

SOUTHEASTERN WISCONSIN CAREGIVING SYMPOSIUM

Young Caregivers: Identifying and Supporting Children, Youth, and Young Adults as Family
Caregivers

8:30 AM Registration & Resource Tables Open

9:00 AM Welcome & Land Honoring

9:05 AM Hidden Caregivers in the U.S
Dr. Melinda S. Kavanaugh, PhD, MSW, LCSW

9:30 AM Local, National & Global Perspectives of Young Carers Panel
Leah Hellwege
Harriet Redman
Dr. Paul Watson PhD, PgDip (SCPHN-SN), BSc (MH), FHEA
Facilitator: Hannah Hutler-Boyd

10:30 AM Break & Resource Tables Open

**10:45 AM Supporting Young Carers Across the Lifespan:
Examples of programs & interventions**
Fred Rogers Productions – Margaret Cavalier & Mallory Mbalia
YCare – Leah Hellwege
Supporting Young Adults – Dr. Melinda S. Kavanaugh, PhD, LCSW

12:15 PM Lunch & Resource Tables Open

1:00 PM LUKi & The Lights! Screening

1:15 PM In Practice: Provider Lived Experience Panel
Dr. Courtney Barry PsyD, MS
Cat Kanter MS, CCC-SLP
Abby Marx MS, CCC-SLP

2:30 PM The State of Caregiving Policy in Wisconsin – Integrating Young Carers
Dr. Beth Fields, PhD, OTR/L, BCG
Dr. Kim Whitmore PhD, RN, CPN

2:45 PM Putting it into Practice

4:00 PM Adjourn

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SPEAKERS

Dr. Courtney Barry PsyD, MS

Director of IPE for the School of Medicine

Medical College of Wisconsin

Courtney Barry, PsyD, MS is a licensed Clinical Health Psychologist and an Associate Professor in the Department of Psychiatry and Behavioral Medicine. She serves as the director of IPE for the School of Medicine at the Medical College of Wisconsin. Dr. Barry completed a research fellowship at the Medical College of Wisconsin, which focused on understanding the importance of utilizing a biopsychosocial approach to care. She has a research interest in trauma and trauma-informed care, which highlights the importance of interprofessional collaboration. Through her work, she emphasizes that educating students in interprofessional care not only supports providers but also helps to provide the best patient-centered care. She also has several research interests including supporting young carers and is actively working with Dr. Kavanaugh on an Advancing Healthier Wisconsin grant on young caregivers who have parents with ALS.

Dr. Beth Fields, PhD, OTR/L, BCG

Associate Professor, Occupational Therapy

University of Wisconsin-Madison

Dr. Beth Fields is a board-certified occupational therapist and Associate Professor at the University of Wisconsin-Madison whose research focuses on caregiving and geriatric health services. She develops and implements person and family-centered assessments and interventions to improve care quality for older adults and their caregivers in hospital and home settings. Actively involved in national and state-level caregiving initiatives, Dr. Fields is committed to bridging research, policy, and practice to drive meaningful systems change.

Margaret Cavalier

Producer

Fred Rogers Productions

Margaret Cavalier is an award-winning children's media producer. At Fred Rogers Productions, she is the Producer for Donkey Hodie and as well as a series of short documentary-style videos spotlighting children who provide care for members of their family. Margaret supports all aspects of series production — from managing schedules and providing creative feedback to organizing the delivery of final assets. Before joining Fred Rogers Productions, Margaret served as a Coordinating Producer at Ideastream Public Media in Cleveland where she led the production of NewsDepth, an interactive children's news show that airs on PBS stations across Ohio. Under her leadership, the series won several awards, including Parents' Choice Gold Awards® and regional Emmy® Awards. Margaret holds a Master's degree in Public Media from Ohio University, where her studies focused on narrative nonfiction and documentary storytelling. She also earned a Bachelor's degree in Broadcast Journalism from Kent State University.

SPEAKERS

Leah Hellwege

Senior Programs Coordinator
Elizabeth Dole Foundation

Leah serves as the Senior Coordinator, Programs for the Elizabeth Dole Foundation where she provides administrative support to the Hidden Helpers Coalition, facilitates caregiver workshops and resources, and helps to maintain the vital work done through the Campaign for Inclusive Care. Prior to this role, Leah was the Programs Intern at the Elizabeth Dole Foundation.

Leah graduated from Fairfield University in Fairfield, CT with a degree in Psychology with a concentration in Behavioral Neuroscience and a minor in Public Health. She comes from the Eastern Shore of Maryland, and now resides in Washington, DC.

Cat Kanter MS, CCC-SLP

AAC Specialist
Bridging Voice

Cat Kanter is a Speech-Language Pathologist (SLP) who specializes in supporting people living with ALS and their caregivers with their communication needs through voice preservation and augmentative and alternative communication (AAC). She joins the Bridging Voice team after 4 years at the Waisman Center's AAC Programs at the University of Wisconsin-Madison and 2 years with the ALS Association. She has a passion for building community among people living with ALS and empowering them to live their fullest lives.

Melinda S. Kavanaugh, PhD, LCSW

Professor, Social Work
Helen Bader School of Social Welfare University of Wisconsin – Milwaukee
Founder of Global Neuro YCare

Dr. Kavanaugh is a Professor of Social Work and a Licensed Clinical Social Worker (LCSW), with clinical expertise in health care professional education and caregiving research across neurological disorders, including children and youth as caregivers, "young carers". Funded by federal, state, and non-profit organizations, Dr. Kavanaugh is an international leader in young carer program development, including YCare, a multidisciplinary youth caregiving skills and support protocol for young carers in ALS, Alzheimer's disease, spinal cord injury, Parkinson's disease, and traumatic brain injury. Additionally, Dr. Kavanaugh is a developer and faculty of the international program, "Breaking the News" using the ALS-SPIKES protocol for health care providers in delivering difficult diagnoses.

Her research is community engaged, partnering to create targeted programs and support for children, youth and young adults as caregivers, informing a series of books for children, young adults, families and schools, including a graphic novel translated into 13 languages. Dr. Kavanaugh is also president of Global Neuro YCare, an international non-profit, focused on developing language and culturally accessible programs and supports for health care professionals, children, youth, and families in neurological disorders around the globe, including the animated short film, "LUKi & the Lights", helping children and families understand and talk about ALS/MND.

SPEAKERS

Abby Marx MS, CCC-SLP

AAC Specialist

Bridging Voice

Abygail “Abby” Marx is a Speech Language Pathologist (SLP) who has spent her career supporting individuals who use Augmentative and Alternative Communication (AAC). Prior to joining the Bridging Voice team, she worked for over 12 years in the Waisman Center AAC Programs at the University of Wisconsin, Madison. There she provided both direct AAC services to clients as well as training and consultation with families, caregivers, and other professionals. Abby is also involved in advocacy and initiatives around AAC through volunteer positions at the state and national level.

Mallory Mbalia

Director of Learning and Education

Fred Rogers Productions

Mallory Mbalia is the Director of Learning and Education at Fred Rogers Productions. As Director of Learning and Education, Mallory Mbalia advises and collaborates with colleagues to further realize the organization’s educational mission for children and families. Previously she was the Director of Education at PBS North Carolina under Children’s Media and Education Services. She worked with PBS NC for over 10 years as one of their educational outreach trainers. She has served as a home family childcare teacher, PreK Instructional Assistant, Kindergarten teacher as well as an Elementary Assistant Principal. She has a passion for art integration, joy integration, media integration, whole child development, early childhood education and equitable access and awareness. She holds a B.S. in Human Development with a focus on child and adolescent, a M.A. Ed in Curriculum and Instruction and a M.S.A. Masters of School Administration. She believes that all children have a gift or talent and that those gifts and talents can be used to make learning relevant, novel, and engaging.

Peggy Nied

Occupational Therapist

UW Health – Retired

Peggy Nied is a recently retired occupational therapist from UW Health in Madison Wisconsin with the focus on Neuro rehabilitation. Peggy served the ALS clinic for 25 years. Her family celebrated a son Kyle, who had Duchene muscular dystrophy. All three of Kyle’s siblings contributed to his daily care and his precious quality of life.

SPEAKERS

Harriet Redman

Founder & Director of Special Projects

WisconSibs, Inc

Harriet Redman M.S. Ed. is Founder of WisconSibs, Inc, the first non-profit organization dedicated to the lifespan interests of children and adults who have siblings with disabilities or long-term illnesses. After earning degrees from Valparaiso University and Purdue University in adult education with a concentration in family systems, Redman developed family education programs for a Fortune 500 company and later became a marketing director for the same company. When her son was born with a rare chromosomal disorder, she turned her program development and marketing skills to the needs and interests of his older sister and other siblings growing up with a sibling with disabilities.

Redman retired as Executive Director in 2022 and continues to support siblings as the Director of Special Projects with WisconSibs, also as a member of the Outagamie Caregiver Coalition, the Aging and Long-Term Support Advisory Committee, and an active member of the Wisconsin Family and Caregiver Support Alliance serving as co-chairman of their Employer Engagement work group.

Dr. Paul Watson PhD, PgDip (SCPHN-SN), BSc (MH), FHEA

Associate Professor in Military-Connected Children and Young People's Health and Wellbeing & Assistant Director of the Northern Hub for Veterans and Military Families Research at Northumbria University

Director of Innovation & Impact at Global Neuro YCare

Trustee to The Bastion Baton

Dr Paul Watson is the Assistant Director of the Northern Hub for Veterans and Military Families Research at Northumbria University (with a focus on Military-Connected Children and Young People) and Associate Professor in Military-Connected Children and Young People's Health and Wellbeing. A veteran and former young carer within the military community, Paul brings vital lived experience to his academic and clinical public health work. His research portfolio focuses on the emotional health and wellbeing of military-connected children, young people, and young carers, with particular attention to Adverse Childhood Experiences (ACEs), Beneficial Childhood Experiences (BCEs), and the Social Determinants of Emotional Health. His work spans education, health, and community settings, championing inclusive approaches to research that centre recognition, voice, and systemic change.

Dr. Kim Whitmore PhD, RN, CPN

Assistant Professor

College of Nursing Marquette University

Kim Whitmore, PhD, RN, CPN has more than 25 years of experience working with communities, families, caregivers, and individuals with disabilities across the lifespan. Currently, Dr. Whitmore is an Assistant Professor in the College of Nursing at Marquette University. The overall goal of her research program is to promote health equity and support positive outcomes for family caregivers. Dr. Whitmore received an Honors Bachelor of Science Degree and a Master of Science Degree in Nursing from Marquette University and a Doctor of Philosophy in Nursing Research from the University of Wisconsin- Milwaukee. Dr. Whitmore is also a research consultant with the ARCH National Respite Network and Resource Center and leads the National Committee for Advancement

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