

WELCOME TO THE

SPATA
FOUNDATION

2025 FAMILY CONFERENCE

FROM GENES TO DREAMS

Our Story



- Luca diagnosed Feb 14, 2023 after dealing with developmental delays & seizures
- Personal research & outreach
- Unable to find SPATA5L1 families at first, we found SPATA5 families who had the same characteristics.
- SPATA Foundation Launch: October 2023



George Family

Our Mission



The SPATA Foundation's Mission is to advocate, educate, and drive research for SPATA5 and SPATA5L1 Related Disorders. Our hope is that our efforts will help us better understand the function of the genes & lead to treatment for disorders related to these genes.

Officially founded October 2023, just 8 months after Luca's diagnosis
International Branches since formed: Australia, Spain, Netherlands

Our History So Far



October 2023: Launched as 501c3

January 2024: Listed on NORD Organization Database

February 2024: Began Development of SPATA5 and SPATA5L1 Mouse Models

April 2024: Launched a Drug Repurposing Study with Unravel BioSciences

May 2024: Began our Scientific Advisory Board

July 2024: AMGEN Global Advocate Grant Recipient

November 2024: SPATA Foundation World Family Map

June 2025: Announced SPATA Foundation Family Conference

SPATA Foundation Family Conference

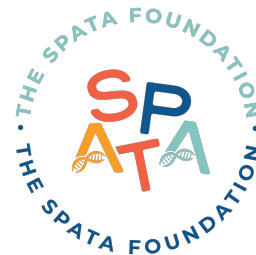


SPATA Families: 15 Families Represented

Speakers:

- Burju Sari, M.Ed., TVI | Cortical Visual Impairment
- Michael Kruer | Epilepsy & Movement Disorders + Drug Repurposing
- Tapas Mukherjee & Dana Philpott | SPATA5 and SPATA5L1 Research
- Richard Novak & Fred Vigneault | Unravel Drug Repurposing

Conference Information



Agendas: Available at each table

Additional Information: Scan QR Code on Postcards in Welcome Bag or on Tables

- Agenda, Hotel Information, Food Information, Resources, Submitting Questions, Photo Upload

We understand this is a long day and there may be times you need to step away to attend to your child.

Please feel free to step away at any time if you need to. We've tried to include multiple breaks throughout the day but understand the need to step away at times.

Changing Area & Play Area Available.

Brief Family Introductions



- **Introduce your Family & Guests**
- **Where you're from**
- **How you're connected to The SPATA Foundation (my child has SPATA5L1)**
- **What you hope to get out of today**