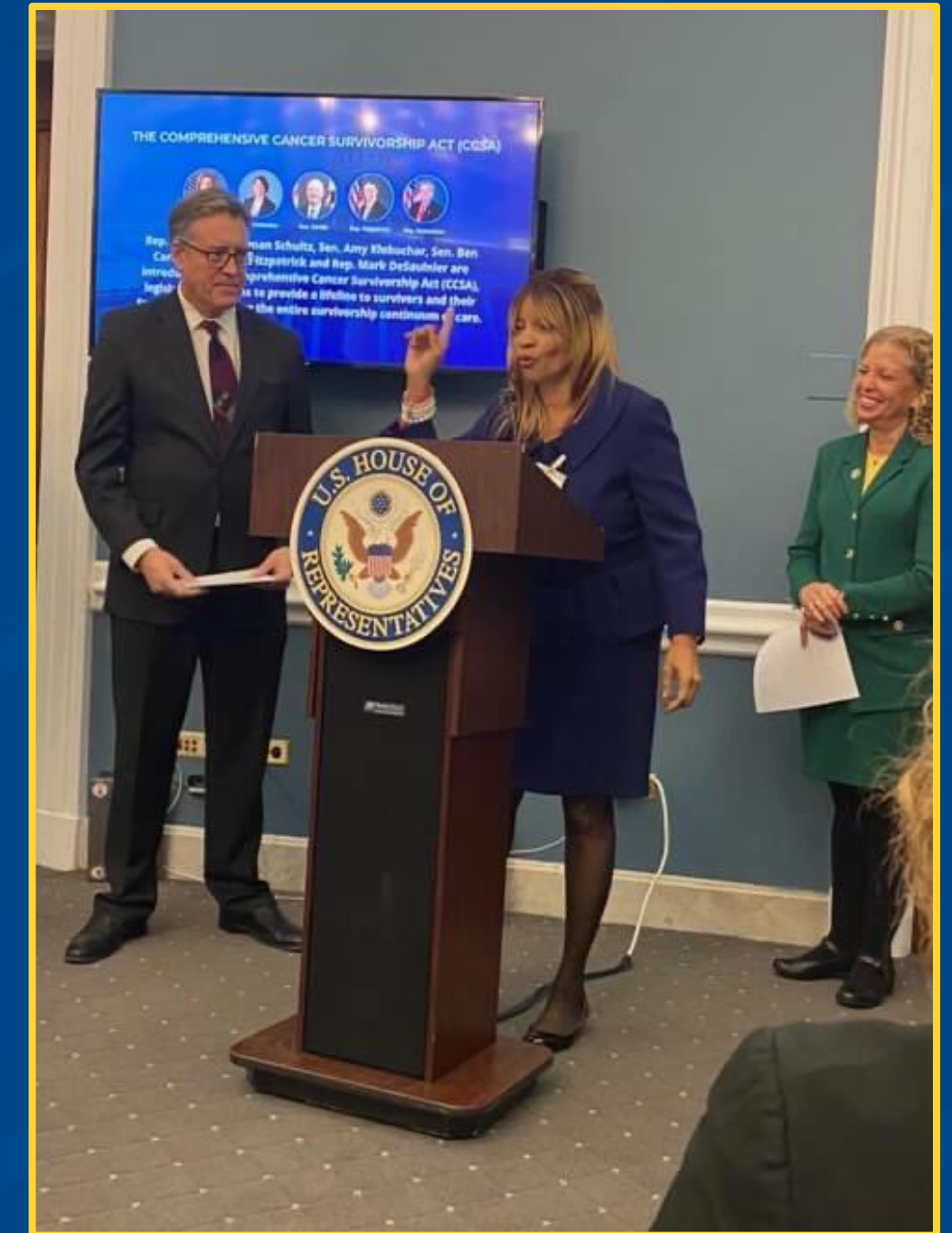
▶ Endorsing Organizations and Cancer Centers

Alliance for Fertility Preservation (AFP)
American Association for Cancer Research (AACR)
Association of American Cancer Institutes
American Cancer Society Cancer Action Network (ACS-CAN)
American Lung Association
American Society of Clinical Oncology (ASCO)
American Society for Reproductive Medicine (ASRM)
Baptist Health South Florida
Breast Care for Washington
Brem Foundation
Cancer Support Community (CSC)
CancerCare
Children's Cancer Cause (CCC)
Disability Rights Legal Center
Emory University, Asian American Studies
FORCE: Facing Our Risk of Cancer Empowered
Gilda's Club of South Florida
Leukemia & Lymphoma Society

LUNGeivity Foundation
Lymphoma Research Foundation (LRF)
Malecare and the National LGBT Cancer Project
METAvivor
Miami Cancer Institute
Moffitt Cancer Center
National Coalition for Cancer Survivorship (NCCS)
National Comprehensive Cancer Network (NCCN)
Nova Southeastern University (NSU)
Nueva Vida
Oncology Nursing Society (ONS)
Prevent Cancer Foundation
Sisters Network
Susan G Komen
Tigerlily
Triage Cancer
UM Sylvester Cancer Center
YMCA of the USA
Young Survival Coalition

▶ How You Can Help

- Call your representative using the US Capitol Switchboard: **(202) 224-3121**
- Share CCSA information on social media and tag your member of Congress
- Ask friends and family to call their representatives
- Meet with your member of Congress during August recess



Representing the millions of Americans touched by cancer.



NATIONAL COALITION
FOR CANCER SURVIVORSHIP
www.canceradvocacy.org

National Coalition for Cancer Survivorship

Non-profit Organization Management · Silver Spring, MD · 1,880 followers · 17 employees



- Members of Congress are back in their districts in August. This is a great time to meet with representatives because they are not as busy and want to make sure their constituents are happy.
- NCCS suggests scheduling a meeting with both senators and your representative since CCOSA has been introduced in the House and Senate.
- Your representative has multiple office locations in the district, so before calling to schedule, pick a location that is convenient for you.

Scheduling a Meeting: *Picking the Office Location*

Serving Florida's 25th Congressional District

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Scheduling a Meeting: *Picking the Office Location*

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DEBBIE WASSERMAN SCHULTZ U.S. HOUSE OF REPRESENTATIVES

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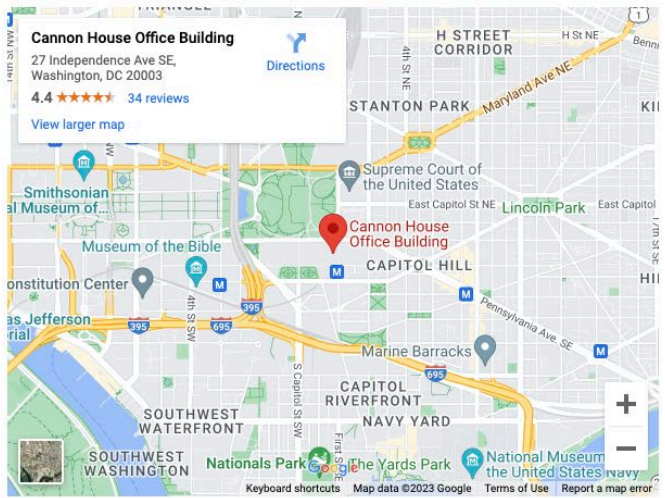
OFFICE INFORMATION

Home // Contact // Office Information

Below you can find information for my offices. You are welcome to phone or send a message to me through the U.S. Postal Service. Please note that postal mail is the slowest method for contacting me. All postal mail sent to my offices must be scanned for security purposes, which means it will take an additional two weeks for me to receive it. If you prefer, you may contact me by e-mail.

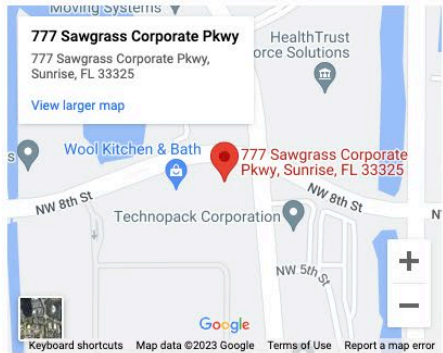
Washington DC

270 Cannon House Office Building
Washington, DC 20515
Phone: 202-225-7931
Fax: 202-226-2052



Sunrise Office

777 Sawgrass Corporate Pkwy
Sunrise, FL 33325
Phone: 954-845-1179
Fax: 954-845-0396



Choose which location works best for you

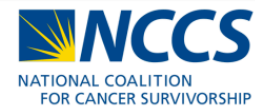
▶ The Meeting

- Bring a copy of the fact sheet (download [CCSA Fact Sheet](#))
- Brief Introductions -
Name, city, connection to cancer, NCCCS advocate
- Purpose of Meeting -
“I am here to talk about the Comprehensive Cancer Survivorship Act”
- Share your story (download [Telling Your Story Worksheet](#))
- The Ask -
“Will you cosponsor the Comprehensive Cancer Survivorship Act?”





Visit canceradvocacy.org/ccsa/



COMPREHENSIVE CANCER SURVIVORSHIP ACT

Representatives Debbie Wasserman Schultz (D-FL-25), Brian Fitzpatrick (R-PA-1), and Mark DeSaulnier (D-CA-10) and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD) introduced H.R. 4363/S. 2213, the Comprehensive Cancer Survivorship Act (CCSA) to improve survivorship, treatment, and transition for all cancer survivors.

NEED FOR SURVIVORSHIP CARE

Cancer survivors are some of the most vulnerable patients in the health care system. Care and the cancer journey do not end once active treatment ends, and survivors need lifelong support for their disease.

- Survivors are at risk of future health issues due to their treatments, sometimes years after completing treatment.¹
- By age 45, 95% of childhood cancer survivors experience a significant side effect due to toxicities from their treatment.²
- Cancer survivors also have a greater risk of being diagnosed with secondary cancers.³

To improve their quality of life and health outcomes, cancer survivors need resources to help monitor for these secondary cancers and late and long-term effects caused by their cancer treatment. Additionally, health care providers need resources to provide appropriate care for survivors throughout the entire continuum of care. The Comprehensive Cancer Survivorship Act will address the existing gaps in survivorship care and improve quality of care and navigation of health care systems for survivors, their loved ones, and their health care providers.

HOW DOES THE COMPREHENSIVE CANCER SURVIVORSHIP ACT HELP CANCER SURVIVORS?

This bipartisan legislation includes the following provisions:

- Coverage of cancer care planning and communication
- Survivorship transition tools
- Alternative payment model
- Survivorship navigation
- Survivorship care demonstration program
- Employment assistance program
- Comprehensive cancer survivorship 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

CANCER CARE PLANNING AND COMMUNICATION

The CCSA creates a Medicare service and payment for care planning and coordination services to help improve coordination of care and transition to primary care.

- A key recommendation from the Institute of Medicine's 2005 report From Cancer Patient to Cancer Survivor: Lost in Transition was that cancer survivors receive an individualized survivorship care plan when completing treatment.⁴
- Coordinated cancer care outlined in a written care plan – care integrating active treatment and symptom management – improves patient outcomes⁵ and increases patient satisfaction.⁶
- Most cancer survivors never receive a care plan, which leaves them to navigate a cancer diagnosis without clear direction. According to the National Coalition for Cancer Survivorship's (NCCS) 2020 State of Cancer Survivorship Survey, only 17% of cancer survivors nationwide reported receiving a survivorship care plan.⁷

EMPLOYMENT ASSISTANCE PROGRAM

This legislation provides education and assistance to survivors and their families and caregivers experiencing barriers to employment as a result of a cancer diagnosis.

- Financial toxicity is a major concern for cancer survivors. Survivors have higher out-of-pocket costs⁸ and are 2.65 times more likely to face bankruptcy than individuals without a cancer history.⁹

[CANCERADVOCACY.ORG](https://canceradvocacy.org)

Take Action

WRITE OR CALL YOUR MEMBERS OF CONGRESS

- Find your Senators on [Senate.gov](https://www.senate.gov) »
- Find your Representative on [House.gov](https://www.house.gov) »

Write Your Members of Congress

- Find your Member's website at one of the links above.
- On their website, they should have a "contact" or "email" section.
- Use the sample script below for your message. Feel free to add your own experience or story to the message.
- Email us at hsnoot@canceradvocacy.org to let us know which office(s) you contacted!

Call Your Members of Congress

- Call the Capitol Switchboard at (202) 224-3121 and ask for the Member of Congress you wish to reach.
- When the office answers, ask if you can speak to a staff member who covers health issues.
- Tell them you are calling to ask your Representative/Senator to cosponsor H.R. 4363/S. 2213. Use the sample script below for help.
- Email us at hsnoot@canceradvocacy.org to let us know which office(s) you contacted!

Sample Script

Hello,

I am a survivor/caregiver/advocate from _____. I am calling to ask that Representative/Senator _____ support the Comprehensive Cancer Survivorship Act, H.R. 4363/S. 2213. The CCSA addresses the health of cancer survivors throughout the entire continuum of care – from diagnosis to active treatment and post-treatment – to improve survivorship, treatment, and transition for all cancer survivors.

[As a cancer survivor/caregiver myself,] I know that the cancer journey does not end once active treatment ends, and survivors need lifelong support. [INCLUDE PERSONAL CANCER EXPERIENCE AND HOW THE CCSA WOULD HELP YOU.]

[Examples: "My cancer care experience could have been better if I had access to cancer care planning and coordination services. Without these services, I struggled to coordinate my care between multiple doctors and often felt lost in the process." OR "Today, I'm a cancer survivor who is grateful for the care and treatment I received, but I know there's much to be learned about late and long-term effects. An adult cancer survivorship study would provide important data and insights to help survivors and their health care providers make informed decisions about their care. By supporting this study, we can help ensure that future survivors have access to the best possible care."]

I hope that your boss will support H.R. 4363/S. 2213, the Comprehensive Cancer Survivorship Act. Thank you for your time and consideration.

► After the Meeting: Following up with Member

Thank-you email template you can customize and send **after your meetings**

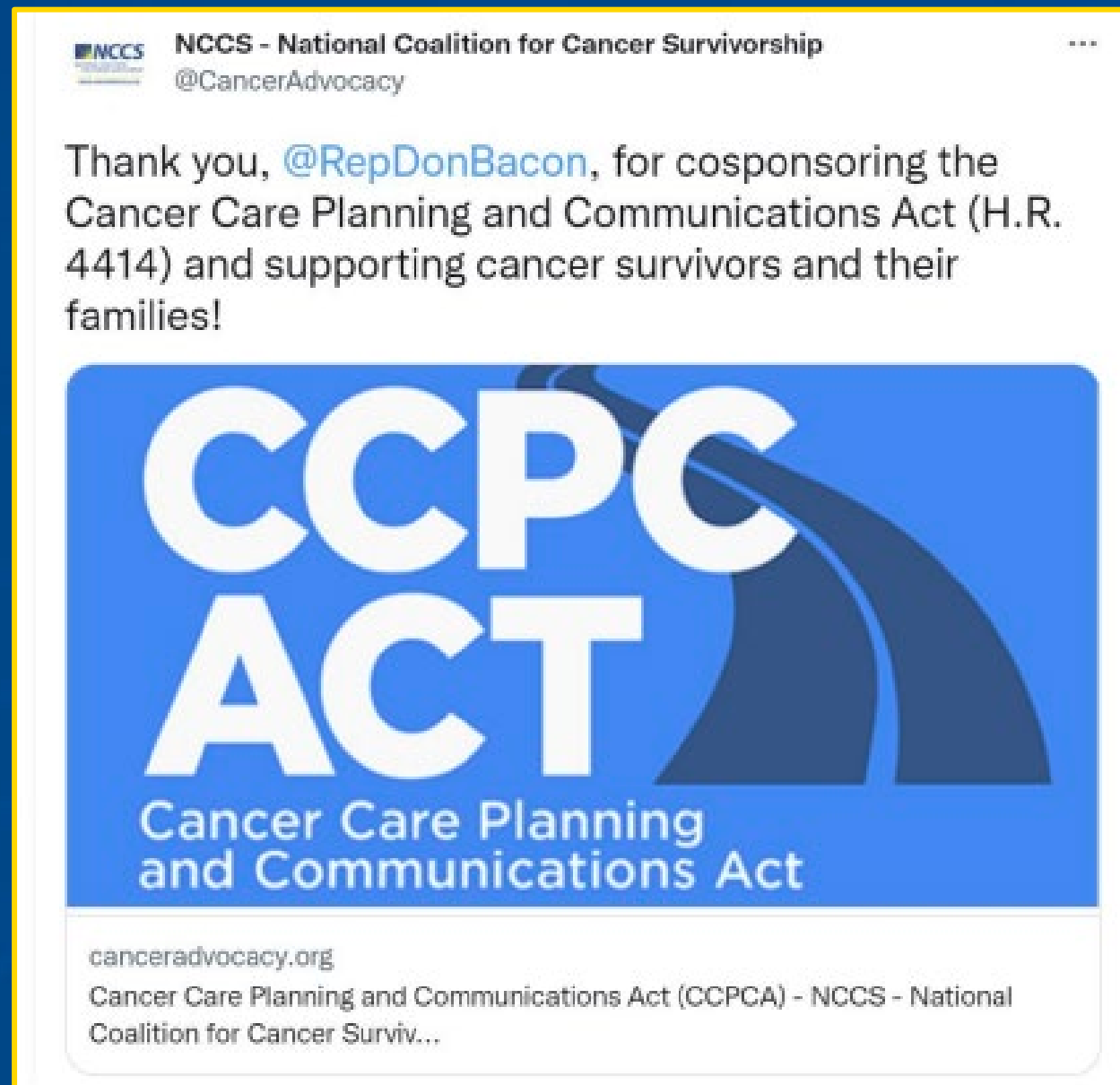
Dear _____,

Thank you for taking the time to speak with me about H.R. 4363/S. 2213, the Comprehensive Cancer Survivorship Act (CCSA). As I mentioned, this bipartisan legislation addresses the health of cancer survivors throughout the entire continuum of care – from diagnosis to active treatment and post-treatment – to improve survivorship, treatment, and transition for all cancer survivors. [INCLUDE PERSONAL EXPERIENCE AND HOW THE CCSA COULD HAVE OR WOULD HELP YOU.]

I truly appreciate you taking the time to discuss this important piece of legislation that would help cancer survivors like myself. I hope your boss will consider supporting this bill. If you have any questions about the CCSA, please contact Haley Smoot at hsmoot@canceradvocacy.org.

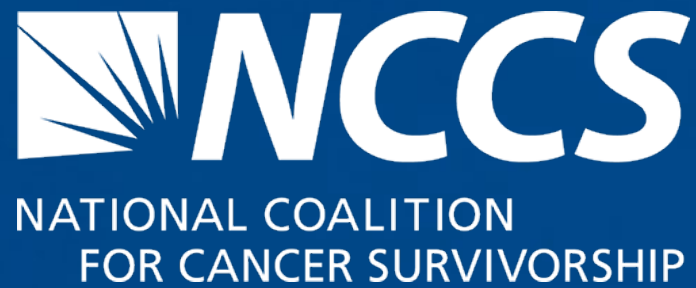
Best,

▶ CCSA Social Media Tips



Purpose: Amplifying our Advocacy

- Ask if you can take a photo and use it in your social media post
- Post about key moments
- Post across multiple platforms (Twitter, Facebook, Instagram)
- Tag NCCS, advocates, and your member of Congress when applicable
- Use hashtags to help with messaging and searchability
- Like, comment, and share NCCS and other advocates' posts



Questions?

If you have any additional questions or would like more information, email hsmoot@canceradvocacy.org



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