Lived Experience for Stronger Neuroscience (LivedX for Neuro)

Participant Biographies

Laura Ana Bustamante

Laura Ana Bustamante, PhD, is a neuroscientist researching the cognitive processes underlying successfully achieving goals and ways to support goal attainment. With the goal of transforming the future of mental health, she integrates her lived experience of neurodivergence with formal training in clinical science and advocacy work. Her research in the field of computational psychiatry addresses challenges with cognitive function and motivation that individuals with mental health conditions sometimes experience. She is currently a postdoctoral fellow at Washington University in St. Louis in the Psychological & Brain Sciences department and earned her PhD at the Princeton Neuroscience Institute. Her goal is to integrate neurodiversity and disability perspectives into psychology and psychiatry research and practice. For example, by understanding cognition in context, targeting increased accessibility, and adopting strengths-based approaches. She has led workshops on "Neurodiversity in Academia" and "Neurodiversity Affirming Computational Psychotherapy" as well as discussing these topics on podcasts and news articles. She contributes her lived expertise to LivedX for Neuro, with an eye towards 1) increasing autonomy for mental and brain health care users, 2) decreasing stigma and bias (e.g., ableism, sanism), and 3) leveraging the tremendous potential of neuroscience to improve well-being. You can learn more about Dr. Bustamante on her personal website at: https://www.lauraanabustamante.com/

Indida Birto

Indida Birto is a dedicated professional in the Atlanta area, specializing in mental health, harm reduction education, case management, and peer navigation. She presently works as the Service Plan Coordinator for Here's to Life Inc., and as a Research Assistant for Emory Rollins School of Public Health's EMpower Research Team. Her personal journey through co-occurring pain and behavioral health disorders, as well as her experiences within the US prison system, foster care, and experiencing substance use disorder while unhoused, have profoundly shaped her mission. Overcoming these barriers inspired Indida to work tirelessly toward building resilient communities and supporting individuals facing similar challenges.

Ian Burkhart

Ian Burkhart is a C5 complete tetraplegic from a diving accident in 2010. He is the founder and president of the BCI Pioneers Coalition and president of the North American Spinal Cord Injury Consortium President. After participating in a few clinical trials, he understood the need for engagement of individuals with lived experience from the start. Ian was the first person in the world to restore movement to a paralyzed limb using a BCI neuroprosthetic. He is also the Executive Director of the Ian Burkhart Foundation, which raises funds for medical equipment for other individuals living with paralysis. His research focuses on amplifying the lived experience of people with disabilities.

Jennifer Handt

Jennifer Handt combines her background as a professional communicator and copywriter and her role as a rare disease parent to advocate for patients and families living with Duchenne muscular dystrophy and other neuromuscular conditions. She founded Charlie's Cure (curecharlie.org)—dedicated to Duchenne research and advocacy—when her son Charlie was diagnosed with the condition in 2020 at the age of three.

As a writer, Jennifer works with leading hospital networks, provider groups and nonprofit health policy organizations. As an advocate, she has helped drive drug approval and patient access, the adoption of Duchenne newborn screening and national awareness around the disease. Her work is published in *STAT*, *The Boston Globe* and *DC Journal*, among others.

Kevin Kwok

Kevin Kwok, PharmD, was diagnosed with Young Onset Parkinson's Disease in 2009 at age 48. He is a retired biopharma executive and led operational and advisory roles in both Pharma and research stage biotech companies. After diagnosis, he pivoted his career to focus on patient engagement and patient focused drug development (PFDD).

In addition to being a participant on the LivedX for Neuro action collaborative, he is a patient advisor to the Michael J. Fox Foundation, the Parkinson's Foundation, Critical Path for Parkinson's, and serves on the board of the Davis Phinney Foundation. Kevin earned his Doctor of Pharmacy degree at the University of Michigan.

He is a frequent speaker and author on Parkinson's advocacy topics and recently published the paper “Parkinson’s Disease: Still Waiting for a Cure” in Clinical and Translational Sciences: https://ascpt.onlinelibrary.wiley.com/doi/10.1111/cts.13898.

Ray Lay

Ray Lay is a formerly homeless, honorably discharged US Marine living with a dual diagnosis of schizoaffective disorder and polysubstance use issues. Today, Ray is a home and business owner and a member of the National Alliance on Mental Illness (NAMI) National and Indiana Boards of Directors and also a Board of Directors member for the Corporation for Supportive Housing (CSH).

Seth Morgan

Seth A. Morgan, MD, FAAN is a Board-Certified Fellow of the American Academy of Neurology diagnosed with Multiple Sclerosis (MS) in 2004 after serving for over 20 years in clinical practice in the Washington, DC area. Since being forced to give up practicing medicine in 2006 because of effects of his MS, Dr. Morgan has been an Advocate for people with MS specifically and for people with disabilities in general. He was a participant in clinical trials on Fingolimod (Gilenya). He has served as a guest lecturer at multiple conferences and national professional meetings. He has served as a Commissioner of the Montgomery County (MD) Commission on People with Disabilities (CPWD) for thirteen years and as Chairman of the CPWD for seven years. He has been Vice Chair of the Maryland Alliance of Disability Commissions and has also served on the Maryland State Disability Commission. He has been a reviewer of the Congressionally Directed Medical Research Program, the PCORI Clinical Trials Advisory Panel and is a former member of the iConquerMS Research Advisory Committee, and the National Multiple Sclerosis Society’s Activism Advisory Committee. Dr. Morgan served on the National Library of Medicine Board of Regents Public Service Working Group on Modernization of ClinicalTrials.gov. He is a member of the National Multiple Sclerosis Society’s (NMSS) Advocacy Hall of Fame, Chairman of the NMSS Maryland Governmental Relations Committee and a NMSS District Activist Leader. He is a board member of the National MS Society, Greater DC and Maryland Board of Directors. Dr. Morgan has published various journal articles both as a neurologist and patient advocate. He has participated as a panelist in various National Academy of Sciences, Engineering and Medicine (NASEM) conferences and is a participant of the inaugural Lived Experience for Stronger Neuroscience Action Collaborative.

Evelyn Polk Green

Evelyn Polk Green, MSEd, is a past president of both ADDA (Attention Deficit Disorder Association) and CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder). She is an adult with ADHD and the mother of two adult sons, Perry and Robert, both of whom also have ADHD. Evelyn attended Duke University where her ADHD first manifested itself intensely enough to disrupt her education. She later received bachelor's and master's degrees from National Louis University and a second master's degree from Northern Illinois University. She has been active in child and adult mental advocacy for almost 30 years, with an emphasis on bringing ADHD awareness to marginalized and underserved communities. Evelyn has served as a leader representing the family and educator voice in the ADHD and mental health communities in many capacities over the last 30 years, including as a member of the Network on Children's Mental Health Services funded by the MacArthur Foundation, as well as the American Academy of Child and Adolescent Psychiatry's (AACAP) Research Forum. She has served as spokesperson on behalf of families dealing with the challenges of ADHD for the National Institutes of Mental Health, the Surgeon General of the United States and most recently, the National Academy of Science Engineering and Medicine's Workshop on ADHD Drug Development. She is the recipient of several honors for her volunteer work in mental health and education, including the Beacon College Achieving Lifetime Vision and Excellence (ALiVE) Award for her advocacy work on behalf of children and adults with learning differences and ADHD.

Evelyn is currently serving as a member of the ADHD Expert Consortium, a group dedicated to improving diagnosis, treatment and outcomes for individuals with ADHD. In addition to representing the African American and/or family perspective of ADHD, Evelyn has been a guest on podcasts such "Life with Lost Keys" by Rene Brooks, creator of Black Girl Lost Keys and Samantha Hiew's Utopia Podcast originating in the UK. She has appeared in numerous articles and news programs discussing ADHD and mental health, including the CBS Evening News and the New York Times. Additionally, Evelyn has written articles for ADDitude Magazine and served as an expert speaker for ADDitude webinars. She has also presented content for both live and recorded seminars and presentations to families, educators and mental health professionals.

Evelyn has been an educator in the Chicago Public Schools for over 35 years, working as a teacher assistant, classroom teacher, resource specialist, coach, trainer and administrator. She currently works as an administrator, planning professional development programs for early childhood special education professionals and families.

John-Ross (JR) Rizzo

John-Ross (JR) Rizzo, MD, MSCI, FACRM is a physician-scientist-leader at NYU Langone Health. He is currently the Health System Director of Disability Inclusion, Endowed Professor of Rehabilitation Medicine, and the Vice Chair of Innovation & Equity in the Rusk Institute of Rehabilitation Medicine at the NYU Grossman School of Medicine, with cross-appointments in the Department of Neurology, Department of Ophthalmology, the Department of Mechanical & Aerospace Engineering, and the Department of Biomedical Engineering at the NYU Tandon School of Engineering. He is the Associate Director of Healthcare for the renowned NYU WIRELESS and associate faculty in the Center for Urban Science and Progress (CUSP) at the NYU Tandon School of Engineering. He leads the Visuomotor Integration Laboratory (VMIL), exploring motor control with a special emphasis on visual guidance, and the Rehabilitation Engineering Alliance and Center Transforming Low Vision Laboratory (REACTIV), exploring bio-inspired, multi-sensory assistive technologies with a special emphasis on advanced wearables.

Dr. Rizzo capitalizes on his lived experience with vision loss in all aspects of his work and is very proud of his disability identity, a source of intense strength for him and his family, both in and out of his professional life. He has been a featured speaker across international and domestic venues and has won myriad awards in domains inclusive of medical innovation, disability justice and accessibility.

Israel Robledo

Israel Robledo is in his 30th year as a special education teacher and reading specialist. He was diagnosed with Parkinson's Disease in 2007 at age 42. After coming to terms with his diagnosis he started advocating for clinical trial participation and health-related quality of life issues.

Israel is a member of the Michael J. Fox Foundation for Parkinson's Research Patient Council, a member of the Integration Panel for the Congressionally Directed Medical Research Program (Parkinson's Research Program) and is a member of the Editorial Board for the Journal of Parkinson's Disease and has been a patient reviewer for the BMJ (formerly the British Medical Journal).

His focus on outreach for Parkinson's Disease awareness and education has resulted in articles being published in *Scientific American*, the *Journal of Parkinson's Disease*, and the *Movement Disorders Journal*.

Israel has served in an advisory/support capacity for the Parkinson’s Foundation as a Research Advocate.

He has participated in grant reviews for the Patient-Centered Outcomes Research Institute, the Congressionally Directed Medical Research Program (Parkinson’s Research Program), and the Michael J. Fox Foundation for Parkinson’s Research.

Linda Shows

Linda Williams Shows, MS, BSN RN, is a lifelong Mississippian and a proud first-generation college graduate. After attending the local community college, she went on to earn her bachelor's and master’s degrees in nursing. Linda's early nursing career included working as a registered nurse in medical-surgical and ICU settings, as well as serving as a Director of Nursing in a long-term care facility. She also worked as a Certified Home Health Oncology nurse, receiving specialized training at the Sloan Kettering Cancer Research Center in New York City.

Linda's nursing career took an unexpected turn when she was diagnosed with keratoconus, leading her to transition into nursing education. She spent 27 years as a Practical Nursing Instructor at her alma mater, now known as Jones College. After retiring from Jones College, Linda served as the Practical Nursing Director at Antonelli College, where she successfully opened a new LPN program. During the COVID-19 pandemic, Linda further demonstrated her versatility by serving on the COVID response team for a local poultry production company and administering vaccines for a local pharmacy.

Throughout her diverse nursing career, Linda has been deeply involved with the Mississippi LPN Association, serving as the Executive Director for over 35 years. She has been honored with numerous awards, including being named the Mississippi Nurses Association's Oncology Nurse of the Year and Home Health Nurse of the Year. Linda's unwavering faith, passion for nursing, and commitment to serving others have been the driving forces behind her remarkable life and career.

In October 2023, at the age of 67, Linda began experiencing seizure-like symptoms, which led to a diagnosis of Alzheimer's disease in March 2024. Despite this challenge, Linda continues to live a full life, undergoing treatment with the IV medication Leqembi and maintaining her responsibilities as the co-caregiver for her 90-year-old mother. Linda remains active in her church, cheers on her five grandchildren, volunteers at a free medical clinic, and finds joy in activities like spending time at the beach and attending music concerts. Linda is honored to have the opportunity to share her story and provide input on the future of healthcare in neuroscience, drawing on her extensive nursing experience and her personal journey with Alzheimer's disease.