CANCER POLICY & ADVOCACY TEAM

2022 IN-PERSON AND VIRTUAL SYMPOSIA

CANCERADVOCACY.ORG
The 2022 Cancer Policy & Advocacy Team (CPAT) Symposium marked the return to in-person meetings for NCCS advocates. We welcomed 55 participants, including advocates, caregivers, and medical students from the CUPID (Cancer in the Under-Privileged Indigent or Disadvantaged) Program at Johns Hopkins, Indiana, and Ohio State Universities. NCCS has welcomed rising second-year medical students in the CUPID program to the CPAT Symposium every year since 2016, an important collaboration that benefits both advocates and students alike.

The CPAT Symposium supports members in their engagement in public policy advocacy with training on health care policy, advocacy, and communication skills. The three days were filled with laughter and learning, a few tears, and most importantly, support for each other. The energy was palpable, and numerous participants said this was the best CPAT Symposium to date. Some highlights from the sessions:

- **Music as Care**: Tamara Wellons from the Smith Center for Healing and the Arts shared the gift of “music as care” in her presentation. She discussed the role of music, the arts, and self-expression to support health, wellness, and healing. She filled the room with love and music and encouraged everyone to participate.

- **Advocate Panel Discussion**: CPAT Members Kimberly Bowles, Michael Holtz, and Nicole Bullock shared their personal cancer stories, their motivation to engage in advocacy, and their advocacy strategies and tactics.

- **Keynote**: Achieving Cultural Humility in Medical Care: Lori Wilson, MD, FACS, from Howard University College of Medicine, presented a framework for providing medical care with cultural humility. She grounded her discussion in her own survivorship story. She described the three dimensions of cultural humility as lifelong learning and critical self-reflection; recognizing and challenging power imbalances, and institutional accountability.
Health Policy Outlook for 2022: NCCS CEO Shelley Fuld Nasso moderated a panel discussion of policy experts, including Anne Hubbard from the American Society for Radiation Oncology, Rebecca Kirch from the National Patient Advocate Foundation, and Haley Smoot from NCCS. Topics included medical debt, value-based payment models, cancer care planning and communication survivorship, and prior authorization.

Integrative Oncology: Empowering through Evidence and Equity: CPAT Steering Committee member Desirée Walker, NCCS Elevate Ambassador Lesley Kailani Glenn, and NCCS Board Member Ana María López, MD, MPH, defined and presented the benefits of integrative oncology and outlined how evidence-based integrative practices can enhance quality of life during and after cancer treatment.

Resiliency and Legacy: CPAT Member Alique Topalian, PhD, MPH, shared the practice of Meaning-Centered Psychotherapy and the scholarly work of Viktor Frankl's Man’s Search for Meaning.

Telling Your Story in 140 Characters: Andrew Conte, PhD, from the Center for Media Innovation at Point Park University, presented an interactive workshop on the value of storytelling. He shared strategies for telling compelling, impactful stories in few words.

Supportive Cancer Care: Thomas J. Smith, MD, medical oncologist and palliative care specialist from Johns Hopkins University, shared lessons learned from his 35-year career in palliative care and supportive oncology, as well as from his own experience living with metastatic cancer. He shared a useful mnemonic for having tough conversations: AMEN: A. Affirm M. Meet them where they are E. Education N. No matter what.

Improving Doctor/Patient Communications Workshop: Medical students and advocates participated in a role-play exercise with three scenarios involving difficult conversations between physicians and patients. Students practiced delivering difficult news and advocates demonstrated ideal communications from the patient perspective.
"It really sucks to have cancer, but I am beyond grateful and thankful to have found NCCS for helping me take control of my cancer story and turn it into advocacy."
— Xenia Rybak

"The CPAT Symposium was an experience of a lifetime. The symposium offered a safe place to ask questions and share personal experiences. As a 15-year breast cancer survivor, just being in the room with other cancer survivors added such joy to my own journey."
— Ruth Travis

"I’ve attended NCCS conferences since June 2016, and what I appreciated the most was how diverse this conference was! The speakers were very informative and passionate about their advocacy work that they’re doing in the cancer community."
— Roberta Albany

"Meeting and networking with other survivors representing different cancers shows how we can all work together for our cancer communities. Like so many said, ‘CPAT is like a family,’ and now I am one of the newest members."
— Lesley Kailani Glenn
"At the CPAT22 in-person symposium, I appreciated the up-to-date research, guidelines, and opinions gained from other cancer survivors, caregivers, and doctors. I also welcomed the opportunity to interact with young doctors from all over the United States."
— Sandra Calloway Fields

"Being able to attend on scholarship was the only way my attendance would have been possible this year. The symposium was great, from start to finish. I thought the sessions were impactful and educational at the same time."
— Michael Holtz

"I have attended many different cancer conferences, but this was, by far, the best. I walked out with information that I was able to use immediately and will be sharing immediately. It was great to be with a group of inspirational advocates from whom I learned."
— Lora McCann

"This year’s event was packed with excitement. The speakers were engaging, and what I loved most was the relevance they conveyed. Much of this could be applied to other organizations—not just our cancer community. That’s real value!"
— Kirby Lewis

#CPAT22
Here are just a few moments from social media:

Shelley Fuld Nasso
@sfuldnasso

Excited to be with this fantastic group of cancer survivors, caregivers, and medical students! It’s wonderful to be in person again. #CPAT22

Allison Rosen M.S.
@ARosen380

Dr. Thomas J. Smith eye opening presentation. He is spreading the awareness about the benefits of #palliativecare! Lower cost, less stress, longer survival, better QOL, less anxiety & depression. Helping each patient as a person, not a number! #CPAT22 @CancerAdvocacy #cancer

Nicole G. Bullock
@nicolegbullock1

Excited to be attending and speaking at my first Cancer Policy & Advocacy Team (CPAT) Symposium with @CancerAdvocacy on behalf of the Nicole Cares Foundation @NicoleCares930 today! #CPAT22 #canceradvocacy #CancerSurvivorship

Andrew Conte
@AndrewConte

Inspired by hearing so many moving, funny, important stories at #CPAT22 @CancerAdvocacy

#CPAT22
NCCS CANCER POLICY & ADVOCACY TEAM (CPAT) SYMPOSIUM

VIRTUAL SYMPOSIUM
July 11, 2022

On July 11, NCCS hosted a Virtual Symposium, allowing advocates who were not able to travel to attend the in-person Symposium to participate. Topics covered included:

- **Cancer Care Planning and Communications Act:** U.S. Rep. Mark DeSaulnier (CA-11) joined NCCS to discuss H.R. 4414, The Cancer Care Planning and Communications Act (CCPCA). Rep. DeSaulnier knows from personal experience how confusing the cancer care system can be for patients. Most cancer patients still do not receive a written plan that explains their diagnosis, prognosis, treatments, and expected symptoms, leaving them to navigate the complexities of a cancer diagnosis without clear direction or knowing what to expect from their care. The CCPCA, introduced by Rep. DeSaulnier, establishes a Medicare service for cancer care planning.

- **Don’t Change Yourself for Other People: How Adolescents and Young Adults (AYAs) Living with Cancer Offer Advice to Other AYA Patients:** Nick Iannarino, PhD, of the University of Michigan Dearborn, Lauren Ghazal, PhD, FNP-BC, of the University of Michigan School of Nursing, and Emily B. Walling, MD, MPHS, of the University of Michigan Mott Children’s Hospital, discussed the unique challenges that Adolescent/Young Adult cancer survivors (AYAs) face and shared their research on how AYAs give advice to each other about their experiences.

- **Self-Care Matters:** Ta’lor L. Pinkston, LSW, MSW, BA, facilitated a workshop on self-care and self-love as a coping skill for mental health and healing. She discussed the “Six Ways to Take Care of Yourself” including emotional, physical, mental, spiritual, social, and practical self-care.

- **Advocate Hill Week Send-off with Congressman Raskin:** U.S. Rep. Jamie Raskin (MD-8) took time out of his busy schedule to join NCCS for the 2022 Virtual CPAT Symposium to talk about his experience as a legislator diagnosed with cancer and share tips for how to talk to lawmakers about important cancer survivorship legislation.

"I must say, I always enjoy 'getting an inside look at the Hill' from Reps. De Saulnier and Raskin regarding ‘the temperature’ on the Hill and tips to prepare for NCCS Hill Day. Equally important, are their personal stories as survivors and how their lived experiences inform their work and commitment to aid NCCS in fulfilling its mission."

— Desirée A.H. Walker

#CPAT22
THANK YOU FOR BEING A MEMBER OF THE NCCS FAMILY

LEARN MORE ABOUT CPAT:
CANCERADVOCACY.ORG/GET-INVOLVED/CPAT

#CPAT22