The Louisa Adelynn Johnson Fund
for Complex Disease

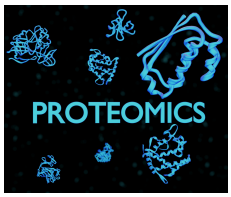
TOGETHER WE ARE

ADVANCING RESEARCH | **RAISING AWARENESS** | **ENGAGING IN ADVOCACY** | **EDUCATING COMMUNITIES**

2025 YEAR IN REVIEW

Advancing Research

This year we were proud to announce a $50,000 matching grant award at Dysautonomia International's (DI) annual conference where Alissa and Lulu's aunt Nicole Miranda (pictured above far right) also hosted an exhibit booth sharing PANS and PANDAS resources and our bimonthly series Hard Truths: How the Health Care System Treats Complex, Chronically Ill Children. The contribution will help support important new POTS research at Johns Hopkins funded by DI. The Johns Hopkins researchers recently identified genetic variants in a subset of POTS patients that may increase ion channel signaling in the autonomic nervous system. The team will conduct placebo controlled exploratory clinical trials on POTS patients of cromolyn sodium and guanfacine—medications that can regulate these ion channels. Doctors often prescribe one of the medications, cromolyn sodium, off label to treat mast cell activation syndrome. The researchers will explore whether it also benefits individuals with POTS who do not have a mast cell disorder. If either trial is successful, published results will help POTS patients gain access to insurance coverage for these medications, if needed, and form the basis for further studies. Researchers also will collect sputum from participants for possible future DNA sequencing.



We joined The Alex Manfull Fund (TAMF) to again support the work of Dr. Lauren Breithaupt, PhD, Assistant Professor of Psychiatry at Massachusetts General Hospital (MGH). The project "Comparative Proteomic Analysis of Flare and Remission Phases in PANS and PANDAS" builds upon Dr. Breithaupt's study in which a machine learning model using a panel of inflammatory proteins identified possible biomarkers for PANS and PANDAS. This endeavor will examine protein expression patterns in patients with PANS and PANDAS vs. controls in collaboration with Dr. Jennifer Frankovich of the Stanford Immune Behavioral Health Clinic, which will provide well characterized flare and remission samples. Our fund will supply one third of the support for biostatisticians at MGH to analyze the proteomic profiling data with TAMF providing the remainder.

In August our fund grabbed the attention of the BBC and the world.

The BBC article 'Unbelievable pain and suffering': How a common throat infection can rewire children's brains featured Lulu and another patient Charlie amid their battle with PANS/PANDAS. The article reached readers across the globe with thousands of comments and shares on social media.

Raising Awareness

In October we held our 2nd annual virtual event "Walking for Lulu" in honor of awareness days for PANS/PANDAS (Oct. 9th) and POTS (Oct. 25th). Participants from 12 states and more online walked in their shoes for Lulu in order to educate others about complex illness, sharing photos along the way. Amigos Por Vida Friends for Life charter school in Houston (pictured top left on page 1) also held awareness events throughout October for the second year in a row, including an assembly, classroom activities and Walk for Lulu with faculty and students in attendance. We are so grateful to these students and all of our participants. Together we potentially made a huge difference in the life of a patient who is undiagnosed, but possibly battling these illnesses, and others who may encounter these conditions in the future.

Engaging in Advocacy

Alissa attended the National Alliance for PANS/PANDAS Action (NAPPA) Capitol Hill days in April with our fund sponsoring a break room for advocates to rest between meetings scheduled. Among its requests, NAPPA sought the addition of PANS and PANDAS to the list of conditions eligible to receive funding under the Department of Defense (DOD) Peer Reviewed Medical Research Program (PRMRP). We are pleased to report that PANS and PANDAS were added to the PRMRP list in the Senate DOD appropriations bill, which will provide a substantial new source of research funding if passed. NAPPA, of which Alissa is a co-founding member, also embarked on an exciting new collaboration with the Center for Lyme Action — the Infection Associated Neuropsychiatric Conditions Initiative — which will seek to increase federal funding for the study of Lyme, Bartonella, PANS and PANDAS. Closer to home Alissa and fellow New Jersey advocates called for the passage of legislation to require health insurance coverage for the treatment of PANS and PANDAS. If enacted, New Jersey will join 15 states with similar laws.

Supporting Families

While some find our series Hard Truths distressing to read, it also provides comfort to families with similar experiences that they are not alone. When families reach out, we provide information, resources and, perhaps most importantly, a compassionate listener with whom they can share their plight. In 2026 we will strive to open even more hearts and minds to the challenges that these patients face in the hopes that proper care and treatment will be easily accessible to patients like Lulu in the future.

Educating Communities

Alissa hosted an exhibit booth for the Neuroimmune Foundation (NF) at the National Conference of State Legislatures annual meeting in August. The booth, sponsored by Lulu's grandparents Dr. Arthur and Marjorie Beaudet for the fourth year, offered PANS and PANDAS resources made available through our fund, NF and TAMF who graciously helped Alissa staff the booth again this year (Alissa with Susan and Towny Manfull pictured above).

In September Alissa, Lulu's Aunt Nicole (pictured below) and uncle Dr. Richard Miranda hosted a booth for NF at the American Academy of Pediatrics meeting sharing the organization's considerable free resources available to pediatricians, including Continuing Medical Education and an Expert Consultation Panel.