



**2024**

**NCSI Coalition  
Year in Review**

**2020**

30 Members

**2021**

80 Members

**2022**

180 Members  
from 98 Organizations

**2023**

200+ Members  
from 100+ Organizations

**2024**

330+ Members  
from 120+ Organizations

# Coalition Membership

Strengthen Membership & Engagement:

Disease Groups, Underserved Populations, Health Systems & Payors, Workforce Development

# NCSI Coalition Interns



2023



Sabita Markose  
UNC-CH



Bernadette Moss  
UNC CH



Steven Nordstrom  
UNC CH



Disha Patel  
UNC CH



Maria Rivera  
UNC CH



Aviti Dombasi  
UNCC



Megan Reid  
UNCC



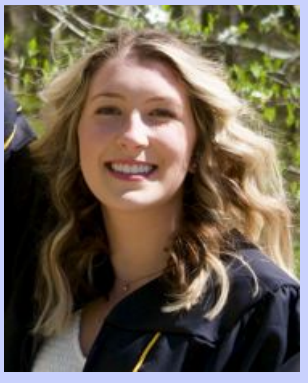
Lauren Stalzer  
UNC CH



Carrie Poole  
UNC CH



English Bonds  
UNC CH



Hannah Dodge  
App State



Manasi Somkuwar  
UNCC



Mannah Patel  
UNC CH



Brooke Middleton  
UNCC



Essence Turner  
UNC CH



Sucharitha Tiyyagura  
UNCC



Shravan Durga  
UNCC

2024

## Focus Areas:

Clinical Training \* Palliative Care \* Health Equity  
Caregiving Policy \* Membership \* Social Media  
ACP Evaluation \* Data Analysis



Jacqueline Zanders  
UNC CH

2025





# 2024 Monthly Meeting Topics

What topics would you like to see in 2025?

**January**  
**UNCC**  
**Caregiver**  
**TLC Program**

**February**  
**Center for**  
**Black Health**  
**& Equity**

**March**  
**Art & Science**  
**of Effective**  
**Advocacy**

**April**  
**Healthcare**  
**Decisions**  
**Support**

**May**  
**US & NC**  
**Caregiver**  
**Programs**

**June**  
**NC Families**  
**Care Coalition**

**July**  
**No**  
**Meeting**

**August**  
**Voter**  
**Education**  
**AARP NC**

**September**  
**Senior**  
**PharmAssist**

**October**  
**Essential Jobs**  
**Essential Care**

**November**  
**Symposium**  
**Feedback**

**December**  
**2024 Year**  
**in Review**



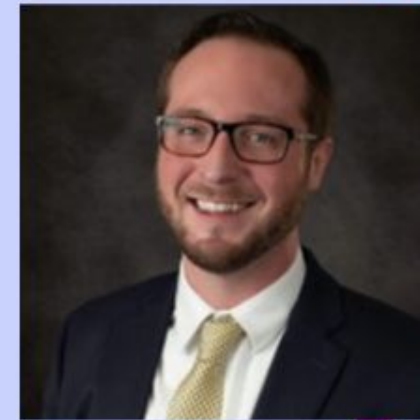
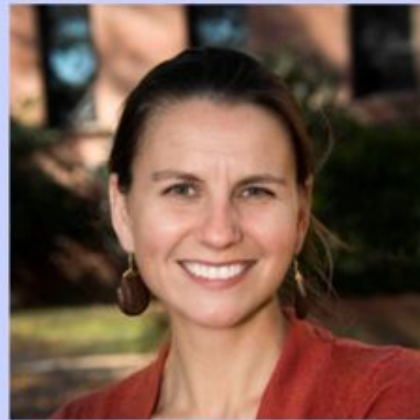
## Healthcare & Research

- Ginger Marshall (HPNA)
- Dr. Megan Shepherd-Banigan (Duke University)
- Dr. Andrea Bozoki & Sutton Salinger (Duke/UNC ADRC)
- Emily Roland & Dean Higgins (NC Healthcare Foundation)
- Dylan Bondy (Solace Health)
- Hope Brooks (Novant Health)
- NCSI Coalition Interns



## Advocacy

- Tara Muller (Disability Rights NC)
- Jon Hoffman (American Kidney Fund)
- Trish Farnham (EJEC)
- Kenya Servia (NC HIEA)
- Dr. Deryl Davis Fulmer (NCRGEA)



# 2024

# Friday Facts 21 Episodes



## Community Organizations

- Colby Wilkerson & Elianna Horner (The G Day)
- Judith Brown (Project 70Forward)
- Dr. Nicole French (Veterans Bridge Home)
- Dagny McDonald (Sickle Cell Partners)
- Carol Henderson (Writing Towards Resilience)



## ACP Education

- Beth Rosenberg (Atrium Health)
- Heather Altman (Mind My Health)
- Jacob Gordon (Trellis Supportive Care)
- Betsy Barton (Transitions LifeCare)



# Governor's Proclamation: North Carolina Healthcare Decisions Month April 2024



## State of North Carolina

ROY COOPER  
GOVERNOR

NORTH CAROLINA HEALTHCARE DECISIONS MONTH

2024

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

### A PROCLAMATION

**WHEREAS**, Healthcare Decisions Month raises public awareness of the need to plan ahead for healthcare decisions, especially those related to end-of-life care, and medical decision-making, when patients are unable to speak for themselves, and to encourage the specific use of advance directives to communicate those important healthcare decisions; and

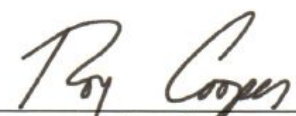
**WHEREAS**, decisions concerning healthcare should be made by individuals in consultation with their healthcare provider, and their families; and

**WHEREAS**, many North Carolinians do not make adequate preparation for healthcare decisions in times of crisis, or at end-of-life, even though such preparation is readily accessible through the medical and legal communities; and

**WHEREAS**, Healthcare Decisions Month helps raise awareness of the need to provide clear and consistent information to the public about advance directives and encourages medical professionals and lawyers to volunteer their time and effort to improve public knowledge and increase the number of North Carolina residents with advance directives;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim April, 2024, as "**NORTH CAROLINA HEALTHCARE DECISIONS MONTH**" in North Carolina, and commend its observance to all citizens.



  
Roy Cooper  
Governor

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this twenty-seventh day of March in the year of our Lord two thousand and twenty-four and of the Independence of the United States of America the two hundred and forty-eighth.



# Joining Our Voices Symposium

## Symposium Participation Stats

Registered: 265

Unique Participants: 154

How the Caregiving Crisis Affects Us All - 111

The Future of AI to Improve Care & Caregiving - 60

My Superpower Documentary & Panel - 50

What did you find most useful or informational about this session?

- Seeing a group of coalition builders who want to make the system better was encouraging
- Direct voices of those with lived experiences
- Good information and insights
- Great balance of experts
- Broad range of caregiver experiences.
- The story. The message. The connections.
- The honesty and vulnerability of the panelists

**Click here or scan the QR code to register**

**ENVISIONING THE FUTURE OF SERIOUS ILLNESS CARE**

**Joining Our Voices**

**OCT 30 - NOV 1, 2024**

A North Carolina Serious Illness Coalition online conference experience

**MY SUPERPOWER**  
A short documentary film from the Children's Tumor Foundation

**ABOUT**

**Joining Our Voices: Envisioning the Future of Serious Illness Care** is a virtual symposium that unites health professionals, providers, caregivers and advocates in conversation to share experiences, innovations, and opportunities for the future of North Carolina's serious illness care.

This event is produced by the North Carolina Serious Illness Coalition in collaboration with its membership and partner coalitions.

Learn more about the coalition at: [www.ncsicoalition.org](http://www.ncsicoalition.org).

**EVENT LINEUP**

**WEDNESDAY, OCT 30, 12:00PM - 1:30PM ET**  
WE ARE IN THIS TOGETHER:  
HOW THE CAREGIVING CRISIS AFFECTS US ALL (AND WHAT WE CAN DO ABOUT IT)

**THURSDAY, OCT 31, 12:00PM - 1:30PM ET**  
THE FUTURE OF AI TO IMPROVE CARE AND CAREGIVING

**FRIDAY, NOV 1, 12:00PM - 1:30PM ET**  
MY SUPERPOWER: DOCUMENTARY SCREENING & CONVERSATION WITH ADVOCATES AND THE FILM'S STARS

**NORTH CAROLINA SERIOUS ILLNESS COALITION**

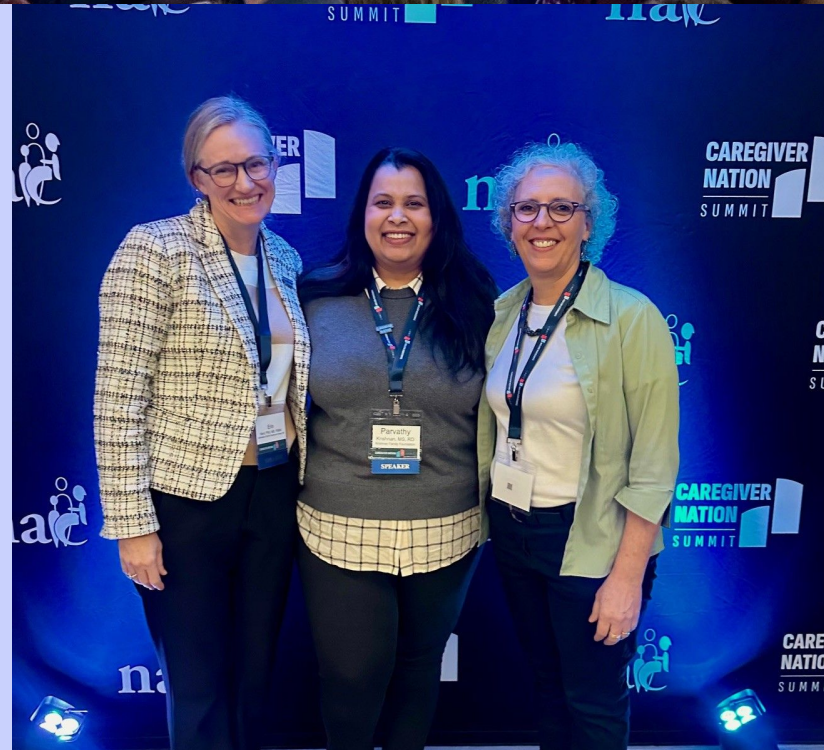
# NC Caregiving Collaborative



- ★ Convenes organizations and individuals engaged in caregiving advocacy
- ★ Represents NC on the Caregiver Nation Network, facilitated by the National Alliance of Caregiving
- ★ Receives funding by Grantmakers in Aging for statewide initiatives

## 2024/2025 Collaborative Goals:

- 1) Coalition building around caregiving
- 2) Analyzing the landscape of existing caregiving resources in NC and how they relate to implementation of the 5 goals of the National Strategy to Support Family Caregivers
- 3) Gathering & promoting additional caregiver stories as part of our advocacy work





# NC Caregiving Collaborative



## NORTH CAROLINA CAREGIVING DATA

- € North Carolina has an estimated **1.3 million** informal caregivers.
- € NC caregivers provide an estimated **1.2 billion care hours**, an unrealized economic value of **\$16.5 billion per year**. These hours limit caregiver contribution to growth of the general economy.
- € NC currently ranks **9<sup>th</sup>** nationally in total population and number of people 65 and older.
- € The population of ages 65+ is projected to increase from 1.9 million in 2024, to **3.04 million** by 2050. The growth in the percentage of those 85 and older, ages at which higher levels of care are often needed, is projected to grow by **152%** over the next 25 years.
- € NC also has a higher relative population proportion (**22%**) of **children and youth** with **complex health needs** compared with the national average (20%). These young people often need in-home caregiving.
- € There are an estimated **80,928 grandparents** responsible for grandchildren under 18, and **45%** were aged 60 and older.

## PROGRAMS THROUGH THE NC DHHS DIVISION OF AGING (SFY 24 July 2023-June 2024)

- **National Family Caregiver Support Program**
  - **1,141**: total caregivers served by respite programs
  - **3,597**: total caregivers across all categories (respite, support groups, education, training)
  - **179**: total caregivers on waitlist for respite
  - **10**: total caregivers on waitlist for supplemental services:
- **American Rescue Plan Act (ARPA) Funding** - set to expire September 2025
  - **557**: total caregivers served by respite programs:
  - **1,020**: total caregivers across all categories (respite, support groups, education, training)
- € **Project C.A.R.E. (Caregiver Alternatives to Running on Empty)**
  - **428** caregivers served. 64% (272 caregivers) new and 36% (156 caregivers) existing clients.
- € **Lifespan Respite Voucher Program**
  - **65** respite vouchers awarded
  - Bi-lingual outreach materials and forms created to better serve Spanish speaking caregivers
- € **Alzheimer's Disease and Related Dementias initiatives**
  - Coalition for Dementia-Capable NC
  - Dementia Friends Program
  - Dementia Friendly Communities and Hospitals Network
  - NC State Health Improvement Plan (NC SHIP), Life Expectancy Priority Work Group Co-Lead
- € **NC Trualta Caregiving Portal** - free online resource for NC caregivers with information such as: caregiving skills, online support groups, information about specific illnesses.
- € **All Ages, All Stages NC** - multi-sector plan for aging finalized September, 2024. Priorities related to caregiving include: *Bolstering family caregiver support*; *Enhancing LTSS*; and *Strengthening the Aging and Health Care Workforces*.

Co-Leads: Karen Appert: karen@appertgroup.com and Heather Altman: haltman@hshig.org

## Other Initiatives with Caregiving Priorities

- € **Medicaid Expansion** – began Dec. 1, 2023. As of October 2024, over **550,000** North Carolinians gained health care coverage through this expansion.
- € **NC Center on the Workforce for Health** - <https://workforceforhealth.org/> - seeks to identify solutions, share best practices and monitor progress in addressing the state's health workforce challenges.
- € **NC Institute of Medicine** – <https://nciom.org/task-force-on-healthy-aging/> - the Task Force on Healthy Aging included a recommendation to support Family Caregivers by increasing access to employment and well-being support for family caregivers.

## BARRIERS AND LIMITATIONS TO SUPPORT FOR CAREGIVERS

- € Although there are many state and federal programs, they assist only a small proportion of the state **1.3 million** informal caregivers. Many caregivers may find themselves with little or no support because they fall outside typical caregiver programs and interventions, such as:
  - Spousal caregivers or care recipients under 65
  - Those under 18 caring for parents with serious illness, disability, and/or cognitive impairments
  - Parents of children with complex medical needs
- € Though the state offers existing respite programs and other interventions, many caregivers aren't able to participate due to (among other reasons) restrictive eligibility requirements, rural locations, age restrictions, and therefore many of the caregivers who need the most help don't receive it.
- € The state's demographics are changing, with increasing racial and ethnic diversity, as well as increasing proportions of older adults. These groups may have difficulty accessing supports.

## Organizations represented by NC Caregiving Collaborative members:

- AARP NC
- ACAP Community
- Advocates For Medically Fragile Kids NC
- Blue Cross Blue Shield NC
- Center for Volunteer Caregiving
- Children's Complex Care Coalition of NC (4CNC)
- Dementia Alliance NC
- Disability Rights NC
- Duke University
- Duke Health
- ECU Health
- Eastern Carolina Council AAA
- Exceptional Children's Assistance Center
- Friends of Residents in Long-Term Care (FOR)
- Institute for Family Caregiving
- Krishnan Family Foundation
- MomsRising
- Mountain Care
- NC Autism Society
- NC Coalition on Aging
- NC Council on Developmental Disabilities
- NC DHHS, Division of Aging
- NC Families Care Coalition
- NC Serious Illness Coalition
- Patient Centered Innovation
- Relate Advocacy
- Silver to Gold Strategies
- The Frankie Mae Foundation
- Transitions Life Care
- UNC Charlotte
- UNC Gillings School of Public Health
- UNC Health

Co-Leads: Karen Appert: karen@appertgroup.com and Heather Altman: haltman@hshig.org

Document also highlights organizations working on:

**BETTER CAREGIVER SUPPORTS IN NORTH CAROLINA**

**ADVOCACY FOR DIRECT CARE WORKFORCE**

**ADVOCACY FOR CHILDREN WITH COMPLEX NEEDS**

# Advance Care Planning Outreach



**OWN  
YOUR HEALTH  
AND PLAN FOR CARE  
IN ADVANCE**  
Questions and Answers  
on Advance Care  
Planning





# Looking Ahead to 2025

Maximizing YOUR time, engagement, interests  
& organizing workgroup efforts around key initiatives...

★ **Caregiving & Patient Engagement:**

- NC Caregiving Collaborative

★ **Clinical Practice & Advance Care Planning**

- NC Clinical Consortium on Serious Illness Conversations Training

- \*New\* NC ACP Educators Collaborative

★ **Communications, Advocacy & Education**

- Legislative & Public Policy Committee

- Special Events: Joining Our Voices Symposium & Healthcare Decisions Month  
Monthly Meeting Topics & Friday Facts Speakers

**\*\* BIG ANNOUNCEMENT - New Date/Time for Friday Facts!**

**Combining with Monthly Meeting on the 3rd Fridays at 11 am**



# Joyful Coalition Members!

Yocasta Bianconi

Lee Dobson

Karen Appert

Jacob Gordon, Trellis Supportive Care

Jason Clamme

Cannon Light Media

Ellie Ward, ECU Health

Destiny Alston (PACE)

Charlotte Sweeney

Krystal Swicegood

Mary Lou Infinito/ECU Health ACP Team

Heather Altman (NCSI Coalition)

