

2022 DIAD Family Conference: (re)United! July 30th Speaker Biographies

Juliana Acosta Uribe, MD, PhD

Neuroscience Research Institute
University of California, Santa Barbara

Juliana Acosta-Urbe received her Medical Doctor degree from the University of Antioquia (Medellin-Colombia) and a Masters and PhD from the University of California Santa Barbara (UCSB). Juliana has over ten years of experience in research of neurodegenerative illnesses and genetic Alzheimers disease, utilizing both clinical and laboratory techniques. She currently works as a project scientist in the Kosik Lab at the Neuroscience Research Institute at UCSB and as coordinator of neurogenetic research at the Neuroscience Group of Antioquia, University of Antioquia. Her research currently centers on understanding the role of population dynamics and demographic history in the genetic burden for neurodegenerative illnesses in Colombian and Latin American populations.

Randall Bateman, MD

Charles F. and Joanne Knight Distinguished Professor of Neurology
Director and Principal Investigator of the Dominantly Inherited Alzheimer Network (DIAN) and the Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU) Washington University School Of Medicine

Randall Bateman, MD is the Charles F. and Joanne Knight Distinguished Professor of Neurology, Director of the Dominantly Inherited Alzheimer Network (DIAN), and Director of the DIAN Trials Unit (DIAN-TU). Dr. Bateman's research focuses on the pathophysiology and development of improved diagnostics and treatments of Alzheimer's disease. His lab recently reported on an accurate blood test for Alzheimer's disease plaques. His research in DIAN has provided evidence for a cascade of events beginning decades before symptom onset that leads to AD dementia, supporting development of Alzheimer's disease prevention trials. Dr. Bateman directs the DIAN-TU, which launched the first prevention trial in families with early onset Alzheimer's disease in 2012. The DIAN-TU trial is an advanced world-wide adaptive trial platform that tests the most advanced therapeutics targeting early onset dominantly inherited Alzheimer's disease. The DIAN-TU goal is to slow, stop or reverse Alzheimer's disease. The DIAN-TU goal is to slow, stop or reverse Alzheimer's disease. The DIAN-TU has launched three Phase 2/3 drug arms with a range of amyloid-beta targets and has now launched tau-directed drugs in combination with amyloid drugs and a primary prevention trial to prevent amyloid plaques from forming. Dr. Bateman has received a number of awards including the Beeson Award for Aging Research, Alzheimer's Association Zenith Award, Scientific American top innovator, the Glenn Award for Aging Research, the MetLife Foundation Award for Medical Research, and the Potamkin Prize. He is an elected member of the National

Academy of Medicine and the National Academy of Inventors and is currently serving as the Appointed Chairman of the Research Sub-Committee of the Health and Human Services NAPA Council, the Advisory Council on Alzheimer's Research, Care, and Services.

Maria Carrillo, PhD

Chief Science Officer
Alzheimer's Association

As chief science officer, Maria C. Carrillo, Ph.D., sets the strategic vision for the Alzheimer's Association global research program. Under her leadership, the Association is the world's largest nonprofit funder of Alzheimer's research — currently investing over \$250 million — and an internationally recognized pioneer in convening the dementia science community. Dr. Carrillo uses her platform as a noted public speaker to play an instrumental role in the Association's efforts to lobby for increased funding for the disease.

Dr. Carrillo oversees the implementation of the Association's growing portfolio of research initiatives, including the Alzheimer's Association International Conference® (AAIC®), the world's largest and most influential dementia science meeting, and the Research Roundtable, which enables international scientific, industry and government leaders to work together to overcome shared obstacles in Alzheimer's science and drug development. In addition, she leads the Association's direct involvement in research by serving as a co-primary investigator for the Association-funded and led U.S. POINTER study, a lifestyle intervention trial to prevent cognitive decline and dementia.

Dr. Carrillo earned her Ph.D. from Northwestern University's Institute for Neuroscience and completed a postdoctoral fellowship focused on Alzheimer's brain imaging and risk factors at Rush University Medical Center in Chicago.

The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia®. For more information, visit alz.org.

Jasmeer Chhatwal, MD, PhD

Associate Professor of Neurology
Harvard Medical School
Massachusetts General Hospital

Dr. Chhatwal is an Associate Professor of Neurology at Harvard Medical School, a practicing neurologist at Massachusetts General Hospital (MGH) and Brigham and Women's Hospitals (BWH), and a member of the Massachusetts Alzheimer's Disease Research Center (MADRC). He cares for patients with Alzheimer's disease (AD) and other neurodegenerative diseases in the Memory Disorders Unit at MGH, with a particular focus on early onset AD. He has a diverse scientific background in molecular, cellular, and systems neuroscience. He currently leads SONNET, a study of sleep disruption as a possible driver of tau pathology, and BIONIC, a blood biomarker study examining plasma analytes indicative of neurodegeneration, inflammation, and tau pathology. Dr. Chhatwal serves as the site leader for the Dominantly Inherited Alzheimer's Network (DIAN) observational study at MGH and BWH, evaluates therapeutics for the DIAN treatment unit, and is a project leader for the Harvard Aging Brain Study (HABS).

Meagan Cochran, MS, CGC

HudsonAlpha Institute for Biotechnology

Meagan Cochran is a licensed and board-certified genetic counselor at the HudsonAlpha Institute for Biotechnology in Huntsville, Alabama. She received a Master of Science in Genetic Counseling from the University of Alabama at Birmingham. Meagan has practiced clinical genetic counseling in a variety of settings including pediatrics, prenatal, adult medicine, and genomics. She currently serves as a clinical genetic counselor for the Smith Family Clinic for Genomic Medicine and participates in clinical genomics research at HudsonAlpha in pediatric rare disease and neurodegeneration.

Nick Cochran, PhD

Faculty Investigator

HudsonAlpha Institute for Biotechnology

Dr. Nick Cochran is a faculty investigator at the HudsonAlpha Institute for Biotechnology in Huntsville, Alabama. He received his PhD training in neuroscience in the lab of Dr. Erik Roberson at the University of Alabama at Birmingham, and also trained as a postdoctoral fellow in genetics in the lab of Dr. Richard Myers at HudsonAlpha. The Cochran lab uses genomic approaches to study Alzheimer's and related dementias.

Carlos Cruchaga, PhD

Professor Dep. of Psychiatry, Genetics and Neurology

Barbara Burton and Reuben Morriss III Professor

Director of NeuroGenomics and Informatics Center

Dr. Cruchaga is a human genomicist with expertise in multiomics, informatics, and neurodegeneration. He completed his PhD in Biochemistry and Molecular Biology in 2005 at University of Navarra (Spain) and postdoctoral training on quantitative human genomics in Dr. Alison Goate's lab. Dr. Cruchaga established his laboratory at Washington University in 2011, studying the genetic architecture of neurodegenerative diseases. In 2019, he became the scientific advisor of the McDonnell Genome Institute (MGI) at Washington University and founding director of the NeuroGenomics and Informatics center. He is also the Knight-ADRC genetics and the DIAN genetics core Leader and the Director of the Hope Center DNA and RNA core.

His laboratory has pioneered the use of next-generation sequencing technology and quantitative traits to identify functional variants implicated in AD and PD. By using these approaches, he has identified several genes associated with CSF tau levels that modify rate of memory decline. More importantly, his research has been instrumental not only in identifying TREM2 as a risk factor for Alzheimer's, but also to demonstrate that MS4A4A modifies risk for AD by modulating TREM2 biology, making it a valid therapeutic target.

Currently Dr. Cruchaga's research is focused on using human genomic and other omic data (proteomic, metabolomics, lipidomics) to identify and understand the biology of neurodegenerative diseases, to create novel molecular prediction models and to identify drug-worthy targets. In summary, the mission of the Cruchaga lab is to leverage genetics, omics and functional genomics studies in neurodegeneration and diseases of the CNS and translate those into improvements in human health through better understanding of the molecular underpinnings of disease.

Caroline Gelman, LCSW, PhD

Director of MSW Program
Associate Professor
Silberman School of Social Work

Dr. Caroline Gelman is an Associate Professor at the Silberman School of Social Work at Hunter College. She has practiced as a clinical social worker for over 30 years, specializing in mental health issues in a variety of settings and with diverse populations. Caroline's teaching and research are strongly grounded in and informed by her practice, which for the past 25 years has explored the experiences and needs of older adults and their caregivers. Through this work, she met several families with early-onset dementia and began exploring such families' experiences and needs in order to develop appropriate, accessible, and relevant resources.

Melanie Hall, PhD

Senior Lecturer in Childhood Studies
Manchester Metropolitan University

Mel Hall is a Senior Lecturer in Childhood and Education Studies at Manchester Metropolitan University where she teaches and conducts research.

Dr. Hall's research is centered around exploring aspects of children and young people's lives – their accounts of health and family life and their education - with a view to informing practice. The applied and interdisciplinary nature of her research has enabled her to share young people's insights within fields where their views have traditionally been silenced. Her research emphasizes the need to listen to children and young people, involve them in their education and health care and provide greater support to them in difficult circumstances.

Dr. Hall was the Research Associate on the Alzheimer's Society (UK) funded project 'The Perceptions and Experiences of Children Who Have a Parent With Dementia'. She is presently part of a research team exploring the stories of those with experience of familial inherited dementia and choosing to undergo testing (or not).

Lindsay Hohsfield, PhD

Project Scientist
University of California, Irvine
Co-Founder
Youngtimers

Lindsay Hohsfield earned her Ph.D. in Neuroscience in 2014 and is currently working as a Project Scientist at the University of California, Irvine. Lindsay's research interests have centered on developing effective therapeutic strategies for Alzheimer's disease, with an emphasis on investigating and manipulating the immune system. Lindsay's path to become an Alzheimer's researcher began at the age of 18 years old when her father was diagnosed with the disease, from that point on she's dedicated her time and career to studying Alzheimer's disease. In 2020, she and passionate stakeholders in the Dominantly Inherited Alzheimer's Disease (DIAD)/early onset familial Alzheimer's disease community launched Youngtimers, an organization dedicated to improving the lives of individuals and families affected by DIAD through education, support, community, and research. In 2021, Youngtimers received its 501(c)3 nonprofit status.

Beth Kallmyer, MSW

Vice President, Care and Support
Alzheimer's Association

As Vice President of Care and Support for the Alzheimer's Association, Beth Kallmyer leads all nationwide programming for individuals living with Alzheimer's and dementia, their families, caregivers and the general public. She is responsible for dementia content development, management and evaluation for the Association's education programs, support groups, web material, brochures and topic sheets. Additionally, Kallmyer oversees implementation of programs via the Association's chapter network in communities across the country, as well as the Association's 24/7 Helpline, which receives over 250,000 calls per year and is staffed by master's level clinicians and dementia specialists.

Kallmyer led the development of the Association's evidenced based Dementia Care Practice Recommendations, which outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion. The recommendations were published as a supplement to *The Gerontologist* and are being used to train care providers and facilities across the U.S.

In addition to nationwide initiatives, Kallmyer and her team work with more than 75 chapters across the country as they enact the Association's programs in local communities through support groups, educational programs and care consultation.

As a frequent Association spokesperson, Kallmyer has been interviewed by numerous national media outlets, including CBS Sunday Morning, The New York Times and The Wall Street Journal.

Kallmyer has more than 30 years of experience in the nonprofit sector, including health care, emergency services, and community mental health and hospice. She holds a master's degree in social work from the University of Illinois Chicago and a bachelor's degree from Saint Mary's College.

Jorge J Llibre Guerra, MD, MSc

Assistant Professor of Neurology
Washington University School of Medicine
DIAN-TU Assistant Director

Jorge Llibre completed his medical training at Havana University School of Medicine, followed by residency in neurology. Llibre created the Cognitive Research Unit at the National Institute of Neurology and was tapped to help in the National Strategy for Dementia. In 2016, he joined the Memory and Aging Center at UCSF and received fellowship training in Behavioral Neurology and Global Health. Dr. Llibre joined the Dominantly Inherited Alzheimer Network at Washington University in 2018, and he now serves as Assistant Director and leads research efforts to expand clinical trials to Hispanics. Dr. Llibre has led significant progress to estimate the burden of neurodegenerative diseases in Latin America, including Alzheimer disease and Parkinson disease-dementia. Recent work focuses on the influence of life-course factors and health disparities on cognitive decline and biomarker rate of change. Llibre has received research funding from the Global Brain Health Institute, World Federation of Neurology, Michael J. Fox Foundation and Alzheimer's Association.

Eric McDade, DO

Professor of Neurology
Washington University School of Medicine
DIAN-TU Co-Director

Dr. McDade is an Assistant Professor in Neurology at Washington University in St. Louis. He was co-Chief resident at the University of Maryland Department of Neurology and completed his Cognitive and Behavioral Neurology Fellowship at Mayo Clinic. Prior to joining Washington University as Associate Director of the Dominantly Inherited Alzheimer Network Trials Unit he served as the site-PI for the DIAN studies at the University of Pittsburgh. Dr. McDade's research interest focus on the exploration of early biomarker and clinical changes in neurodegenerative dementias including familial dementia syndromes and applying this to prevention trials.

Darby Morhardt, PhD, LCSW

Research Professor, Mesulam Center for Cognitive Neurology and Alzheimer's Disease
Northwestern University Feinberg School of Medicine

Darby Morhardt, PhD, LCSW is Professor at the Mesulam Center for Cognitive Neurology and Alzheimer's Disease and Department of Preventive Medicine, Northwestern University Feinberg School of Medicine. Dr. Morhardt directs the Center's Outreach, Recruitment and Engagement Core, Clinical Social Work Services, in addition to the Miller Post-Graduate Social Work Fellowship in Neurocognitive Disorders. Areas of research include the experience of families living with dementia; the process of tailoring care to specific needs and symptoms; and the development and evaluation of quality-of-life enrichment interventions, including the Buddy Program, an experiential learning program for first year medical students and persons living with dementia which has been replicated internationally. She has worked specifically with families living with younger onset dementia and served on the Taskforce for Children and Teens for the Association for Frontotemporal Degeneration. In addition, Dr. Morhardt is responsible for organizing the Mesulam Center's community engagement to increase dementia education, awareness, and research participation throughout Chicago especially with underrepresented groups. She is a member of the State of Illinois Alzheimer's Disease Advisory Committee, contributes to the writing of the Illinois Alzheimer's Disease State Plan and is a leader in the Illinois Cognitive Resources Network coordinating state-wide efforts for workforce development and dementia friendly communities. She was recently appointed to the Illinois Supreme Court Commission on Elderlaw, tasked with helping the Illinois Supreme Court more effectively address the needs and legal issues of older adults, particularly those living with dementia, and their families in the state of Illinois.

Natalie Ryan, MRCP, PhD

University of London Chadburn Clinical Lecturer
Dementia Research Centre
Department of Neurodegenerative Disease
UCL Queen Square Institute of Neurology

Natalie Ryan is a neurologist with a clinical and research interest in young onset and inherited dementia, particularly autosomal dominantly inherited familial Alzheimer's disease. She studied medicine at Cambridge University and Imperial College London and trained as a clinical neurologist at St George's University Hospitals NHS Foundation Trust and the National Hospital for Neurology and Neurosurgery. She completed her PhD at the Dementia Research Centre, University College London Queen Square Institute of Neurology, supervised by Professor Nick Fox. She has held an MRC Clinical Research Training Fellowship and Brain Exit Fellowship, and is currently supported by a University of London Chadburn Academic Clinical Lectureship. Her research investigates relationships between clinical, neuroimaging

and neuropathological features in familial and young onset sporadic Alzheimer's disease, with a particular interest in studying how variability in these features may provide insights into underlying disease mechanisms. Natalie and her colleagues run a support group for familial Alzheimer's disease families, part of Rare Dementia Support, which meets annually in London.

Katie Sandler, MA

Impact Coach

Katie Sandler is an Impact Coach. She combines a background as a therapist, 15 years of research on purpose, and a depth of personal experience to help clients experience transformation. Her unique method propels clients to meet their unmet potential, align with their purpose, harness their resilience, and ultimately become leaders who make a positive impact on the world.

Sandler herself has overcome immense physical and mental hurdles, including being born without an ear, overcoming paralysis as a teen, and facing depression head-on. From her struggles, Sandler discovered the life-changing benefits of mind-body medicine. She holds a Master's in Mental Health Counseling, a Bachelor's in Psychology, and has worked as a psychiatric research assistant at Johns Hopkins. Sandler utilizes her expertise to impact clients through one-on-one sessions, group consultations, and her immersive Impact Retreat and Group Impact Experiences, which take place in inspiring locations around the globe.

Pat Sikes, PhD

Professor Emeritus of Qualitative Inquiry
University of Sheffield, UK

Dr Pat Sikes is Professor Emeritus of Qualitative Inquiry at the University of Sheffield. Throughout an academic career that began in 1978, Pat has been committed to using narrative auto/biographical approaches to explore social justice issues with a view to prompting change. She began researching the perceptions and experiences of children and young people who have a parent with a young onset dementia when her husband, David, was diagnosed with vascular and posterior cortical atrophy dementias when their children were in their early teens. The family lived with dementia for 17 years until David's death, at the age of 72, in 2020.

Pat's current work brings her together with Professor Caroline Gelman at the Silberman School of Social Work, Hunter College, City University of New York and Dr Mel Hall, Manchester Metropolitan University, looking at how young people who have a parent with an inheritable form of dementia make decisions about genetic testing. Pat's university web page gives links to her publications, including those written with Mel Hall, based on findings from their initial study about young people's perceptions and experiences of dementia: see <https://www.sheffield.ac.uk/education/people/academic/pat-sikes>