



C+TAC

SERIOUS ILLNESS + QUALITY OF LIFE

2021 ANNUAL REPORT

LETTER FROM LEADERSHIP

To our members, supporters, and friends,

Rev. Diane Smalley was a longtime warrior for social justice who turned her own battle with cancer into a campaign for health equity and a mission to “open doors” to care that respects patients’ goals and values.

When Shirley Roberson learned she had stage 4 breast cancer, she refused to just let things “take their course.” She was determined to take an active role in her own care, asserting her right to be seen and heard “as a whole person.”

Norma Bauerschmidt refused to go gently into that good night and at the age of 90, diagnosed with uterine cancer, she took to #vanlife with her son and daughter-in-law, living and ultimately dying with joy and on her own terms.

These extraordinary women are just three of the 12 million patients, their family-caregivers facing serious illness in our country. They are our constituency. And thanks to you and organizations like yours, C-TAC can remain their champion and their voice, elevating their issues, representing their interests, and working to craft policies that deliver the care they need and deserve.

As we reflect on the past tumultuous year, we are pleased to report some important advances:

- With member input, we drafted and shared our Core Principles for Models to improve care in existing care models to better support patients and families facing serious illness. We shared these within CMS which was received with enthusiasm.
- We made inroads among Congressional leaders and leaders at the Centers for Medicare and Medicaid Services (CMS) in an effort to achieve our 2030 Moonshot goal of ensuring 12 million people living with serious illness have a high quality of life
- We unrolled our new strategic plan at the 2021 Summit, featuring key policy initiatives around:
 - Integration of community-based organizations into value-based payment models
 - Ramping up on state action on Medicaid, building on the work in Hawaii, and elsewhere
 - Ensuring equal access to advance care planning among patients, unpaid caregivers and clinicians

Serious illness knows no social class. No nationality. It can come for any of us at any time. For C-TAC and you, our partners, serving patients and their caregivers is our highest mission, the foundation of everything we do.

We are grateful for your continued support.



Jon Broyles, CEO



POLICY IMPACT LEGISLATIVE

Hill Communications and Advocacy

- Ongoing communication with key Members of Congress, including discussions with staff of Sens. Whitehouse and Warner, and Rep. Blumenauer regarding use of C-TAC Core Principles for Models.
- Provided amendment ideas on serious illness to numerous offices for potential inclusion in the American Rescue Plan legislation.
- Communicated with the staff of Sens. Rosen, Warner, Whitehouse, Casey, Scott, Wyden, and Reps. Blumenauer, Neal, and Scott about including several C-TAC proposals in Build Back Better (BBB).
- Met with Sarah Khasawinah and Ranking Member Scott's staff of the Aging Committee on a proposal for creation of community-based organization grants and Advance Care Planning (ACP) issue material. As of December, they were still considering the bill ideas.
- Provided C-TAC care infrastructure input for BBB to dozens of Hill offices.
- Received videos of support for our C-TAC Policy Forum from Sens. Whitehouse, Rosen, Warner, and Rep. Blumenuaer.
- Met to discuss the C-TAC Policy Agenda with staff of Ways & Means, Finance, Education & Labor, Aging, HELP committees.
- Secured language in Leadership Council of Aging Organizations (LCAO) letters to the Hill in support of funding under the Title III-D of the Older Americans Act (OAA) for evidence-based programs, including Respecting Choices. As of December, the program has received an increase of \$6.8 million in the House and \$1.5 million in the Senate.
- Supported inclusion of the Palliative Care and Hospice Education and Training Act funding of \$100 million in BBB.
- Secured language in LCAO letters to the Hill in support to funding of \$75 million for the new Research, Demonstration, and Evaluation Center for the Aging Network included in the House passed BBB.
- Sent letter to Congress about visitation restrictions, particularly for long-term care facilities and for those who are isolated with serious illness. More than \$250 million is provided in BBB for programs, training, and technical assistance related to social engagement and isolation. The CARES Act included language supporting the long-term care ombudsman program's access to facilities and the Administration recently lifted restrictions.
- Signed on to a letter regarding the Part D Enhanced Medication Therapy Management Model (EMTM) that serves vulnerable Medicare beneficiaries.
- Assisted Sen. Whitehouse's staff with strategies for redrafting and introducing his legislation: Removing Barriers to Person-and Family-Centered Care Act. Secured about fifteen organizations' endorsement of the bill for staff.

POLICY IMPACT LEGISLATIVE

Hearings/Legislative Endorsements

- Provided background and questions used by Sens. Warner and Whitehouse, and Rep. Blumenauer in hearings. One Q&A by Rep. Blumenauer in the hearing was transcribed used for a C-TAC blog.
- Secured quote from Jon Broyles, CEO of C-TAC, in Sens. Rosen's and Barrasso's press release on the introduction of the bipartisan S. 2565, Expanding Access to Palliative Care Act.
- Secured quote from Jon Broyles, CEO of C-TAC, in Sen. Rosen's press release regarding Sens. Rosen's and Murkowski's bill introduction: Provider Training in Palliative Care Act.
- Secured Sen. Rosen's staff to participate in the National Academies meeting.
- Drafted questions for hearing related to pandemic issues for staff.
- Distributed a press release in support of Sen. Whitehouse's reintroduction of the Removing Barriers to Person-and Family-Centered Care Act.
- Arranged for Rachel Fybel from Sen. Whitehouse's staff to join a C-TAC Policy Update webinar as a special guest.

Legislative Development

- Drafted a concept for a payment model add-on leading to C-TAC's Core Principles for Models and potential introduction of a bill to ensure all models and programs better cover care for serious illness.
- Redrafted parts of the Patient Choice and Quality Care Act (PCQCA) and brought together core support group for Sen. Whitehouse and Rep. Blumenauer. This included streamlined the model payment provisions of PCQCA and added new payment model concept.
- Developed legislative ideas around supporting minority communities with grants for assessment, coordination, and community-based services. As of December, conversation are ongoing with potential bill sponsors.
- Worked to include ACP in LCAO Hill letter.
- Served as a stakeholder observer on drafting committee that the Uniform Law Commission is creating to revise the Uniform Health Care Decisions (UHCD) Act.

POLICY IMPACT REGULATORY

ACP Cost Sharing

- Identified this as an issue and raised it to our members and federal policy stakeholders.
- Applied to the United States Preventative Services Task Force (USPSTF) to have ACP designated a preventive service, which would eliminate cost sharing, and got confirmation that was not in their purview.
- Confirmed that CMS counsel feels they also lack the ability to waive cost sharing and are now pursuing this legislatively.
COVID-19 Visitation Restriction Concerns
- Sent a letter to Congress and the Administration about our concerns on the impact of restricted COVID-19 visitation on patients, families, and staff and received media coverage and member recognition.
- Published a blog in Health Affairs on this topic.

ACP Process

- Interviewed by the Office of Inspector General's (OIG's) team doing an audit of ACP billing practices and shared that our intel showed federal guidance was not as clear as it could be to ensure compliance.
- Interviewed by the Assistant Secretary for Planning and Evaluation (ASPE) team doing a report on ACP.
- Participated in Post-Acute Care Interoperability (PACIO) sessions and contributed to the implementation guide they are developing for advance directive interoperability.

POLICY IMPACT REGULATORY

Payment Models

- Developed and disseminated core principles for models providing care for those with serious illness for policy makers and leaders in healthcare.
- Interviewed by the Physician-Focused Payment Model Technical Advisory Committee (PTAC) for their report on how to implement care coordination in alternate payment models.
- Met with CMMI regarding their new strategy and are recognized as a key stakeholder when it comes to models for those with serious illness.

CMS Rules

- Acknowledged C-TAC's comments on the following final rules:
 - Adding measures to the End-Stage Renal Disease (ESRD) Treatment Choice Model for ACP, palliative care, and timely referral to hospice.
 - Requiring a skilled nursing facility (SNF) frailty assessment.
 - Advocating for audio-only telehealth for ACP during pandemic.
- Submitted responses to CMS Requests for Information (RFIs) on equity and interoperability for the hospice, home health, and SNF proposed rules.



C+TAC
SUMMIT

MEMBERS AS OF THE END OF 2021

Academic Institutions

- The CSU Shiley Haynes Institute for Palliative Care
- Marian University
- Trillium Institute
- University of Pennsylvania School of Nursing

Advance Care Planning Products and Services

- Aging With Dignity / Five Wishes
- EternallyTak
- Health Care Agent Literacy Project
- Institute on HealthCare Directives | MIDEO®
- Koda Health
- Life in Motion Guide
- Respecting Choices®
- The Conversation Project
- WiserCare, Inc.
- Vynca, Inc.

Community-Based Services and Supports

- A Sacred Passing
- Aging & In-Home Services of Northeast Indiana, Inc.
- Betsy Trapasso - End of Life Guide and Advocate
- Chaplaincy Innovation Lab
- GoodEnding
- HealthCare Chaplaincy
- Healwell
- LGBTQ Caregiver Center
- The Oasis Institute
- The Peaceful Presence Project
- Progressive National Baptist Convention
- Verde Valley Caregivers Coalition
- Vital Comm Lines

Consumer Products

- Keeper
- MemoryWell

Network Managers

- Alivia Care, Inc.
- Hucu.ai
- Teleios Collaborative Network
- Votive Health

Consulting Organizations

- Be Present Care
- Grief Advocacy
- Patient Advocacy MD
- The Sonnet Group
- Thyme Care
- Turnlane

Foundations

- Benjamin Rose Institute on Aging
- Cambia Health Foundation
- The David and Lura Lovell Foundation
- The Elisabeth Kübler-Ross Foundation
- The John A. Hartford Foundation
- John & Wauna Harman Foundation
- Partners in Care Foundation
- Ralph C. Wilson, Jr. Foundation
- Roots & Roads Community Hospice Foundation
- The SCAN Foundation
- Stupski Foundation
- St. David's Foundation

MEMBERS AS OF THE END OF 2021

Healthcare Providers

- Alive Hospice
- Big Bend Hospice
- Bluegrass Care Navigators
- Bluestone Physician Services
- Capital Caring Health
- Community Hospice and Palliative Care
- COMPASS Pathways
- Compassus
- Cornerstone Hospice and Palliative Care
- The Elizabeth Hospice
- George Mark Children's House
- Good Samaritan Hospice
- Good Shepherd Community Care
- Guadalupe Regional Medical Center
- Home Centered Care Institute
- Hope HealthCare Services
- HopeWest
- Hosparus Health
- Hospice and Palliative Care Buffalo
- Hospice East Bay
- Hospice of Acadiana
- Hospice of Chattanooga
- Hospice of Cincinnati
- Hospice of Santa Cruz County
- Hospice of the Valley
- Hospice of the Western Reserve
- Hospice of Washington County
- Iowa City Hospice
- Livio Health
- MJHS
- Mountain Valley Hospice & Palliative Care

- PalliCare
- Ryan House
- Samaritan Healthcare & Hospice
- Trellis Supportive Care
- Unity Hospice

Health Systems

- Advocate Aurora Health
- Cedars-Sinai Medical Center
- Gundersen Health System
- MedStar Health
- Northeast Georgia Health System
- Population Health
- Sutter Care at Home/Sutter Health

National Nonprofit Organizations

- AARP
- Alliance for Home Health Quality and Innovation
- American Cancer Society / Cancer Action Network
- American Heart Association
- Caregiver Action Network
- Center for Practical Bioethics
- Center to Advance Palliative Care (CAPC)
- Family Caregiver Alliance
- Healthcare Hospitality Network
- Humane Prison Hospice Project
- National Academy of Medicine
- National Alliance for Caregiving
- National Alliance for Hispanic Health
- National End of Life Doula Alliance (NEDA)
- National Partnership for Women & Families
- National POLST

MEMBERS AS OF THE END OF 2021

National Professional and Trade Associations

- American Geriatrics Society
- America's Health Insurance Plans (AHIP)
- American Academy of Home Care Medicine (AAHCM)
- American Hospital Association
- Association of American Medical Colleges (AAMC)
- Hospice and Palliative Nurses Association (HPNA)
- National Partnership for Hospice Innovation (NPHI)
- National Academy of Elder Law Attorneys (NAELA)
- Social Work Hospice and Palliative Care Network

Payers

- Aetna
- Anthem
- Cambia Health Solutions
- CareFirst
- CareMore and Aspire Health
- CareSource
- Centene
- Cigna
- HealthPartners
- Humana
- Kaiser Permanente
- UnitedHealth

State Associations, Coalitions and Collaboratives

- Association for Home & Hospice Care of North Carolina
- The Carolinas Center for Hospice and End of Life Care
- Center for Improving Value in Health Care (CIVHC)
- Center for Advancing Serious Illness Communication

- Coalition for Compassionate Care of California
- Georgia Hospice and Palliative Care Organization
- Honoring Choices North Dakota
- Honoring Choices Pacific Northwest
- Honoring Choices Tennessee
- Honoring Choices Virginia
- Hospice Council of West Virginia
- Hospice & Palliative Care Association of New York State
- Hospice & Palliative Care Federation of Massachusetts
- Kōkua Mau
- Louisiana Health Care Quality Forum
- Louisiana-Mississippi Hospice and Palliative Care Organization
- Maine Hospice Council
- Minnesota Network of Hospice & Palliative Care (MNHPC)
- The Missouri Hospice & Palliative Care Association (MHPCA)
- Oklahoma Hospice & Palliative Care Association
- Pediatric Palliative Care Coalition
- South Carolina Home Care and Hospice Association (SCHCHA)
- South Dakota Association of Healthcare Organizations
- Texas & New Mexico Hospice Organization
- Tennessee End-of-Life Partnership (TELP)

Quality Improvement Organizations

- Community Health Accreditation Partner (CHAP)
- Connecticut Center for Patient Safety
- Mountain-Pacific Quality Health
- Turn-Key Health
- Stratis Health



GIVING

Grants

- Stupski Foundation
- Peterson Center for Healthcare
- Ralph C. Wilson, Jr. Foundation
- John A. Hartford Foundation
- Gordon and Betty Moore Foundation

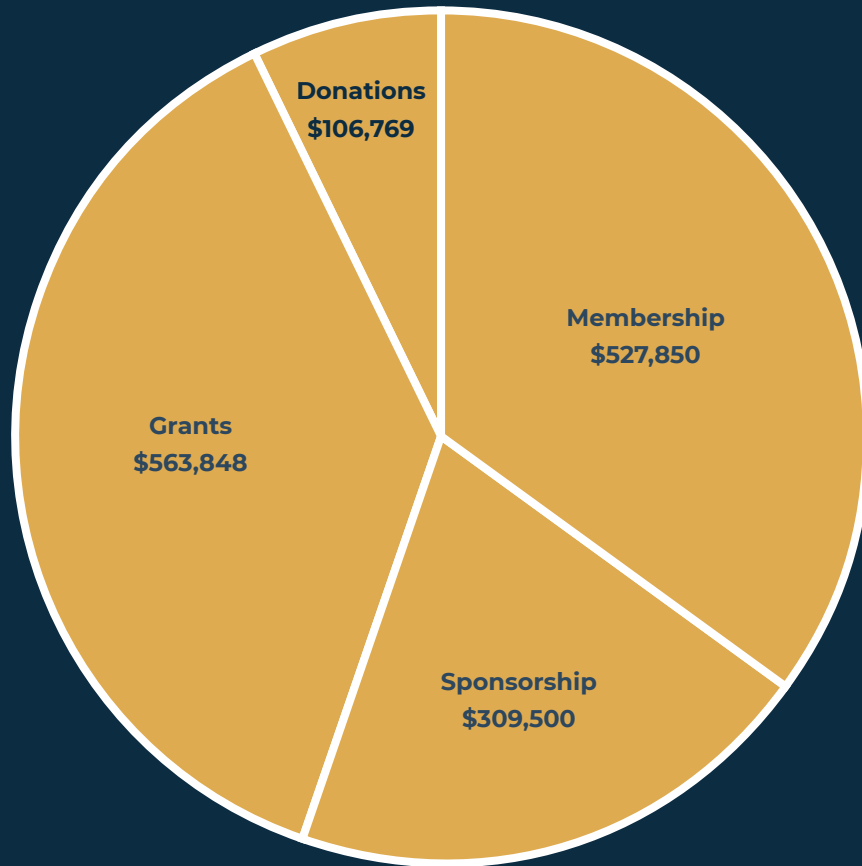
Major Gifts

- Bill Novelli
- Alexandra Drane
- Nancy Brown
- Rev. Yvonne Delk
- David Jones
- Charlotte Yeh
- Heising Simons Fund
- Lucy Kalanithi
- David Longnecker

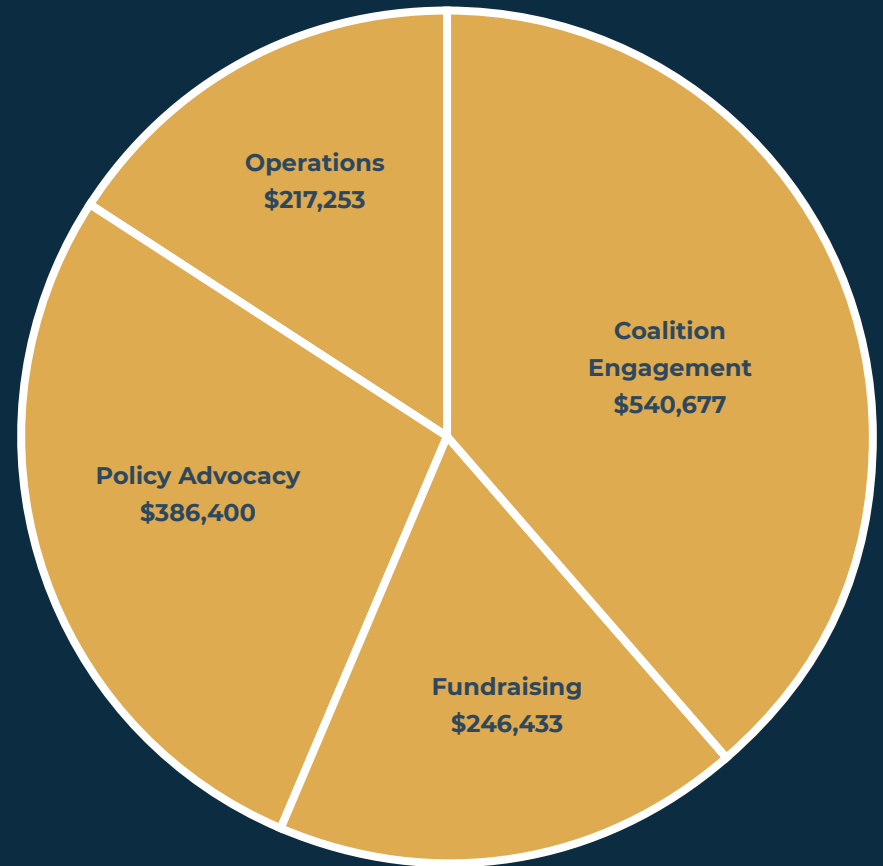
2021 Summit Sponsors

- AARP
- AHA - American Heart Association
- Archstone Foundation
- HCCI – Home Centered Care Institute
- Humana
- Ralph C. Wilson, Jr. Foundation
- Peterson Center on Healthcare
- Cambia Health Foundation
- The John A. Hartford Foundation
- UCB
- Pfizer
- Compassus
- The David & Laura Lovell Foundation
- MemoryWell
- Vynca
- Koda Health
- Grantmakers in Aging
- Reimagine End of Life
- WiserCare
- ResolutionCare
- NEDA
- HO | CHIANG Foundation

2021 FINANCIALS



Revenue Sources



Expenses by Program



FROM OUR MEMBERS



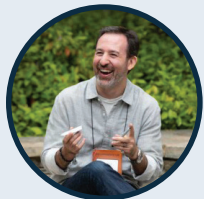
“While we originally joined C-TAC for the opportunity to engage in the national conversation around Advance Care Planning and serious illness, we found there was so much more! This coalition has been a robust space to foster impactful and innovative partnerships across disciplines and industries that enrich the field and our organization immensely.”

Tatiana Fofanova, PhD CEO of Koda Health



“C-TAC is an incredibly valuable and useful resource within the toolbox of a leader and organization. C-TAC’s skillful ability to convene a highly reputable and knowledgeable coalition of experts to collectively advocate for people experiencing serious illness is outstanding. Each educational opportunity, written resource, and conversation adds value and offers a true return on investment. C-TAC has helped to create meaningful connections to other leaders and offers many opportunities to engage and learn. Thank you, C-TAC!”

Heidi Warpinski, MS, RN, CPNP Director for Pediatrics and Palliative Care Services, Unity



“Cedars-Sinai Health System is an engaged and committed member of C-TAC. Their convening strength through the National Summit and informative webinars allows us to learn from other important partners in the field as well as connect with like-minded leaders looking to transform how serious illness care is delivered.”

Bradley T. Rosen, MD Vice President, Physician Alignment and Care Transitions, Cedars-Sinai Health System



“I have been a member of a wide variety of professional and health-based organizations during my career, but my experience as a member of C-TAC has far exceeded any prior experience. The level of member engagement, spirit of active collaboration and access to valuable and free education and networking events is truly excellent. As a member of C-TAC, I feel like my organization is an active participant in the transformation of advanced illness care. Thank you, C-TAC!”

Cal Cates Executive Director, Healwell

FROM OUR MEMBERS



"I am repeatedly impressed with C-TAC's commitment to concretely addressing racial equity in transforming serious illness care. It's inspiring to see a national organization stand up for what they believe in such an uncompromising way and do the real work of engaging communities and truly sharing the stage."

Julie Boudreau Executive Director, The John & Wauna Harman Foundation



"I got involved in C-TAC because their advocacy is based on visionary goals and realistic initiatives that translate into positive changes in the care of seriously ill patients and their loved ones' experiences."

Dr. Silvia Perez Protto, MSc, FCCM

Medical Director, End Of Life Center Office Of Patient Experience, Cleveland Clinic



"The LGBTQ Caregiver Center is a committed member of the Coalition to Transform Advanced Care (C-TAC). Zander Keig, LCSW and I wholeheartedly support and endorse CTAC's nonpartisan and unbiased source of expertise as a convener of more than 190 organizations that share our vision of a healthcare system that recognizes caregivers as a critical member of the patient's care team and advocates to strengthen policies and programs to enhance the well-being of both the patient and the caregiver with culturally competent services that honors their dignity."

Jennifer Henius, LCSW Co-Founder, LGBTQ Caregiver Center



"AARP has supported C-TAC since its inception. We believe that all Americans with advanced illness, especially the sickest and most vulnerable, should receive comprehensive, high-quality, person-and-family-centered care that is consistent with their values and honors their dignity. While advanced illness can strike any one of any age, the vast number of people with advanced illness are those in older age groups. As our society ages, those numbers are only going to increase. This places unprecedented demands on family caregivers—half of whom are over the age of 50. C-TAC is bringing all facets of society together to ensure that those experiencing serious illness and those who care for them have the support they need."

Jo Ann Jenkins Chief Executive Officer, AARP

FROM OUR MEMBERS



“When we were introduced to C-TAC by one of our grantee partners we had a lot to learn. C-TAC quickly opened our eyes to the world of organizations and people who were collaborating at the leading edge of serious illness care, policy, and advocacy across the country. We have since enjoyed the connections and synergies that C-TAC creates for its members. By taking advantage of all they have to offer, we are closer to our vision of a future where person-centered approaches to whole health and goal concordant care, spanning the spectrum of life’s choices, are available to all.”

John Amoroso Executive Director, David and Lura Lovell Foundation



“Partners was drawn to C-TAC because as a Community Based Organization that is mission driven to improve health care systems our values align and complement each other. C-TAC policies surrounding health equity, community support, caregivers, workforce development and care models are among our main priorities. We hope that by joining we could be on the front end of policy work, as well as be able to connect and share information and best practices from other leaders. We would like to unite our client voices to the overall impact that C-TAC provides.”

June Simmons President and CEO, Partners in Care Foundation



“We at Humane Prison Hospice Project are deeply grateful for the support and energy the C-TAC team has around promoting and advocating for serious illness care and compassionate end-of-life care for the most left behind and forgotten in our society, including those who reside in our nation’s 1,800 prisons. With C-TAC’s partnership, we were able to bring awareness of the needs of aging and dying prisoners and what can be done to support them to our colleagues in hospice and palliative care across the country. Our work with C-TAC also will inform our policy-advocacy strategies going forward.”

Lisa Deal, RN, MPH, SCD Executive Director, Humane Prison Hospice Project

FROM OUR MEMBERS



“The Chaplaincy Innovation Lab is thrilled to see C-TAC’s inclusion of spiritual care as a vital component of advanced care. Chaplains long have known that care for the spirit is an essential part of whole-person care, and we are grateful to see this understanding becoming more and more common in all spheres of patient and family care. C-TAC has been an essential partner in conveying the importance of spiritual care to the broader health profession. We are eager to continue this partnership and indeed get to know more like-minded organizations in the C-TAC network.”

Michael Skaggs, PhD Director of Programs, Chaplaincy Innovation Lab



“Too often, people with advanced cardiovascular diseases, including heart disease, heart failure and stroke, and their families are not made aware of how palliative care provides holistic support to relieve symptoms and improve quality of life. Additionally, emergency room and hospital visits take a substantial emotional and financial toll that can be averted with patient-centered care programs administered at home and at treatment centers from hospice and advanced illness providers. I am so proud of the American Heart Association’s work in support of C-TAC to inform policy, engage the community and state, as well as provide support for family caregivers.”

Nancy Brown, CEO American Heart Association



“PAUSE was drawn to join C-TAC after a connection was made by a mutual connection in the end-of-life field. We are so glad that introduction was made, as it has inspired an incredible opportunity for storytelling and connection around how we can better support People of Color at the end of their lives. We are so grateful to be part of C-TAC, a coalition that prioritizes community and collaboration. I am deeply appreciative of the C-TAC team’s level of engagement with members and amplification of our work within the network and industry.”

Alica Forneret Executive Director, Pause



“THORO CARE is delighted to join C-TAC and wants to be part of the solution to advance care through innovation, observation, and collaboration. THORO CARE is excited to work with and learn from the vast network of innovative leaders at C-TAC.”

Renu Thomas Co-Founder, Thoro Care



C-TAC
COALITION TO TRANSFORM
ADVANCED CARE



FROM POLICY MAKERS



"I want to recognize C-TAC for its tireless work to transform advanced care so that all Americans with a serious illness have access to comprehensive, high-quality care."

Senator Jacky Rosen (D-NV)



"I've been proud to work with C-TAC since its beginning – issues around end of life are incredibly important and critical. For too long these issues have been underappreciated, under-resourced, and under researched.... I look forward to working with C-TAC on these important issues going forward."

Senator Mark Warner (D-VA)



2021 C-TAC BOARD OF DIRECTORS

Bill Novelli

C-TAC Board Co-Chair
Professor, McDonough School of Business,
Georgetown University

Tom Koutsoumpas

C-TAC Board Co-Chair and President
CEO, Capital Caring Health

Nancy Brown

Chief Executive Officer, American Heart Association,

Jeffrey Burnich, MD

Former Chief Physician Enterprise Executive, Canopy Health

Patrick T. Courneya, MD

Chief Health Plan Medical Officer, HealthPartners

Reverend Dr. Yvonne V. Delk

Minister, United Church of Christ

Alexandra Drane

Co-founder and CEO of Rebel Health and ARCHANGELS

Mark Ganz

President and CEO Emeritus, Cambia Health Solutions

Lucy Kalanithi, MD

Clinical Assistant Professor of Medicine,
Stanford School of Medicine

BJ Miller, MD

President and Counselor, Mettle Health

Ravi Parikh, MD, MPP

Assistant Professor, Medical Ethics and Health Policy and
Medicine, University of Pennsylvania

Shirley Roberson,

Patient Advocate and Originator of the “Blue Chair” story

Meena Seshamani, MD, PhD

Vice President of Clinical Care Transformation,
Medstar Health

Richard Umbdenstock

President Emeritus, American Hospital Association

Charlotte Yeh, MD

Chief Medical Officer at AARP Services, Inc.

OUR TEAM

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Joy Braun

VP of Development

Luke Scuitto

Partnerships Director

Jennifer Driscoll

Operations Director

Sarah Park

Program Manager

Sandra Arias

Partnerships Associate

C+TAC

SERIOUS ILLNESS + QUALITY OF LIFE

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