

2024 YEAR IN REVIEW

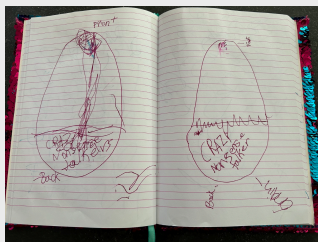
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<https://tlajfundforcomplexdisease.com/>

HARD TRUTHS

In May we launched a bimonthly series, *HARD TRUTHS: How the Health Care System Treats Complex, Chronically Ill Children*. In *Hard Truths* we share Lulu's experiences through the lens of a caregiver and mother, incorporating her sentiments expressed to family whenever possible. We hope that others may learn from the challenges that she faced and have greater compassion for those who continue to suffer similarly.

FROM OUR SIXTH STORY...



"...she repeatedly draws a picture, yet again trying to convey her predicament. She draws the outline of a brain. In the front it says "ME." Inside the back of the brain she has drawn an area writing inside CRAZY NONSENSE TALKERS."



Supporting Research

We are pleased to report that our first grant award to Stanford Immune Behavioral Health Clinic has enabled researchers to enter siblings, a portion of whom have POTS, into the database of patients enrolled in the ongoing PANS Illuminate project. Conducted in collaboration with researchers across the country and internationally, this project will utilize techniques such as autoantibody profiles, proteomics, metabolomics, and genetics to identify indicators of PANS.¹

In March we contributed to The Alex Manfull Fund (TAMF) alongside the Neuroimmune Foundation to support the exciting work of Lauren Breithaupt, PhD, Assistant Professor of Psychiatry at Massachusetts General Hospital. Through TAMF's award to Dr. Breithaupt, biostatisticians are analyzing data from targeted proteome sequencing of patients to identify biomarkers associated with PANS and PANDAS.

1. Stanford Immune Behavioral Health Clinic, <https://med.stanford.edu/pans/our-team/clinic-team.html>



CONNECTING WITH POLICYMAKERS

In February Alissa attended NIH Rare Disease Day with Susan Manfull of TAMF and Amanda Crowley, Executive Director of the National Alliance for PANS/PANDAS Action (NAPPA), pictured above. Together we made new connections, learned of valuable resources and raised awareness about the needs of PANS and PANDAS patients.

Alissa continues to participate in NAPPA, of which she is a co-founding member. In April she and fellow advocates met with members of Congress on NAPPA's Hill Day to request increased federal funding for PANS and PANDAS.

In August, Alissa hosted an exhibit booth on behalf of the Neuroimmune Foundation with Susan and William Manfull at the National Conference of State Legislatures' Summit to share the potential role of state policymakers in improving the lives of those suffering from PANS and PANDAS.

Engaging with Researchers, Clinicians and Advocates

In addition to meeting with policymakers, we engaged with researchers, clinicians and infection-associated chronic condition and illnesses (IACCI) advocates throughout the year at events such as the Steve and Alexandra Cohen Foundation's Edge of Medicine conference, Dysautonomia International's annual meeting, the Children's National IACCI Symposium, the STAT Summit, and the TAMF Symposium.

Raising Awareness: WALKING FOR LULU

Throughout October we hosted our first virtual walk to raise awareness about PANS, PANDAS and POTS. Advocates from around the country walked a mile in their shoes for Lulu and listened to our official [WALKING FOR LULU Spotify playlist](#) with songs from Lulu's record collection. Pictured below, middle school students participate in WALKING FOR LULU while learning about POTS and PANS together with educators.



PLEASE SUPPORT OUR EFFORTS

In the year ahead we will continue to educate others about the profound impact of complex, chronic illness on the lives of children and their families while maintaining our primary focus—supporting the work of researchers investigating these conditions. Please consider a donation to help us fund much-needed studies that will bring hope for a better future to patients like Lulu. Our sincere thanks to our generous donors. To donate, please visit:

<https://tlajfundforcomplexdisease.com/donate>