



BRIEF OVERVIEW

Foundation Origin

- Isabella Elaine Lazzara was born on January 21, 2023, in Jacksonville, Florida. During her first 6 months, physical developmental delays were noted, followed by cognitive concerns. In February 2024, Isa was diagnosed with an ultra-rare disorder, Beta-propeller protein-associated neurodegeneration (BPAN) based on the presence of a single mutation to the WDR45 gene, MRI findings and extensive clinical assessments. Today, Isa is still learning to walk and talk but is a happy little girl.

Foundation Research Goal

- Discover the critical cellular changes in the brain that cause BPAN disorder, to develop successful treatments for BPAN, Alzheimer's and Parkinson's diseases.

Game-changing Discovery from the Foundation's Chief Scientific Advisor

- Dr. Marc Fariss, PhD, a distinguished researcher in Pathobiology and Toxicology, identified parallels between BPAN and Alzheimer's & Parkinson's diseases. He has compelling scientific evidence that BPAN disorder is a very accelerated form of Parkinson's & Alzheimer's diseases, and these 3 disorders share a common pathway to neurodegeneration.
 - Dr. Fariss has over 30 years of expertise in leading both academic and private research institutions to find the critical cellular changes that lead to human diseases including Alzheimer's and Parkinson's and that lead to the discovery of treatments.

BPAN Disorder as a Very Accelerated Form of Alzheimer's & Parkinson's Diseases

- At the age of 1 yr., Isabella already showed the same hallmark signs of neurodegeneration reported for late onset Alzheimer's & Parkinson's diseases (60+ yrs old patients).
- The common signs of neurodegeneration observed in BPAN patients, like Isa, and Alzheimer's and Parkinson's patients include: the loss of movement, language and cognitive function as well as the same brain regions damaged with neuronal demyelination and cell death and the accumulation of iron and cell debris (tangles of damaged protein and lipid).



Why is it Urgent to Study Isabella and other BPAN patients like her?

- Isabella is most likely the youngest person diagnosed with BPAN that has rapid neurodegeneration and has been extensively studied (genetic testing, MRI, and clinical assessments). She and others like her are ideal patients to monitor their active phase of neurodegeneration over time to increase our ability to identify critical cellular changes in the brain. In older neurodegenerative patients (60+ years old) it is difficult to determine if cellular changes in the brain are responsible for the disease or merely the result of normal aging.
- Cells obtained from young patients (like Isa) have a functional and survival advantage, permitting more detailed studies for longer periods of time that often are not possible in cells from older, adolescent patients. Therefore, it is urgent that we begin studying cells obtained from these very young BPAN patients as soon as possible (e.g. cells from cheek swabs and blood).

FOUNDATION LEADERSHIP

- In July 2024, Christopher Lazzara, Isa's father, founded the Isa Elaine Foundation to create a dedicated platform for research exploring the connection between BPAN, Alzheimer's, and Parkinson's diseases.
- The Foundation board is made up of Christopher Lazzara, Dale Pirkle, Freddie Figgers and Dr. Lenn Murrelle, MSPH, PhD with Dr. Marc Fariss, PhD as the Chief Scientific Advisor.
- Collaborating with the Rose H. Weiss Orphan Disease Center at the University of Pennsylvania, the Foundation is currently planning a Think Tank event in 2025 to bring together leading experts from various research fields to identify key gaps in our current understanding of treatments for BPAN.