

# **Strategies and Interventions to Strengthen Support for Family Caregiving and to Alleviate Caregiver Burden: A Workshop**

## **Committee**

### **Peggy Maguire**

#### **Chair**

Peggy Maguire, JD is the President of the Cambia Health Foundation, where connects the philanthropic dollars of Cambia Health Solutions to communities through non-profit partnerships. Peggy leads all of Cambia's philanthropic programs and activities, including strategic grantmaking, convening partners to address shared challenges, and engaging employees in giving and volunteerism. Dedicated to responsible stewardship, Peggy's team purposefully invests in underserved communities in Washington, Oregon, Utah and Idaho to advance equity through whole-person health. Founded in 2007, the Foundation has funded more than \$127M in grants to advance person-focused and economically sustainable healthcare. This includes a significant investment in the nationally recognized Sojourns® Scholarship Leadership Program supporting the next generation of palliative care leaders with the goal of improving the care of people with serious illness and supporting their caregivers.

After examining its role as a corporate philanthropist in a world forever changed by COVID-19, the Foundation released its new strategic plan in 2022 to focus on local partnerships that expand access to behavioral health within whole-person health models by investing in the paid and unpaid health care workforce, fostering resilient children and families and promoting healthy and connected aging for older adults. The new vision builds upon the Foundation's work in palliative care and is aligned with the cause of Cambia Health Solutions.

In 1997, Peggy joined Cambia Health as an associate general counsel and has held several posts including chief of staff to the prior CEO, vice president of legal services, director of litigation & enterprise risk management, as well as leadership roles in ethics, compliance and palliative care solutions. Previously, Peggy worked as an attorney at Garvey Schubert & Barer.

Peggy serves on the national board of Friends of the Children and the regional board of the American Heart Association for the Western States Region. She is the vice chair of the Grantmakers in Aging board and co-chair of the Roundtable on Quality of Care for People with Serious Illness at the National Academy of Sciences, Engineering and Medicine.

Peggy received her bachelor's degree from Lawrence University and her law degree from Northwestern School of Law of Lewis and Clark College. She has also completed the Stanford Executive Program and is a member of the Stanford Graduate School of Business Alumni Association.

## **Alison N. Barkoff**

### **Member**

Alison Barkoff is the Harold and Jane Hirsh Associate Professor and Director of the Hirsh Health Law and Policy Program at the George Washington University Milken Institute School of Public Health. From January 2021 to October 2024, she led the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services, serving in the role of ACL Administrator and Assistant Secretary for Aging. She was the advisor to the HHS Secretary on aging and disability policy, oversaw national disability and aging programs, and led initiatives related to long-term services and supports (LTSS), direct care workforce, family caregiving, civil rights, housing, elder justice, healthy aging and public health. Under her leadership, ACL issued the first ever National Strategy for Support Family Caregivers and regulations implementing the national family caregiver support program. Earlier in her career, she held leadership roles at the U.S. Department of Justice, Bazelon Center for Mental Health Law and Center for Public Representation, working on issues related to disability and aging policy, LTSS and civil rights.

Ms. Barkoff has testified before Congress on disability and aging issues and before the U.S. Commission on Civil Rights. She has received numerous awards for her work, including by the National Historic Recognition Project for Significant Contribution in the Field of Intellectual and Developmental Disabilities, National Association of State Directors of Developmental Disabilities Services, and Association of University Centers on Disabilities. She is a graduate of Cornell University and Emory University School of Law, where she was the Sol I. Golden scholar.

## **Jori F. Bogetz**

### **Member**

Jori F. Bogetz, MD, is an Assistant Professor of Pediatrics at the University of Washington School of Medicine, the Director of Research at the Treuman Katz Center for Pediatric Bioethics and Palliative Care, and an attending physician in pediatric palliative care at Seattle Children's Hospital. Dr. Bogetz completed her pediatric residency and an Academic General Pediatrics Fellowship at Stanford University and a Pediatric Hospice and Palliative Medicine Fellowship at Harvard University/Boston Children's Hospital. Her research focuses on improving care for children with severe neurological impairment and their families through interventions that support high quality communication and family-centered care. Dr. Bogetz has received funding for her research from the National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Cambia Health Foundation, the National Palliative Care Research Center, the Seattle Children's Research Institute, and the Lucile Packard Foundation for Children's Health. Dr. Bogetz has published >50 papers in peer reviewed journals and contributed to 4 foundational textbooks in her field. She serves as a member-at-large on the National Academies of Science, Engineering, and Medicine Roundtable on Quality Care for Patients with Serious Illness.

## **Rita Choula**

### **Member**

Rita B. Choula, MA is the Senior Director of Caregiving with the AARP Public Policy Institute. She leads and provides content expertise on family caregiving initiatives throughout AARP and externally. Her work bridges policy and research to practice, centered on identifying and supporting the needs of family caregivers elevating the unique nature of each caregiving experience. In collaboration with clinical experts and key stakeholders, Rita leads the development of policy and practice solutions that enable health care and social service providers to better recognize the diverse needs of family caregivers and provide supports to them across settings. Rita holds a Master's degree in the Management of Aging Services from the University of Maryland Baltimore County. She is currently a member of the Board of Directors for the Association of Frontotemporal Dementia (AFTD) and the National Alliance for Caregiving (NAC). She is also a member of the Gerontological Society of America (GSA), American Society on Aging (ASA), and the National Academy of Social Insurance (NASI).

Rita is a recipient of the CARE 100 List of the Most Influential People in Care of 2020 and the National Hispanic Council on Aging Caregiving AARP Award of 2019. Rita is a former family caregiver to her mother of fifteen years while caring for two young children.

## **Rory Farrand**

### **Member**

Rory Farrand is the Vice President of Palliative and Advanced Care at the National Alliance for Care at Home (formerly NHPCO), with over 20 years of experience in healthcare leadership. Her expertise spans palliative care, geriatric psychiatry, clinical training and operations, Alzheimer's/dementia care, and innovative program development. Prior to joining the Alliance, she served as National Director of Palliative Care at VITAS Healthcare, where she led initiatives to enhance palliative care services, developed community-based programs, and advocated for regulatory advancements. Rory's also served as Vice President of Medical Management at Centene Corporation, where she led national programs focused on palliative care and social determinants of health, and as both RVP of Clinical Operations, then VP of Clinical Learning & Development at Aspire Health. She is a board-certified adult nurse practitioner with an MSN in geriatric health, an advanced practice certificate in palliative care, and degrees in psychology, behavioral neuroscience, and art therapy. Rory is an active member of HPNA and the Gerontological Advanced Practice Nurses Association, and frequently speaks to various coalitions and organizations on topics related to Serious Illness. She has been a member of NASEM's Serious Illness Roundtable since 2022.

## **Jeffery T. Garland**

### **Member**

Rev. Dr. Jeffery T. Garland has served as a board-certified chaplain and a Palliative Care and Hospice Advanced Certification with the Association of Professional Chaplains for more than 25 years. Since 2000, Garland has worked full-time as a chaplain with Visiting Nurses Home Health Hospice and Palliative Care in West Orange, New Jersey. Garland works with homecare, facilities, and general inpatients units. His expertise would be working in predominantly urban neighborhoods providing educational and medical information on hospice and palliative care. Garland has served as the president of Association of Professional Chaplains from 2020-2021. He currently serves on the National Hospice and Palliative Care Organization. Garland has also worked with the National Academies Sciences, Engineering, and Medicines as part of the Association of Professional Chaplains. Garland is an adjunct professor at Seton Hall University teaching Christianity and Ethics.

## **Sharon B. Hamill**

### **Member**

Sharon B. Hamill received her Ph.D. in Social Ecology from the University of California, Irvine in 1990. She is the Executive Director of the CSU Shiley Haynes Institute for Palliative Care. She has been a Professor of Psychological Sciences/ Child and Adolescent Development at CSU San Marcos for 28 years. Her interests include the development of personal and social responsibility among adolescent and emerging adult caregivers, multi-generational families of Alzheimer's Disease patients, and ethnic group differences in caregiving. A primary focus of her research program and teaching is on promoting quality of life through palliative care in order to decrease suffering in patients and their caregiving families. Dr. Hamill is a former WASC Commissioner, a past recipient of the Harry E Brakebill Distinguished Professor Award for excellence in teaching, research and service, and a recipient of the California State University Faculty Innovation and Leadership Award. Dr. Hamill is currently a member of the NASEM Roundtable on Quality Care for People with Serious Illness and The National Alliance for Caregiving Cancer Collaborative Steering Committee.

## **Rebecca A. Kirch**

### **Member**

Rebecca Kirch, JD, is EVP Policy and Programs for the National Patient Advocate Foundation (NPAF). As a leading health policy expert and advocate in her field, Rebecca is dedicated to advancing person-centered solutions that make the healthcare system work for all of us. She previously directed quality of life and survivorship initiatives with the American Cancer Society to integrate palliative care, psychosocial support and rehabilitation services with disease-directed treatment. Known for her expertise in patient and caregiver research engagement, Rebecca currently serves in leadership roles on several academic projects funded by NIH and PCORI. She co-founded Patient Advocate Foundation's Patient Insight Institute and is also board chair for Care Camps Foundation that supports pediatric oncology camps for children and families.

## **Kashelle Lockman**

### **Member**

Kashelle Lockman, PharmD, MA is a Clinical Associate Professor within the Office of Consultation and Research in Medical Education (OCRME) and Department of Internal Medicine at the University of Iowa Carver College of Medicine, President-Elect for the Society of Pain and Palliative Care Pharmacists (SPPCP), a 2019 Cambia Health Foundation Sojourns Scholar, and a palliative care pharmacist. Prior to joining OCRME, she was faculty in the SOLACE Palliative Care Collaborative at University of Iowa College of Pharmacy, where she co-designed and directed a palliative care certificate and practiced as a palliative care pharmacist within the Iowa Healthcare outpatient palliative care clinic. Dr. Lockman represents SPPCP on the NASEM Roundtable on Quality Care for People with Serious Illness.

Dr. Lockman earned a Bachelor of Science at the College of Charleston, Doctor of Pharmacy from the University of Maryland, and Master of Arts in Instructional Systems Development, with certificates in instructional design and instructional technology, from University of Maryland Baltimore County. After a PGY-1 Pharmacy Practice residency at the University of Maryland Medical Center, she completed a PGY-2 pharmacy residency in Pain Management and Palliative Care and a fellowship in instructional design at the University of Maryland School of Pharmacy.

# Jason Resendez

## Member

Jason Resendez is a nationally recognized care advocate. He currently serves as the President and CEO of the National Alliance for Caregiving, where he leads research, policy, and programmatic initiatives to build health, wealth, and equity for America's 53 million family caregivers. In 2023, Jason was named one of the most consequential leaders in health and medicine by STAT News.

Prior to joining NAC, Jason was the founding executive director of the UsAgainstAlzheimer's Center for Brain Health Equity where he pioneered the concept of Brain Health Equity through peer-reviewed research, public health partnerships, and public policy. In 2020, Jason was named one of America's top influencers in aging by PBS's Next Avenue alongside Michael J. Fox and Surgeon General Dr. Vivek Murthy. He has been quoted by The New York Times, The Washington Post, The Wall Street Journal, STAT News, and Univision on issues related to caregiving and health equity. Jason is from South Texas and graduated from Georgetown University.

# Susan M. Schneider

## Member

Dr. Schneider, earned PhD, MS and BSN degrees in Nursing. Currently she is an Associate Professor Emeritus at Duke University. She is a Past President of the Oncology Nursing Society and an Advanced Oncology Certified Nurse.

Dr. Schneider has over 40 years of experience as a clinical nurse, advanced practice nurse and researcher caring for individuals with cancer. In these roles she has both implemented and conducted clinical trials at three comprehensive cancer centers. She has expertise in conducting phase I pharmaceutical trials and has been a primary investigator for funded supportive care trials.

As a researcher, she focused on developing interventions to manage symptom distress to improve cancer patients' quality of life and increase survival. Such interventions hold significant potential for enhancing an individual's ability to adhere to treatment regimens and cope with the disease. She has received funding from the National Institutes of Health, the American Cancer Society and the Oncology Nursing Society Foundation.

Dr. Schneider has devoted her teaching career to the development of oncology nurse leaders. Examples of her program development skills include obtaining funding for innovative models of educating advanced practice oncology nurses at two universities. She received the Excellence in Cancer Nursing Research Award and Excellence in Cancer Nursing Education Award from the Oncology Nursing Society. She was selected as a Fellow in the American Academy of Nursing. Dr. Schneider served on the Biden Cancer Initiative Board.

Dr. Schneider uses her extensive clinical knowledge to advocate for quality care for the cancer population. As a support group leader, she assists individuals with metastatic cancer to make decisions about clinical trials and supportive care. As a leader of a professional organization, she is an experienced advocate for cancer research funding and patient access to care. She has been a member of the National Cancer Policy Forum since 2019.