

NINDS U13: Understanding and Advancing Neuropalliative Care Research

Vision: to create the evidence necessary for a world where high quality, person-centered care for persons affected by neurologic illness and their care-partners is the rule rather than the exception – this includes stroke, dementia, Parkinson’s disease, ALS and many other diseases.

Mission: Review current evidence and identify priorities to move the field of neuropalliative care forward

Where we are we now and what critical knowledge gaps must be filled?

Friday, April 12 th , 2024	
7-7.30am	Meet, greet, coffee, Introductions
7.30-8.55	<p>Round table I: Why is Neuropalliative care Critical “to reduce the burden of neurological disease for all people”?</p> <p>Speakers: Christine Ritchie, Ana-Maria Vranceanu, Lauren Treat, Walter Koroshetz, Claire Creutzfeldt</p> <p><i>This session will present a paradigm shift by integrating a biopsychosocial focus into Neuroscience research. We will discuss why this is necessary in particular for Neurologic illness and discuss key gaps in (neuro-)palliative care research including multidimensional needs, behavioral interventions and outcomes. We will also discuss potential funding opportunities and mechanisms for neuropalliative care research.</i></p>
9.00 -9.30	<p>Scientific Session I: Choosing Research outcomes for Neuropalliative care research; from early diagnoses through end-of-life – the challenges of dyadic outcomes.</p> <p>Speakers: Katie Colborn, Heather Leeper, Monica Lemmon</p> <p><i>This session will start with an overview of the challenges and opportunities associated with outcomes in neuropalliative care research. Speakers will review current state of PRO’s in neuropalliative care, determine most important gaps for PRO development in neuropalliative care, and describe considerations in the statistical design and analysis of dyadic Neuropalliative care research.</i></p>
9.30-10.00	Coffee break
10.00-11.25	<p>Round Table II: Advancing healthcare equity in neuropalliative care – from research to systems</p> <p>Speakers: Romana Hasnain-Wynia, Altaf Saadi, Caroline Crooms, Carey Candrian</p> <p><i>This session will be based on the NINDS Social Determinants of Health Framework and discuss how the framework can be used across intervention development through implementation. “From research to systems” is meant to describe the move from describing the impact of SDOH to determining “their causes in such a way that our explanations will more precisely inform strategies to improve human health and reduce or eliminate health inequities.” Speakers will provide examples of health equity research and discuss how to train the future generation of Neuropalliative care researchers with a focus on health equity</i></p>
11.30 – 12.55 pm	<p style="text-align: center;">~ Lunch workshops ~ (catered lunch)</p> <p style="text-align: center;">Junior investigator selected presentations and guided discussion</p> <p>Workshop I: Research Projects: Alexander Presciutti, Whitley Aamodt, Amy Ogilve Moderated by Darin Zahuranec, Jori Fleisher</p> <p>Workshop II: Research Projects: Hitoshi Koshiya, Mira Reichman, Christina Rush, Moderated by David Hwang, Benzi Kluger</p>

1.00 – 1.30	<p>Scientific Session II: Including patients & family care partners in neuropalliative care research – how & why</p> <p>Speakers: Malenna Sumrall, Jori Fleisher, Maria Hopfgarten</p> <p><i>Speakers will discuss the importance of involving patients and caregivers in designing research and creating interventions (“nothing about us (or for us) without us”). This includes (a) how to create community advisory boards; bring patients on as research partners; and ensuring equity/representativeness as we do that, and (b) how to include perspectives from all interested partners (patients, families, clinicians, administrators etc.) early on through surveys, qualitative research</i></p>
1.30 -2	<p>Scientific Session III: Behavioral health interventions in neuropalliative care research</p> <p>Speakers: Ana-Maria Vranceanu, Jori Bogetz</p> <p><i>In this session, speakers will highlight the important role of behavioral interventions within neuropalliative care. The speakers will argue that increased methodological rigor is required in neuropalliative care research and discuss how to use the NIH stage model and the experimental method to develop interventions that are mechanistically sound, potent, effective and implementable. The pivotal role of team science and the need for increased funding for neuropalliative care interventions will be highlighted.</i></p>
2 – 2.30	<p>Scientific Session IV: Common Data Elements for Neuropalliative care</p> <p>Speakers: Susanne Muehlschlegel, David Hwang, Amy Tsou</p> <p><i>NIH Staff will discuss the importance of using Common Data Elements to Advance Science, including an overview of the NIH CDE development process and best practices for use in research. We will identify existing CDEs relevant to neuropalliative care and consider a suggested process for development of future neuropalliative care CDE, including how to get funding for this type of work. Speakers will also present their experience developing CDE for goals of care and surrogate decision making for patients with Disorders of Consciousness and lessons learned (this work was an important initial effort, but compromises were necessary in the process due to scope, budget, timing). End with next steps</i></p>
2.30-3	<p>Coffee break</p>
3 -3.30	<p>Scientific Session V: Health services research in neuropalliative care: Using “Big Data”</p> <p>Speakers: Christine Ritchie, Corey Fehnel</p> <p><i>Speakers will describe their own experience working with big data and discuss what types of neuropalliative care questions can be answered through health services research. Existing work has focused predictors/drivers of hospice and palliative care utilization, but there are limitations to this type of work. What are the gaps and how do we use big data to move this field forward?</i></p>
3.30-4.45	<p>Round Table III: NIH-inter-institutional Collaboration on Palliative Care</p> <p>Speakers: Basil Eldadah, Rebecca Hommer, Richard Benson, Alexis Bakos</p> <p><i>In this session, speakers will review the new development of NIH-wide palliative care efforts including the Consortium for Palliative care across the Lifespan, and the role of NINDS.</i></p>
4.45-5.00	<p>Research priorities, survey and Q&A</p>
5.00	<p>Adjourn, closing comments</p>

NeuroCARE Summit 2024 Travel Award Recipients

Name	Project title	Institution
Whitley Aamodt, MD, MPH*	<i>Improving End-of-Life Care for Hospitalized Patients with Lewy Body Disorders</i>	University of Pennsylvania
Stephanie Bartlett, PT, MS	<i>Does Physician Use of Best Case/ Worst Case Acute Ischemic Stroke Improve Patient and Families Anxiety, Understanding, and Confidence During Medical Decision-Making</i>	Indiana University, Indianapolis
Jennifer Corcoran, MD	<i>Building a Better Roadmap: Creating a Foundation for Anticipatory Guidance in Parkinson's Disease</i>	University of Rochester Medical Center
Kristopher Hendershot, MD	<i>Care Trajectory for Older Patients with Severe Traumatic Brain Injury</i>	University of Washington
Andrew Huang, MD	<i>Reimagining Life After Cardiac Death: Meeting the Needs of Cardiac Arrest Survivors with Neurologic Disability</i>	University of Rochester Medical Center
Hitoshi Koshiya, MD†	<i>Differentiation of epileptic seizures from paroxysmal sympathetic hyperactivity in children with medical complexities based on ictal videos</i>	University of Pittsburgh Medical Center
Christi Lero, MSW	<i>Initial Conceptualization to Develop a Measure of Self-Compassion for Informal Caregivers of Persons Living with Neurodegenerative Disease</i>	Washington University in St. Louis
Amy Ogilve, PhD*	<i>Understanding Uncertainty for Patients with Huntington's Disease, their Care Partners, and their Neurologists</i>	University of Colorado Anschutz Medical Campus
Alexander Presciutti, PhD*	<i>The COMA Family Program (COMA-F) – a multi-site open pilot of a mind-body intervention for caregivers of comatose patients</i>	Harvard Medical School
Mira Reichman, BA†	<i>Mind-Body Peer Support for Family Caregivers to Patients with Severe Acute Brain Injury</i>	University of Washington
Christina Rush, PhD†	<i>Resilient Together-ALS (RT-ALS)</i>	Harvard Medical School
Sandhya Seshadri, PhD	<i>Competence, Autonomy, Relatedness, and Connections (CARE Connections): A Peer-Led Intervention Designed with Parkinson's Disease & Related Disorders Care Partners to Improve Holistic Support</i>	University of Rochester School of Medicine & Dentistry
Akanksha Sharma, MD	<i>Pilot trial of psilocybin-assisted therapy for psychiatric distress in patients with brain tumors</i>	Pacific Neuroscience Institute

*Oral Presentation in lunch workshop room 1

†Oral Presentation in lunch workshop room 2

Speakers in alphabetical order

- Dr. Alexis **Bakos** is a program director in the Geriatrics Branch, Division of Geriatrics and Clinical Gerontology at the National Institute on Aging (NIA) where she oversees extramural research on palliative care and symptom science. She is part of the Palliative Care Workgroup co-leading the charge around the new NIH-wide funding opportunity to develop the *Consortium for Palliative Care Research Across the Lifespan*.
- Dr. Richard **Benson** is Director of the Office of Global Health and Health Disparities (OGHHD) in the NINDS Division of Clinical Research. He is a leader in the fields of vascular neurology and health disparities research.
- Dr. Jori **Bogetz** is an Assistant Professor in the Department of Pediatrics at the University of Washington School of Medicine, a pediatric palliative care physician at Seattle Children's Hospital, and the Associate Director of Research at the Treuman Katz Center for Pediatric Bioethics and Palliative Care at Seattle Children's Research Institute. Her research focuses on improving serious illness care for children with severe neurological impairment and their families through interventions to promote high quality communication and family-centered care.
- Dr. Carey **Candrian** is an associate professor at the University of Colorado School of Medicine. Her research explores how communication shapes -- and is shaped by -- perceptions, attitudes, and biases in the community. Race, gender, economics, language, sexual orientation, age, illness, and/or power dynamics can constrain people from having meaningful interactions. Her work has been funded by the National Institute on Aging, The Colorado Health Foundation, NextFifty Initiative, The Lesbian Health Fund, and the Cambia Health Foundation.
- Dr. Katie **Colborn** is an Associate Professor the Division of Healthcare Policy and Research in the Department of Medicine at the University of Colorado. She is also the chair of the Data, Informatics, and Statistics Core of the Palliative Care Research Cooperative Group. Her expertise includes the applications of statistical models for clustered longitudinal data and machine learning methods for prediction of health outcomes
- Dr. Claire **Creutzfeldt** is an associate professor of Neurology and the director of Neuropalliative care at the University of Washington. She is a founding officer and the secretary of the International Neuropalliative Care society and Co-chair of the INPCS Research committee. As a Vascular Neurologist, Dr. Creutzfeldt's research has focused on palliative care needs of patients with severe acute brain injury including stroke. She has been funded by NINDS and NINR.
- Dr. Caroline **Crooms** is an instructor of Neurology at Mount Sinai Health System. She is board certified in Neurology and Palliative care and her research funded by NIA focuses on palliative care needs and symptom management for patients with brain tumor and their families.
- Dr. Basil **Eldadah** is Program Officer and Chief, Geriatrics Branch, Division of Geriatrics and Clinical Gerontology at the National Institute of Aging (NIA). He oversees a portfolio of translational and clinical research in older adults across a variety of areas and mechanisms and most recently, has been part of the group co-leading the charge around the new NIH-wide funding opportunity to develop the *Consortium for Palliative Care Research Across the Lifespan*.
- Dr. Corey **Fehnel** is Assistant Professor at Harvard Medical school and Director of Neurocritical Care at BIDMC. His research focuses on neurocritical care/aging and neuropalliative care. He uses health services research to better describe and understand long-term outcomes for older persons with critical neurological illness.
- Dr. Jori **Fleisher** is Associate Professor of Neurological Sciences at Rush University, where she also directs the Lewy Body Dementia Association Research Center of Excellence and CurePSP Center of Care. She is funded by NINDS and NIA with a research focus on developing and disseminating interdisciplinary models of care, support, and education to improve patient and caregiver outcomes in Parkinson's Disease, Lewy Body Dementia, and related disorders.
- Dr. Romana **Hasnain-Wynia** was the Program Director for Addressing Disparities at the Patient-Centered Outcomes Research Institute (PCORI) from 2012 to 2016 and is now Chief Research Officer at Denver Health, where she oversees research and sponsored programs through the Office of Research.
- Dr. Rebecca **Hommer** is a program director in NINDS's Division of Clinical Research with a background in adult, child, and adolescent psychiatry and clinical trials research. She oversees a diverse portfolio at the intersection of psychiatry and neurology including projects focused on pain, Alzheimer's Disease Related Dementias, and women's health.

- Maria **Hopfgarten** is Jacob's mom and has written about his life with mitochondrial disease in the book "Letters to Jacob". She is a parent advocate and was the President of Miracles for Mito serving families living with mitochondrial disease in the Rocky Mountain Region for 11 years. Maria is now a Parent Champion for Courageous Parents Network serving families and physicians.
- Dr. David Y. **Hwang** is Professor of Neurology and Chief of Neurocritical Care at the University of North Carolina School of Medicine. His scholarly work focuses on outcome prognostication for severe acute brain injury patients and support for families of intensive care unit patients. He is the former Director of Mentorship within the Department of Neurology at the Yale School of Medicine and has mentored numerous trainees in developing original research projects. He is Co-chair of the Research Committee of the INPCS.
- Dr. Benzi **Kluger** is Professor of Neurology at University of Rochester Medical Center (URMC), the Director of the Palliative Care Research Center at URMC and the President of the INPCS. His neuropalliative care research focusses on patients with neurodegenerative illness in particular Parkinson's disease and has been funded by NIH, PCORI and the Parkinson Foundation among others.
- Dr. Heather **Leeper** is Assistant Professor at the University of Chicago and a hospice and palliative medicine and neuro-oncology fellowship trained physician. Her research interests focus on improving person-centered care for people living with serious neurologic disease by implementing palliative medicine principles within primary or specialty palliative care and leveraging the use of patient-reported outcomes.
- Dr. Monica **Lemmon** is an Associate Professor of Pediatrics and Population Health Sciences at Duke University School of Medicine, where she also serves as the Associate Dean for Scientific Integrity. Her NIH-funded research program centers on prognostic communication, shared decision making, and the caregiver experience of infant illness.
- Dr. Susanne **Muehlschlegel** is an Associate Professor and neurointensivist at John-Hopkins School of Medicine. Her NIH-funded research focusses on shared decision making, in the Neurocritical care unit with specific interest and expertise in the development, testing and implementation of patient- and family-centered shared decision making interventions in patients with severe acute brain injury.
- Dr. Christine **Ritchie** is professor of Medicine at Harvard Medical School, Director of the Center for Aging and Serious Illness and Director of Research for Division of Geriatrics and Palliative Care at Massachusetts General Hospital. She is a founding board member of the INPCS. Dr. Ritchie has expertise in palliative care research and has been principal investigator on over 20 federal and foundation grants. She was MPI on the Palliative Care Research Collaborative (PCRC).
- Dr. Altaf **Saadi** is an Assistant Professor at Harvard Medical School and a Neurologist at MGH. Her research research focuses on neurologic health disparities and social and structural determinants of health among racial/ethnic minorities, immigrants, and refugees.
- Dr. Malenna **Sumrall** has been a long-time passionate family advocate and has extensive experience working with Neuropalliative care researchers to include the voices of patients and families in their work. She has worked on a number of patient/family advisory councils for research related to Parkinson's disease.
- Dr. Lauren **Treat** is Assistant Professor of Pediatrics at Children's hospital in Colorado. Trained in Neuropediatrics and Palliative care, her clinical and research focus are on helping individuals with neurological illness live as well as possible for as long as possible, and to support families to help balance the impact of disease and treatments with overall quality of life.
- Dr. Amy **Tsou** is Program Director in the Division of Clinical Research at NINDS. As a neuromuscular-trained neurologist, her work has spanned a wide range of clinical areas and involved collaborations with AHRQ, PCORI, and other organizations to perform high quality evidence synthesis to inform health care delivery, identify evidence gaps, and future research priorities.
- Dr. Ana-Maria **Vranceanu** is a Clinical Psychologist, the David T. Rovee PhD and Joanne E. Rovee Endowed Chair in Psychiatry, and Director of the Center for Health Outcomes and Interdisciplinary Research at MGH. She served as PI on over 30 grants, co-leads a T32 focused on behavioral interventions in persistent and serious illness, and the Research and Education Core of the MGH Dementia Resource Center for Minority Aging Research. She co-directed the Clinical Trials Intensive of the PCRC and is Co-chair of the Research Committee of the INPCS.
- Dr. Darin **Zahuranec** is Professor of Neurology at the University of Michigan. His research focuses on decision making on life-sustaining treatments for patients with severe neurological disease and outcomes among family surrogate decision makers. He has been funded by NINDS, NIA and NINR. He has mentored multiple junior researchers from the undergraduate to the faculty level. He is Co-chair of the Research Committee of the INPCS.