

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

HEALTH AND MEDICINE DIVISION

COMMITTEE ON CARE INTERVENTIONS FOR INDIVIDUALS WITH DEMENTIA AND THEIR CAREGIVERS

Open Session | May 29, 2020

Invited Speaker Biographical Sketches

Cynthia Huling Hummel is a resident of Elmira, NY. She works tirelessly to represent individuals living with Alzheimer's disease and related dementias. She recently completed a term of service as a member of the National Advisory Council on Alzheimer's Research, Care, and Services. She has served as a National Early-Stage Advisor for the Alzheimer's Association. She presented at the 2017 and 2019 NIH Alzheimer's Research Summits, and has given many other talks in her role as an advocate. She is also active on a local level. She is co-leading a respite care group called "Faithful Friends," and serving on a local committee that plans social programs for those with ADRD. She is especially interested in Alzheimer's research and enrolled in the ADNI study in 2010. Cynthia received her BS from Rutgers College, her MDiv from New Brunswick Theological Seminary and her DMin from McCormick Seminary. She enrolled at Elmira College in 2011 and will be taking her 37th class this fall. A retired pastor, Cynthia speaks to faith communities about offering dementia-friendly programs and services. An artist and author, she also enjoys singing with the band, "Country Magic."

Marie Martinez Israelite is the Director of Victim Services at the Human Trafficking Institute. She previously served as the Chief of the Victim Assistance Program at Homeland Security Investigations, where she directed policy efforts, program development, and victim services for all federal crime victims, including survivors of human trafficking and child exploitation. Marie has held several positions within the Department of Homeland Security and the Department of Justice related to human trafficking, sexual assault, and domestic violence prevention and services. Most recently, she served as a Senior Program Manager with ICF, where she facilitated the work of the U.S. Advisory Council on Human Trafficking. Marie is a graduate of Bucknell University and the University of Pennsylvania. She lives in Washington, DC with her husband and two daughters. Her mother Lucy, a retired pediatrician, was diagnosed with Alzheimer's disease in 2017. Marie shares caregiving responsibilities with her mother's younger sister and her brothers.

Karen Love is the Executive Director of the Dementia Action Alliance, is a gerontologist and a nationally known dementia specialist. She began professionally as a speech therapist and transitioned into long-term care administration in nursing homes, assisted living, and continuing care retirement communities. She has been working to advance practices of excellence in dementia care for over 30 years; the past 20 years at a national leadership level. She co-founded three national advocacy and education organizations – the Dementia Action Alliance, the Direct Care Alliance, and the Center for Excellence in Assisted Living, received two National Institute on Aging Small Business Innovative Research Awards for dementia research [2010, 2012], twice testified before the U.S. Senate Special Subcommittee on Aging, been extensively published, and interviewed on national television.

John-Richard (JR) Pagan is a disabled veteran with a background in Marriage and Family Therapy. In 2012, John-Richard decided to continue his education by working on a doctorate degree in clinical psychology. Unfortunately, at age 47, with one year into his program, John-Richard began to suffer cognitive challenges which impacted his studies, and even after receiving a diagnosis that included mild cognitive impairment and sudden onset adult attention deficit disorder, he was dismissed from his program and left wondering where these changes would take him.

At this time, VA medical doctors have only been able to definitively diagnosis John-Richard's condition as a progressive neurodegenerative disease with moderate cognitive impairments in processing, language, and attention, thus meeting the requirements for early stage dementia with additional symptoms relating to mobility and autonomic dysfunction. However, John-Richard has not allowed this disease to be what defines him. He continues to advocate for his own health and the health of others who live with dementia and Dementia with Lewy Bodies. He is active in his spiritual and social community, and often describes his immediate family as the most vital part of his ongoing support team.

Ed Patterson is a resident of Clermont, FL, and works part-time at Disney World. He was diagnosed with Alzheimer's disease in 2018, at the age of 71. Ed, who formerly worked in the financial sales industry, states that it was his husband David who first started noticing changes in his cognition. The first warning signs were Ed experiencing difficulty with stressful tasks like making airline reservations, and episodes of repetition. David also noticed that Ed's mood was affected – he seemed to have a short fuse and quick mood swings – and convinced Ed to bring these symptoms up with his doctor. After performing poorly on cognitive tests, Ed was given a PET scan that was inconclusive for Alzheimer's. Ultimately, Ed entered a clinical trial for medication through Bioclinica, which allowed him to access another PET scan and a spinal tap that were positive for amyloid and tau.

After receiving his diagnosis Ed states he "shut down," stayed home and didn't talk much to others about what was going on. Eventually he started looking for information and resources related to Alzheimer's and came across individuals living with the disease giving speeches and talking publicly about their experience. "Their messages woke me up, and got me going," Ed says. He "went public" with his diagnosis on Facebook and became involved with the Florida Gulf Coast chapter in advocacy, fundraising, and programming.

Brian Van Buren is an Alzheimer's advocate and public speaker, a Board Member of the Western Carolina Chapter of the Alzheimer's Association, and an Advisory Council Member for the Dementia Action Alliance. He was diagnosed in 2015 with early onset Alzheimer's. He was also a caretaker for his mother, who died in January from Alzheimer's. After losing his job as an international flight attendant, Mr. Van Buren reimagined himself as an advocate, giving his voice to Alzheimer's. Being an Afro American man, he felt he needed to give a face to the disease. He was featured in a video for AARP's announcement presenting \$60 million to fund dementia research. He also feels a need to address marginalized populations such as the LGBTQ community.

Geraldine Woolfolk is a retired teacher, and has had decades of experience as a caregiver for her father, mother, and then her husband who developed early on-set Alzheimer's disease (AD). As an Adult Education teacher for almost twenty-five years, she – among her many other assignments – had leadership roles in the development and delivery of programs that were specifically designed for people with Alzheimer's Disease or Related Dementias, as well as for their families. She continues to be active with AD support groups, forums, and conferences. She is a valuable resource for individuals, families, and groups who frequently call upon her for information, referrals, and presentations. Ms. Woolfolk is a longtime advocate on all levels of government for varied causes. As an example, she lobbies legislators and policymakers for increased funding for AD research and caregiver support projects that will enable families to keep their loved ones in the home environment and out of institutional settings for as long as possible. In 2011 Ms. Woolfolk was appointed to the first National Alzheimer's Project Act Advisory Council and served on that groundbreaking body for six years. She has a BA in Music, a Lifetime Secondary Teaching Credential, an MPA, a First Tier School Administrative Credential, and many other certifications and recognitions that herald her leadership, accomplishments, and service. A widow, she has three remarkable children and two awesome grandsons.