



C-TAC National Leadership Summit

October 21 – 22, 2024 / Capital Hilton, Washington. DC

The [*Coalition to Transform Advanced Care \(C-TAC\)*](#) is hosting a two-day National Leadership Summit – *Transforming Care for People with Serious Illness*. The Summit will focus on public policy advocacy, listening to patient voices, state and community action, partnerships for comprehensive care, supporting innovative care models, payment and financing, support for family caregivers, addressing social and spiritual needs, pediatric care, mental health, and metrics of success.

Agenda at a glance:

- **EARLY REGISTRATION 4pm-7pm**

Monday, October 21

- **REGISTRATION opens at 8am**
- **PRE-SUMMIT SESSION from 8:30am-11:30am**
- **POLICY INSIGHTS FROM INSIDE THE BELTWAY SESSION from 11am-12pm**
- **EXHIBITOR ROOM opens at 11:30am**
- **LUNCH SERVICE begins at 12pm**
- **SUMMIT KICKS OFF at 1pm**
- **NETWORKING RECEPTION to follow Closing Keynote from 5:30pm-7pm**

Tuesday, October 22

- **BREAKFAST, REGISTRATION & EXHIBITOR ROOM opens at 7am**
- **SUMMIT begins at 8am**
- **LUNCH will be served.**
- **DAY CONCLUDES at 3:45pm**

Agenda: ALL MEETING ROOMS LOCATED ON THE 2ND FLOOR

Monday, October 21

8:00am Registration Opens - located outside the Presidential Ballroom

8:30am – 11:30am Pre-Summit Sessions - Open to all attendees at no additional cost. Breakfast included. Please register if you plan to attend – limited seating. Both sessions held at the same time so please select only one.

Session One: located in the Federal A room

- ***Part I: State Policy Windows of Opportunity: Palliative Care and Advance Directives- How to Harness State Data to Improve Palliative Care***

This workshop is designed to examine best practice strategies in retrieving state specific palliative care data by examining essential common data elements and funding streams that can assist states in moving forward with sharing relevant palliative care delivery data with legislators, consumers, and providers.

Speakers:

- Marisette Hasan, RN, BSN, VP of Community Action & Policy, C-TAC
- Stacie Sinclair, MPP, Associate Director, Policy and Care Transformation, Center to Advance Palliative Care (CAPC)
- ***Part II: Successful State Strategies for Advance Directives***

This workshop is designed to inspire serious illness activists in each state to work together to learn the importance of policy advocacy and how to do it well by walking through a case study utilizing the recently released Uniform Healthcare Decisions Act.

Speakers:

- Jarad Calfee, State Advocacy Director, AARP
- Nora Winkelman, Esq., Chair, Drafting Committee, Uniform Healthcare Decisions Act
- Deborah Soholt, RN, MS, FAAN, SD State Senator 2013 - 2021, Chair Senate Health & Human Services. Former Director Women's Health. National speaker and podcaster. Caregiver for her mother.
- Stephanie Anderson, DNP, RN, Executive Director, C-TAC Innovations

Session Two: located in the Federal B room

Increasing Hospice and Palliative Care Referrals via Population Health Programs

Community-based hospice and palliative care organizations can enhance their expertise by providing care to people earlier in a serious illness and thus improve enrollment and length of stay. This will also position them to for value-based payment arrangements. NPHI, a national association of non-profit hospice organizations developed and implemented three population health programs with their members. Learnings on how to start such programs along with the free patients and caregiver resources will be reviewed. Participants will break into smaller groups to discuss how their organizations could explore such programs and make use of the existing patient and family resources.

Speakers:

- Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN, Senior Regulatory Advisor, C-TAC
- Cameron Muir, MD, Chief Innovation Office, NPHI

11:00am - 12:00pm - Policy Insights from Inside the Beltway - located in the Pan American Room

This session brings together for a panel discussion diverse advocacy groups represented by their Hill advocates and lobbyists to discuss federal legislation and regulation. Issues will include, Medicare, Medicaid, serious illness care, the Elder Justice Act, social isolation, the Older Americans Act, telehealth, and what the rest of the 118th Congress may address after the election.

Speakers:

- Brian W. Lindberg, Senior Public Policy Advisor, C-TAC
- Bob Blancato, National Coordinator, Elder Justice Coalition
- Rachel Jordan, Policy Manager, Coalition to End Social Isolation and Loneliness (CESIL)
- Mike Wittke, Former Vice President, Policy & Advocacy, National Alliance for Caregiving
- Ethan McChesney, Policy Director, National Partnership for Healthcare and Hospice Innovation (NPHI)

11:30am Exhibitor Room opens located in the Congressional Room

12:00pm Lunch Service located in the Congressional Room

1:00pm Summit Kick Off – Day 1 – Opening Plenary Session with Jon Broyles, CEO, C-TAC located in the Presidential Ballroom

A View from Capitol Hill – Public Policy Plenary Session

This session will provide up to the minute information on what the 118th Congress has done and may still do to support the needs of people with serious illness and their family caregivers. It brings together for a panel discussion key Hill staff in the House and Senate working to improve serious illness care. They will discuss federal legislation including bills to address hospice integrity and modernization, advance care planning, payment models, palliative care education and training, and telehealth. They will share thoughts on how serious illness care fits into the broader congressional work on Medicare, Medicaid, Chronic Care 2.0, and other initiatives.

Featuring:

- Bill Novelli, Co-Founder and Co-Chair, Coalition to Transform Advanced Care (C-TAC) (moderator)
- Rachel Dolin, Professional Staff, Subcommittee on Health, Committee on Ways and Means
- Conor Sheehey, Senior Advisor for Health Policy, Senate Finance Committee
- Alison Council, Policy Director, Senate Special Committee on Aging
- Asha Samuel, Legislative Director, Congressman Blumenauer
- Colleen Nguyen, Senior Health Policy Advisor, Office of Senator Mark Warner

2:15pm – 2:45pm Networking Break located in the Congressional room

2:50pm – 4:05pm Breakout Sessions

Emerging Policy Opportunities: Advance Care Planning and Pediatric Palliative Care - located in the Pan American room

This session offers panelists and the audience the opportunity to share the challenges that families and practitioners face in providing comprehensive serious illness care. Two emerging policy opportunities will be discussed: the need to ensure that adults with serious illness, their families and practitioners are able to access advance care planning, so their care preferences are understood, recorded, and followed and pediatric palliative care.

Speakers:

- Brian W. Lindberg, Senior Public Policy Advisor, CTAC
- Jessica Hausauer, PhD, Executive Director, National Coalition for Hospice and Palliative Care
- Arul Thangavel, MD, Chief Executive Officer, WiserCare
- Conrad Williams MD, FAAP, FAAHPM, Director, Palliative Care Program, MUSC Health System, Associate Professor, Department of Pediatrics, Medical University of South Carolina

Advancing Health Equity – One State at a Time "Expanding Access to Care & Health Equity for People with Serious Illness Through State Medicaid Palliative Care Benefits" - located in the Federal A room

Policymaking can often be seen as a scary topic, fraught with politics and partisanship. But what about when it comes to improving care for people with serious illness for people who are covered by Medicaid, or for dual eligible populations? Over fifteen states have taken steps to expand access to team-based palliative care services by advancing benefits to cover community-based palliative care at the state level. Hear from a Medicaid Director, Policy Analyst, State Medical Director, and state policymaker about why they have advanced palliative care benefits for their beneficiaries and how they got it done.

Speakers:

- Sandra Clark, MPH, Director of Population Health, TFA Analytics
- Peggy Funk, CAE, Executive Director, Hospice & Palliative Care Network of Maryland
- Senator Angela McKnight, New Jersey State Senate
- Jamie Teuteberg, MS, Director of Health Aging Initiatives, WA State Health Care Authority

The Future is Now: Implications of AI for Serious Illness Care Delivery - located in the Federal B room

Artificial intelligence is transforming many aspects of American life. The nature and speed of this transformation is something completely different from other technological breakthroughs. It is changing how we work, how we interact, what we produce, even who we are – and resistance is futile. Healthcare is at the forefront of industries poised to reap enormous benefits as well as contend with huge risks. Leaders, especially those in palliative/serious illness/end-of-life care, traditionally considered “high touch–low tech,” must gain a working understanding of AI applications in healthcare and grasp the operational and ethical infrastructure required to exploit the opportunities while mitigating harms. This presentation and panel will

explore several domains of AI influence in healthcare, organizational and leadership strategies, and community engagement particular implications for serious illness care.

Speakers:

- Jennifer Moore Ballentine, MA, Chief Executive Officer, Coalition for Compassionate Care of California
- Ravi B. Parikh, MD, MPP, Associate Professor, Department of Hematology and Medical Oncology, Emory University School of Medicine & Medical Director, Winship Data and Technology Applications Shared Resource, Winship Cancer Institute of Emory University
- Sonoo Thadaney Israni, Executive Director, Presence (a Center at Stanford Medicine) & The Program in Bedside Medicine, Director, HBMC Summer Research Program, Racial Equity to Advance a Community of Health (REACH) Initiative, Stanford Medicine
- Adam Myers, MD, MHCM, FACHE, CHCQM, CPHRM, Fractional Chief Clinical Officer, Eldera.ai

Family Caregivers and Medicare Payment Models, including GUIDE - located in the Senate Room

Discussion to focus on recent CMS and CMMI policies incorporating family caregivers, challenges of including family caregivers in serious illness payment models, and opportunities to include family caregivers in future alternate payment models.

Speakers:

- Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN, Senior Regulatory Advisor, C-TAC
- Tonya L. Saffer, MPH, Director, Division of Healthcare Payment Models, Patient Care Models Group, Center for Medicare & Medicaid Innovation
- Laura Makaroff, DO, Senior Vice President of Prevention and Early Detection, American Cancer Society
- Steven Lee, Co-founder and CEO, Ianacare

4:10pm – 5:30pm - First 100 Days of the Next Administration and Congress hosted by Marisette Hasan, RN, BSN, VP of Community Action & Policy, C-TAC & Stephanie Anderson, DNP, RN, Executive Director, C-TAC Innovations - located in the Presidential Ballroom

Sneak Preview of New Bradley Cooper / WETA "Caregiving" Documentary Sizzle Reel

5:30pm – 7:00pm Networking Reception - located in the Congressional room

Tuesday, October 22, 2024

7:00am Breakfast, Registration, and Exhibitor Room Opens

8:00am Summit Kick Off – Day 2 - located in the Presidential Ballroom

- Day One Recap with Marisette Hasan, VP of Community Action & Policy, C-TAC

8:45am – 9:30am Blue Chair Lifetime Achievement Awards

Join us for a panel of patient and caregiver perspectives on their needs and opportunities to transform the care system. An award ceremony to recognize advocates who have displayed the “Blue Chair” values of empathy and action in their leadership.

Our honorees:

- Ebony Lowman, Pediatric Cancer Caregiver & Advocate for caring for her son and advocacy work to raise funding for pediatric cancer research and to bring awareness on the importance of blood stem cell donations.
- Jo Ann C. Jenkins, AARP, CEO, Lifetime Achievement Award for her innovation and leadership to improve the quality of life for people with serious illness and their caregivers.

Music Makers Foundation

Featuring Co-founders Tim & Denise Duffy & a special viewing of our Freeman Vines Video

9:30am – 10:00am Networking Break - located in the Congressional room

10:00am – 11:15am Breakout Sessions

Innovation in Home-Based Care Models - located in the Federal A room

Creating a continuum of care from diagnosis is C-TAC's top goal. What's good care look at different stages of an illness, delivered in different settings, under different payment models, by different teams? There's clearly a lot of complexity to cut through! Join this discussion on how to create a high-quality seamless care experience for patients and unpaid caregivers across care models such as Home-Based Primary Care, Palliative Care, PACE, and hospice.

Speakers:

- Patrick T. Courneya, MD, Former Chief Health Plan Medical Officer, HealthPartners
- Dana Crosby, Vice President, Education and Practice Development, Home Centered Care Institute (HCCI)
- Susan Ponder-Stansel, President & CEO, Alivia Care, Inc.
- Michelle Ward, MSN, ANP-BC, ACHPN, Chief Operations Officer, VyncaCare

Advocacy Engagement for Medicare Hospice Modernization - located in the Federal B room

The Medicare Hospice Program has taken center stage in the current serious illness policy discussions in Washington, DC. Pushed to the forefront by issues of program integrity and quality of service, policymakers are now seriously considering how to modernize what has been an extremely successful part of the Medicare

program. This panel will dive into the current program, its strengths, and weaknesses, and how changing in program design could benefit those who need hospice and individuals with serious illness who need hospice-type supports and services but are not yet eligible for the benefit.

Speakers:

- Brian W. Lindberg, Senior Public Policy Advisor, C-TAC
- Ethan McChesney, Policy Director, National Partnership for Healthcare and Hospice Innovation (NPHI)
- Mollie Gurian, VP, Policy and Government Affairs, LeadingAge
- Tomas Bednar, Senior Vice President & Counsel, Healthspieren

The Palliative Pulse: Taking the Field's Temperature - located in the Senate Room

In the spring of this year, the Center to Advance Palliative Care (CAPC) fielded a national survey of palliative care professionals. More than 750 program leaders and team members told us how they are feeling, which strategic and operational issues they are focused on, how they are perceived within their organizations, and how they are coping with high volumes. In this session, we will share the insights gained from the Palliative Pulse survey, the implications for palliative care teams, and how this information can inform resource development and strategic planning.

Speakers:

- Brynn Bowman, MPA, Chief Executive Officer, Center to Advance Palliative Care (CAPC)
- Andrew E. Esch, MD, MBA, Senior Education Advisor, Center to Advance Palliative Care (CAPC)
- Rachael Heitner, MPH, Associate Director, Research & Insights, Center to Advance Palliative Care (CAPC)

Successful Strategies for Public Messaging and Serious Illness Care - located in the Pan American room

While many in the public know about advance care planning and hospice, some have misconceptions about them. On the other hand, palliative care awareness is low, and people have misconceptions there as well. Helping the public better understand these types of serious illness care would make patients and families more willing when clinicians suggest them. A national grant-funded effort has distilled the evidence on this into useful education principles for these types of care and this session will provide examples of them and their successes.

Speakers:

- Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN, Senior Regulatory Advisor, C-TAC
- Tony Back, MD, Co-founder, VitalTalk; Co-director, University of Washington Center for Excellence in Palliative Care

11:20am – 12:30pm Plenary Session: The Medicare Perspective - located in the Presidential Ballroom

Fire Side Chat Featuring Meena Seshamani, MD, PhD, Deputy Administrator and Director of the Center for Medicare at the Centers for Medicare and Medicaid Services and **Ravi Parikh**, MD, MPP, Associate Professor, Department of Hematology and Medical Oncology, Emory University School of Medicine & Medical Director, Winship Data and Technology Applications Shared Resource, Winship Cancer Institute of Emory University

Spreading Community Models: Addressing Health Equity through Trusted Local Organizations Featuring Aaron G. Perry, President & CEO of Rebalanced-Life Wellness Association

12:30pm – 1:00pm Lunch Service - located in the Congressional room

1:00pm – 1:30pm - Emerging Policy Opportunities for Patients and Unpaid Caregivers - located in the Presidential Ballroom

Speakers:

- Kris Smith, MD, MPP, Consultant, Oxeon
- Gary Bacher, Chief Strategy Officer, CINQCARE
- Diane Ty, Managing Director, Future of Aging, Milken Institute Health

1:35pm – 2:50pm Breakout Sessions

Leveraging Data to Transform Care: The ACT Index - located in the Federal A room

Getting access to data can be daunting for state coalitions and policymakers to advance concepts and initiatives that they know must take place. Through the ACT Index State Scorecards, C-TAC offers communities a powerful tool as a starting place to develop legislative concepts at the state and local levels. Hear from communities that have leveraged the data from the ACT Index State Scorecards to make meaningful change in their community and how they built upon the ACT Index to get better access to the data they needed to prove the business case to advance efforts at the state level.

Speakers:

- Lea Tessitore, MSB, MBA, Director, Strategy and Partnerships, TFA Analytics
- Jeannette G. Kojane, MPH, Executive Director, Kōkua Mau
- Ramy Sedhom, MD, Medical Oncologist & Palliative Care Physician, Penn Medicine
- Jeanne M. Chirico, MPA, President and CEO, Hospice and Palliative Care Association of New York State (HPCANYS)

Improving Access to Care: Community Care Models That Work - located in the Federal B room

So often health systems and community-based organizations are siloed. This session will reveal best practice strategies for effective and successful community collaborations and partnerships that lead to increased access for equitable high quality care delivery.

Speakers:

- Elder Angela Overton, M.Div., Director of Faith Community Partnerships, C-TAC
- Erik Fromme, MD, MCR, FAAHPM, Senior Scientist & Lead Faculty for the Serious Illness Care Program, Ariadne Labs
- Stachelle Bussey, Founder & Executive Director, Hope Village, Louisville, KY
- Marisette Hasan, RN, BSN, VP of Community Action & Policy, C-TAC

Tearing Down the Walls of Social Isolation and Loneliness in Our Communities - located in the Senate room

Social isolation and loneliness (SIL) can significantly impact mental health, especially those with serious illness and their caregivers. Research suggests ongoing SIL can lead to increased depression, anxiety, and other psychological, psychiatric, and cognitive disorders. Join us for a discussion with diverse stakeholders on the impact of health equity, social connection, engagement of trusted leaders and other interventions may help reduce SIL in your community.

Speakers:

- Stephanie Anderson, DNP, RN, Executive Director, C-TAC Innovations
- Cassandra D. Harris-Gray, LCADC, LMFT, BIP, Chief Executive Officer & Clinical Director, Creative Spirits Behavioral Health
- Sallie Carney, Caregiver, Louisville, KY
- Jillian Racoosin, MPH, Executive Director, Foundation for Social Connection
- Camilia Ronderos Bernal, Executive Director, Keralty Compassionate Communities

Ethical and Equitable care: Navigating Serious Illness Care in Individuals with Serious Persistent Mental Illness - located in the Pan American room

This panel of palliative, psychiatric, and medical ethics specialists will examine the challenges faced by individuals with serious mental illness to accessing equitable serious illness care. Persons with life-limiting medical illness or with treatment-refractory mental illness benefit from nuanced, ethically informed care delivered by collaborative multidisciplinary teams. This session will review evidence-based practices that promote engagement in advance care planning, caregiver support, symptom management, respect for autonomy, and goal-concordant care. Special attention will be paid to policy considerations with the aim of optimizing equitable, high-quality serious illness care for this vulnerable, often marginalized population. Current debate regarding palliative psychiatry will also be discussed, along with implications for clinicians, administrators, policymakers, and researchers.

Speakers:

- Elizabeth Sivertsen, MBE, CCRN, HEC-C, Clinical Ethicist, Grady Memorial Hospital
- Ashley Smith, Board-Certified Physician Assistant, Psychiatry Consultation-Liaison Service, Grady Hospital
- Carina Oltmann, LCSW, Manager of Research Projects, Emory Palliative Care Center, Emory School of Medicine
- Leigh Ann Kingsbury, MPA, Gerontologist, Principal, InLeads Consulting

2:55pm – 3:30 pm Fireside Chat featuring Adam Boehler, Founder & Managing Partner of Rubicon Founders; former director of the CMS Innovation Center & **Tom Koutsoumpas**, Co-Founder and Co-Chair, Coalition to Transform Advanced Care (C-TAC) - **located in the Presidential Ballroom**

3:30pm – 3:45pm Closing Remarks with Jon Broyles, CEO, C-TAC

3:45pm Summit Adjourns