



The Louisa Adelynn Johnson Fund

for Complex Disease

News and View For the Year Ahead

In its inaugural year, the Louisa Adelynn Johnson Fund for Complex Disease provided grants to support vital scientific research that will aid our understanding of Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS), Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infection (PANDAS), and Postural Orthostatic Tachycardia Syndrome (POTS), thanks to your generous support. These achievements have fostered fruitful collaborations with patient advocacy organizations and necessary conversations with physicians, scientists and researchers to ensure a brighter future for patients like Lulu. Please accept our sincere gratitude for your support which enabled the fund's success in 2023 and established a strong foundation for future progress.

Advocacy in Washington, DC



Celebrating a successful day in DC with co-founding NAPPA members (from left) Alissa Johnson, Bibiana Castaneda, Ramesh Allen and Executive Director Amanda Peel Crowley.

On several occasions we discussed concerns of complex patients, including the need for increased federal research funding, with members of Congress. In May Alissa, Curt and Nate Johnson participated in The Alex Manfull Fund's (TAMF) 5K to raise awareness about PANS and PANDAS. Following the event, Alissa and Curt met with Congressional staff as part of an advocacy day on the Hill organized by the National Alliance for PANS/PANDAS Action (NAPPA). Alissa returned to DC with her sister Nicola Miranda for Dysautonomia International's annual conference and meetings on the Hill to share challenges facing POTS patients and request their assistance.

The fund awarded \$92,500 to Stanford's Immune Behavioral Health Clinic.

Researchers will utilize the funds to initiate studies on siblings of PANS cases, with a portion having POTS.



In partnership with the Neuroimmune Foundation, the fund provided support for a first year fellowship at UCSF. Dr. Greer Waldrop will study the Neuroinflammatory Diseases Cohort (currently >2500 patients) to identify shared clinical features and outcomes related factors in this large cohort of patients with encephalitis, meningitis and post-infectious neuroinflammation.

PANS/PANDAS Recognized As Infection-Associated Chronic Illness Alongside Long COVID, POTS, ME/CFS and Chronic Lyme

In June Alissa attended the National Academies of Sciences, Engineering and Medicine conference "Toward a Common Research Agenda in Infection - Associated Chronic Illnesses: A Workshop to Examine Common, Overlapping Clinical and Biological Factors." She shared Lulu's devastating PANS/PANDAS symptoms with experts, who concurred that these conditions deserve inclusion as exploration of a common research agenda for post-infection illness continues.

Goals for the Fund in 2024

We look forward to our ongoing collaborations with patient advocacy organizations and the community of physicians and scientists devoted to improving the lives of those with complex disease. Through these efforts, we have learned of many exciting opportunities to advance research that require support from donors. While we continue to advocate for additional federal funding, contributions to the fund of any amount will help us to fill the present gap in funding.



Alissa with TAMF's Christine Metzner, William Manfull and Susan Manfull (pictured above) at the National Conference of State Legislatures' (NCSL) Summit in August. The group hosted an exhibit booth for the Neuroimmune Foundation at NCSL, where Alissa is a former staff member. They engaged in very productive conversations with state legislators, legislative staff, and other key stakeholders about PANS, PANDAS and the incredible work of the Neuroimmune Foundation and its Executive Director Anna Conkey (not pictured) in support of this community. Read our brief produced in conjunction with TAMF and the Neuroimmune Foundation to learn more about the role of state policymakers in improving the lives of patients with neuroimmune disorders.

THANK YOU FOR YOUR CONTINUED SUPPORT

As we prepare to welcome the new year, please consider a donation to The Louisa Adelynn Johnson Fund for Complex Disease so that we can continue to work toward a better future for children with complex disease. To donate, please see <https://tlajfundforcomplexdisease.com> or contact us at (202) 258-5529 or email ajohnson@policyconsult.com. Like us on Facebook.

