Isa Elaine Foundation: Brief Overview for Chief of Staff

**Foundation Origin:**

* Isabella Elaine Lazzara was born on January 21, 2023, in Jacksonville, Florida.
* By June 2023, physical developmental delays were noted, followed by cognitive concerns in November. In February 2024, Isa was diagnosed with Beta-propeller protein-associated neurodegeneration (BPAN) WDR45, a rare degenerative genetic mutation.
  + BPAN is classified as an ultra-rare disorder and is part of a group of conditions known as Neurodegeneration with Brain Iron Accumulation (NBIA). The specific disorder was only discovered in 2012.

**Scientific Connection:**

* Dr. Marc Fariss, PhD, Isa’s uncle and a distinguished researcher in Toxicology, identified parallels between BPAN and other degenerative disorders like Alzheimer’s and Parkinson’s disease.
  + Dr. Fariss has over 30 years of expertise on leading both academic and private research institutions to find cures for major degenerative brain diseases, particularly Alzheimer’s and Parkinson’s.
* Isa has undergone extensive testing since infancy, including an MRI at Wolfson’s Children’s Hospital, utilizing one of only four advanced infant MRI machines globally. This early data collection offers valuable insights for longitudinal studies on BPAN.
* While the parallels between BPAN and other degenerative disorders may have been previously discovered, there has been no research in linking the beginning of life BPAN disorder to end of life diseases such as Alzheimer’s and Parkinson’s.
* Isabella may be the youngest person diagnosed with BPAN and has the earliest data collected to study. BPAN is on a spectrum of symptoms and onset, and she is ultra rare being diagnosed so early.

**Foundation Establishment:**

* 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, and Lenn Murrelle, MSPH, PhD with Dr. Marc Fariss, PhD as the Senior Scientific Advisor.
* Collaborating with the Rose H. Weiss Orphan Disease Center at the University of Pennsylvania, the foundation has begun planning a Think Tank event in 2025 to bring together leading experts from various research fields to identify key gaps in current understanding.

**Funding Request:**

* The foundation is seeking $50 million to engage top experts in the field of degenerative brain disorders and solve Alzheimer’s and Parkinson’s disease. This funding will support:
  + Organizing three to four specialized Think Tanks, focusing on addressing identified research gaps and advancing knowledge in the field.
  + Facilitating collaboration with scientists to publish research articles on BPAN’s potential to provide insights into broader degenerative disorders.