Toward a Common Research Agenda in Infection-Associated Chronic Illnesses: A Workshop to Examine Common, Overlapping Clinical and Biological Factors

Committee

Timothy Coetzee

Co-Chair

Timothy Coetzee, Ph.D., Chief Advocacy, Services and Science Officer at the National MS Society, has been a leader in the pursuit of innovative ways to move us closer to a world free of multiple sclerosis since receiving his PhD in microbiology and immunology in 1993. Dr. Coetzee has contributed to the field of MS research in numerous ways, including everything from his postdoctoral work researching the structure and function of myelin, to ultimately helping to create programs such as the Society's Translational Research Partnerships in Nervous System Repair and Protection in MS. His diverse experience in multiple areas of MS has provided him the insight and ability to create critical partnerships and effective collaborations worldwide; his leadership and commitment to the NOW $250 million fundraising initiative will propel research and treatment advances for people affected by all forms of MS. Under Dr. Coetzee's leadership, the National MS Society created its Career Transition Fellowship, the first transition award for postdoctoral fellows to be established by a patient advocacy organization, and the MS Clinician Scientist Development Award, a joint venture award between the National MS Society and the American Academy of Neurology to recruit young physician-scientists to MS clinical research. Dr. Coetzee was also a leader in establishing the Translational Research Partnerships in Nervous System Repair and Protection in MS Program, a five-year, $15 million commitment to fund four large collaborative research teams focused on developing tools and strategies to promote nervous system repair and protection in MS. This program became the cornerstone of the Society's $32 million Promise: 2010 campaign and Dr. Coetzee was a major force in raising funds for the accomplishment of those efforts. Dr. Coetzee received his PhD in microbiology and immunology from Albany Medical College in Albany, NY in 1993. He began his lifelong commitment to ending MS when he received the National MS Society's Advanced Postdoctoral Fellowship to support his research on the structure and function of myelin. Dr. Coetzee joined the National MS Society's Research Department in 2000 as the Director of Research Training Programs. Subsequently, he held various positions, including Director of Research Initiatives and Outreach, Associate Vice President of Research Initiatives and Outreach, and Vice President of Discovery Partnerships where he assumed responsibility for the development, launch and leadership of Fast Forward in 2006, a Society initiative that continues to break down barriers that impede commercial development, clinical trials, and ultimate patient availability of new treatments for all forms of MS. Research articles by Dr. Coetzee have been published in a variety of journals, including, Journal of Neuroscience, Journal of Neurochemistry, Molecular and Cellular Neuroscience, Neurochemical Research, Journal of Neurocytology, Cell, Genomics, Genes & Development, and the Journal of Molecular Biology. Dr. Coetzee has been a requested panelist and presenter at multiple conferences and summits, and testified at several Congressional hearings in Washington, DC. Dr. Coetzee has served as a member of the Forum on Neuroscience and Nervous System Disorders, Institute of Medicine of the National Academics since 2006.

Timothy Endy

Co-Chair

Timothy Endy, M.D, MPH, currently serves as a Program Leader for the Coalition for Epidemic Preparedness Innovations (CEPI) and is a Professor Emeritus Department of Microbiology and Immunology at the State University of New York Upstate Medical University in Syracuse, NY. Dr. Endy served in virology and emerging diseases in the U.S. Army Military Component in Bangkok, Thailand, from 1996 to 2001. Dr. Endy subsequently served in the Department of Virology at the U.S. Army Medical Research Institute of Infectious Diseases, as Assistant Chief and then Chief of the division. From July 2003 until his retirement from the military at the rank of colonel in 2006, Dr. Endy served as Director of the Division of Communicable Diseases and Immunology of the Walter Reed Army Institute of Research. At SUNY Upstate Dr Endy served as Chief of Infectious Disease then Chair, Department of Microbiology until he retired in 2021. He then joined CEPI as the program leader for Disease X and CHIKV vaccines. He has published extensively on the topic of infectious disease. In 2007, he served on the NRC Committee on Prevention of Proliferation of Biological Weapons. Dr. Endy received an M.P.H. from the University of Michigan and an M.D. from the Uniformed Services University.

Brian Fallon

Member

Brian Fallon, MD, MPH directs the Lyme & Tick-Borne Diseases Research Center and the Clinical Trials Network Coordinating Center for Tick-borne Disease at the Columbia University Irving Medical Center. As Professor of Clinical Psychiatry at Columbia University, Dr. Fallon’s research has focused on the neuropsychiatric and persistent sequelae of Lyme disease as well as on neuroimaging and clinical trials related to Lyme disease and trials related to anxiety and somatic symptom disorders. Dr. Fallon has received numerous NIH and foundation grants, served on HHS Tick-borne Diseases Working Group subcommittees, and currently serves on the NIH Steering Committee to provide guidance for clinical trials conducted under the “Researching COVID to Enhance Recovery” (RECOVER) Initiative. Dr. Fallon received his BA from Harvard College, MD and MPH from Columbia University and completed his residency training and NIH-sponsored research fellowship at Columbia University and the NYS Psychiatric Institute.

Lorraine Johnson

Member

Lorraine Johnson, JD, MBA, is the Chief Executive Officer of LymeDisease.org and the Principal Investigator of its patient registry and research platform, MyLymeData--which has enrolled over 17,000 patients. In addition to her legal and business degrees, her undergraduate major was in psychology, with a focus research design and statistics. She is regarded as a subject matter expert on patient engagement, data privacy, big data research, patient registries, and Lyme disease. She has authored over 50 peer reviewed publications on Lyme disease and patient centered healthcare, including five big data studies for which she served as Principal Investigator. She is an author of two college text book chapters on patient engagement, big data and patient registries. She has served on several federal advisory committees related to big data, patient centered research, and patient registries including the inaugural Patient Engagement Advisory Panel for the Patient Centered Outcomes Research Institute (PCORI), both the Steering Committee and the Executive Committee of its big data project, PCORnet, and chair of its Patient Council on data privacy. She participated in the White House Precision Medicine Summit. She sat on the Steering Committee of Consumers United for Evidence Based Healthcare, and has presented extensively at professional, medical, and governmental conferences including the Cochrane Colloquium (Plenary Session), the American Association for the Advancement of Science, the NIH Collaboratory, the NIH Science of Team Science Conference, PCORnet, and the Society to Improve Diagnosis in Medicine.

Avindra Nath

Member

Avindra Nath, M.D., is the clinical director of the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health, where he is also chief of the Section of Infections of the Nervous System and the director of the Translational Center for Neurological Sciences. Dr. Avindra Nath is a physician–scientist who specializes in neuro-immunology and neurovirology. His research is focused on the clinical manifestations, pathophysiology and treatment of emerging neurological infections with a focus on HIV infection. In recent years, he has studied the neurological complications of endogenous retroviruses, Ebola, Zika virus and SARS-CoV-2 and conducts research on patients with undiagnosed neuroinflammatory disorders. He has served on advisory committees to the NIH, Centers for Disease Control, Food and Drug Administration and World Health Organization. The International Society of NeuroVirology gave him the Pioneer in NeuroVirology Award for his contributions to HIV neuropathogenesis and elected him as the president of the society. He received the Wybran award from the Society of Neuroimmune Pharmacology for contributions to Neurovirology. He also received the NIH Director’s award for his work on SARS-CoV-2 and the Health and Human Services Secretary’s award for his work on Ebola infection.

Melissa Nolan

Member

Melissa Nolan, Ph.D., M.P.H., is a faculty member at the University of South Carolina’s Arnold School of Public Health. Prior to joining her current institution, she worked at Texas Children’s Hospital and Baylor College of Medicine. Dr Nolan has established expertise in infectious disease epidemiology with an emphasis on health disparities and diagnostics. She is a productive public health researcher with more than $12 million in extramural funding, 90 peer-reviewed publications, and 76 scientific presentations. Dr Nolan has established field sites in the United States, El Salvador, Colombia, and Brazil, where her implementation science work focuses on designing field-deployable diagnostics with real-world efficacy.

Rafael Obregon

Member

Rafael Obregon, Ph.D., M.A., is the country representative for the United Nations Children’s Fund (UNICEF) in Paraguay. He leads UNICEF's strategic engagement with and technical support to the Government of Paraguay across several development and health issues, including to the country's ongoing response to COVID-19. Prior to his current role, Dr. Obregon led the UNICEF global team in Communication for Development through which he provided technical leadership and guidance on the development of standards, guidelines, and quality assurance for the application of risk communication and community engagement principles and strategies, including in emergency response and humanitarian action. Throughout his career, Dr. Obregon has engaged in several responses to public health emergencies and disease outbreaks such as the 2014–2015 West Africa Ebola Outbreak and the 2016 Zika outbreak. In 2016 Dr. Obregon served as a member of the Advisory Committee to the World Health Organization’s (WHO) International Health Regulations (IHR) Emergency Committee on Zika virus and observed increase in neurological disorders and neonatal malformations. Prior to joining UNICEF, Dr. Obregon served as regional health communication adviser in Family and Community Health at the Pan American Health Organization (PAHO), and served as a technical advisor, researcher, and resource/focal person for international/national cooperation agencies and government and nongovernmental organizations. His duties have focused on formative research, project design and evaluation, and capacity strengthening. Dr. Obregon has been an associate professor and guest faculty member at a number of universities, including Ohio University, the Universidad Autónoma in Barcelona, Spain, and the Universidad del Norte in Barranquilla, Colombia. He has published several books, book chapters, monographs, manuals, peer-reviewed journal articles, and reports on public health communication, participatory communication, and capacity development. He recently co-edited “Risk Communication and Community Engagement: Dealing with Rights, Culture, Complexity, and Context” (Springer). He served as the founding chair of the Global Alliance for Social and Behavior Change, and is a member of several editorial boards including the Journal of Health Communication and the Journal of Health Care Communication. He has been a member of several scientific committees and technical advisory groups including the Global Pandemic Preparedness and Response Initiative (Institute for Development Studies), the Technical Advisory Group for the Social and Behavior Change Program at the University of Witwatersrand´s MPH (South Africa), and the Secretariat of the International Summit on Social and Behavior Change Communication. Dr. Obregon earned his Ph.D. in an interdisciplinary program in mass communications, with a concentration on international health, at the College of Communications at Pennsylvania State University. He received his Master of Arts in international affairs from Ohio University, and obtained a diploma in education and pedagogy through the National Apprenticeship Service in Colombia.

Amy Proal

Member

Dr. Proal is a microbiologist that serves as President/CEO of PolyBio Research Foundation and directs the Organization's Long Covid Research Consortium (LCRC). Her work examines the molecular mechanisms by which viral, bacterial, and fungal pathogens dysregulate human gene expression, immunity, and metabolism. In her work with PolyBio Research Foundation and the LCRC she conceptualizes and coordinates large-scale collaborative research projects among research teams studying infection-associated chronic illnesses such as LongCovid, ME/CFS and LongLyme. She has written multiple review articles that delineate core biological drivers of both the LongCovid and ME/CFS disease processes. She holds a Bachelor of Science in biology from Georgetown University and a PhD in microbiology from Murdoch University in Australia.

Peter Rowe

Member

Dr. Rowe is a Professor of Pediatrics in the Division of Adolescent and Young Adult Medicine at the Johns Hopkins University School of Medicine. His clinical and research interests for the last 30 years have focused on medical conditions characterized by chronic fatigue. His work has emphasized the importance of a variety of physiologic risk factors for ME/CFS, including orthostatic intolerance, joint hypermobility, allergic inflammation, and adverse biomechanical strain. He has directed the Chronic Fatigue Clinic at the Johns Hopkins Children’s Center since 1996, where he is the inaugural recipient of the Sunshine Natural Wellbeing Foundation Chair in Chronic Fatigue and Related Disorders. In 2014, he received the Research Award from the International Association for CFS/ME, for outstanding research contributions to the field of CFS/ME. He is a graduate of Trinity College, University of Toronto, and the McMaster University School of Medicine, Canada. He completed his residency training in Pediatrics, General Pediatric Academic Development fellowship training, and Chief Residency at the Johns Hopkins Hospital. He was a member of the Institute of Medicine Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.