



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

CANCER POLICY & ADVOCACY TEAM



2024 CPAT SYMPOSIUM & HILL DAY

CANCERADVOCACY.ORG

NCCS CANCER POLICY & ADVOCACY TEAM (CPAT) SYMPOSIUM

IN-PERSON SYMPOSIUM

June 26-28, 2024 | Arlington, VA

The 2024 Cancer Policy & Advocacy Team (CPAT) Symposium welcomed nearly 100 participants, including cancer survivors, caregivers, medical and non-profit professionals, and students focused on health care policy, medicine, and cancer research. The rising second-year medical students from the CUPID (Cancer in the Under-Privileged Indigent or Disadvantaged) Program at Johns Hopkins, Indiana, and Ohio State Universities joined us again this year. The CUPID program has attended the CPAT Symposium every year since 2016, and it continues to be a life-

changing experience for the medical students. The CPAT members take pride in supporting the education of the next generation of health care providers.

The CPAT Symposium supports advocates in their engagement in public policy advocacy with training on health care policy and participating in legislative advocacy. CPAT members spend their final day learning from the leading voices in Cancer Survivorship to learn about topics that will improve their quality of life. With this knowledge, CPAT members will support the lives of those touched by cancer in their local communities by sharing what they have learned. The three days were filled with laughter and learning, a few tears, and most importantly, support for each other. The energy was palpable, and participants tell us it gets better every year.

Read on for highlights from the sessions...



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- **Sharing Advocacy on Social Media:** Kara Kenan, NCCS Marketing and Communications Manager shared how amplifying your message with social media builds and engages a community of supporters that influences positive change. She highlighted treads, dos and don'ts and tools to craft an engaging message. Kara invited Tamron Little, NCCS Elevate Ambassador, to join her on stage to discuss how Tamron has built and continues to engage her social media community. Tamron leverages her social media platforms to spread awareness about the importance of mental health in survivorship.
- **Hill Day Preparation:** Shelley Fuld Nasso, MPP, NCCS CEO and Veronika Panagiotou, PhD, NCCS Advocacy and Program Manager gave an overview of the Comprehensive Cancer Survivorship Act and Cancer Care Planning and Communications Act, discussed how advocates can weave the legislation into their cancer story and provided guidance on how to engage with legislative staffers and members of Congress in meetings on Capitol Hill. NCCS staffers roleplayed with advocates different scenarios that they may encounter when participating in legislative meetings.
- **Improving Doctor Patient Communication Role Play Activity:** Ana Maria López, MD, MPH from Jefferson Health New Jersey Sidney Kimmel Cancer Center led the role play exercise on improving communication. Medical students and advocates participated in the activity with three scenarios involving difficult conversations between physicians and patients. Students practiced delivering difficult news and advocates demonstrated ideal communications from the patient perspective. The discussion that followed focused on the need for medical students to recognize the importance of treating the “whole” person instead of just dealing with the cancer. Advocates focused on the importance of building a healthcare team that respected their values and beliefs.
- **Demystifying Palliative Care:** Nurse Scientist C. Robert Bennett, PhD, CPNP-AC, PPNP-BC from Mayo Clinic Phoenix discussed the common myths and truths about palliative care. He shared the benefits of exploring what it means to live as well as possible for as long as possible and how to share that with your medical team and loved ones. Dr. Bennett concluded that anyone with a serious illness, regardless of trajectory would benefit from holistic care that is in alignment with a patients' preferences and goals from the beginning of treatment through the end of life.

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- **Keynote: Skin In The Game: A Physician Couples' Cancer Survivorship Perspective and Experience:** Director of Cancer Survivorship Samantha Siegel, MD from Kaiser Permanente San Francisco and Pediatrician Samuel Siegel, MD at Dignity Health Woodland Clinic shared their powerful story of young adult survivorship. They each described what it was like to be diagnosed with cancer while being health care providers. Dr. Samantha and Dr. Samuel described what it was like when the roles were reversed, and they needed to support each other as care partners. They illustrated how cancer continues to have an impact on their family life, working in medicine and their overall health and wellbeing. Dr. Samantha and Dr. Samuel shared how they strive every day to live a meaningful, purpose-driven life after a cancer diagnosis.
- **Sexual Health and Intimacy in Survivorship:** Assistant Professor Georgia Anderson, PHD, MSW from University of Cincinnati highlighted the importance that sexual health and intimacy plays in a survivor's quality of life. She explored the physical and psychosocial changes that occur after a cancer diagnosis that have the potential to create sexual dysfunction. Dr. Anderson explored different forms of intimacy and how cancer survivors and caregivers can talk about them to increase their sense of closeness and feelings of well-being.



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HILL DAY 2024

June 27, 2024 | Washington, DC

On June 27, 2024, CPAT members spent the day on Capitol Hill supporting two pieces of legislation:

- HR 4363 / S 2213, Comprehensive Cancer Survivorship Act (CCSA)
- HR 5183, Cancer Care Planning & Communications Act (CCPCA)



The CCSA is bipartisan legislation addressing 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 survivors. The CCSA addresses the existing gaps in survivorship care to improve the quality of care and navigation of health care systems for survivors, their loved ones, and their health care providers.

The CCPCA would establish a Medicare service for cancer care planning. A plan can be developed and shared with the Medicare beneficiary at several points in the cancer care continuum, including at time of diagnosis, when there is any substantial change in treatment, and at the completion of primary treatment for cancer, when the plan may serve as a follow-up survivorship care plan.

CPAT members who participated in Hill Day meetings received both virtual and in-person training to help prepare for their meetings and convey the importance of this legislation using their experiences and personal cancer stories.

We kicked off the day gathering on Capitol Hill, joined by Representatives Debbie Wasserman Schultz (D-FL) and Mark DeSaulnier (D-CA), who thanked CPAT members for their support and advocacy.

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NCCS successfully secured 124 scheduled meetings with congressional offices in both the House and Senate, with more than 90 advocates from 26 states participating. Within these meetings, NCCS and advocates talked with their members of Congress and congressional staff about the significance and benefits of the bills for cancer survivors.

Following Hill Day, Representatives Sanford Bishop (D-GA), Bonnie Watson Coleman (D-NJ), Andy Kim (D-NJ), Dina Titus (D-NV), Alma Adams (D-NC), and Raul Grijalva (D-AZ) cosponsored one or both of the bills after meeting with NCCS and advocates.



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"This Symposium stands out as the best ever. The speakers were top-notch and the connections I made with other advocates are unmatched!"
— Rebecca Esparza



"I am now more equipped to drive meaningful change and support cancer-related policies that matter."
— Melinda Bachini



"Being selected to be a CPAT Advocate and participate in the 2024 Symposium and Capitol Hill Day has truly been transformative for me as a metastatic breast cancer patient and advocate. From the very beginning of the three-day conference, it was jam packed with informative sessions that were both interactive and engaging."
— April Donaldson



"I realized on a deep level that I am not alone in a wilderness. We may be pioneers of a kind, but we are pioneers together. I walked away from the CPAT symposium a better advocate, a better friend, and with a steady, warm flicker of hope in my heart. The CPAT Symposium was an experience that will resonate through the rest of my life"
— Anastasia Forrest

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"... deeply grateful to NCCS for providing us with the tools, knowledge, and support needed to elevate our work. The experience has been transformative!"
 — Kristie Fields



"NCCS creates a space for us to come together and turn our suffering into power and that power into meaningful action. Ultimately it allows us to heal ourselves while helping to change the world of cancer survivorship."
 — Stef Gayhart



"NCCS has given me a voice to advocate for children and adults with a cancer experience. Thank you for being an encouragement to me and helping me to reach my potential."
 — Sandra Calloway Fields



"I highly encourage any survivors or health care professionals who are involved in or hope to get more involved in cancer policy and advocacy to attend future NCCS events. I promise the experience will leave you empowered, hopeful, and with the tools needed to make durable change in the survivorship space."
 — Ryan Hannon, MD

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Here are just a few moments from social media:



 sarcoh23 As we wrap up #cpat24, I want to share a special thank you to my representative, Brian Fitzpatrick, and his staffer Jacqueline for their support of cancer patients and survivors.

He was held up in a committee meeting on healthcare issues yesterday but invited us to come to the meeting and even made time to sit and talk with us there, hear our stories, and update us on the cancer and healthcare efforts his office is a part of.

Not only is he a cosponsor of the Comprehensive Cancer Survivorship Act, he is a champion for cancer and healthcare




 i_am_erika_weathers My 3 days in DC advocating for NCCS #CPAT24 @cancersurvivorship were exhilarating especially our day on Capitol Hill speaking with Representatives & Senators along with their staff members. Sharing our individual journeys with cancer in order to attain support for Comprehensive Cancer Survivorship Act & The Cancer Care Planning & Communications Act! @canceradvocacy #capitalhill We got a Hell Yeah from Rep. Sanford Bishop Ga-02 D & we hope to get other Georgia Representatives & Senators to support are bills. Let's Go Georgia @repsanfordbishop @replucymbath @repclyde @senatorwarnock @senatorossoff #nccscancersurvivorship #cancersurvivor #cancersucks & #cancersurvivorship #cancersurvivorship #cancersurvivorship



 lorettaherring70 This is for Real!!! I'm on Capital Hill with NCCSCPAT. #cpat24 #hillday24. #CAN @fearcutters.



 andreaanampag So happy that one of my first actions after becoming a US citizen is going to #CapitolHill to advocate for the Cancer Care Planning and Communications Act (HR 5183) and the Comprehensive Cancer Survivorship Act (HR4363/S2213). These crucial bills will improve care for cancer survivors. I represented my American hometown, Buffalo, in the office of Tim Kennedy. Thank you to the National Coalition for Cancer Survivorship @cancersurvivorship for this awesome opportunity to advocate for better care!

#CCSA #CCPCA #CPAT24 #CancerAdvocacy #CancerSurvivorship

THANK YOU FOR BEING A MEMBER OF THE NCCS FAMILY



LEARN MORE ABOUT CPAT:
[CANCERADVOCACY.ORG/CPAT](https://canceradvocacy.org/cpat)