

Seeking Answers: Our Journey and Our Path Forward



Flora Shala



- Music
- School
- The beach
- Shapes
- The Outdoors (walking barefoot)
- Trampoline
- Big sister

My goal today is to advocate for interagency collaboration to help families like mine efficiently seek testing and answers for their children with complex, undiagnosed, or rarely diagnosed conditions.

Early Intervention- 18 months
Autism- 4 years old
Vision- 7 years old
FERRY3 Genetic Disorder- 8 years old

July 2022

July 2021



Challenges

The Diagnostic Journey

- Time and Effort
- Emotional Toll
- Financial Burden
- Lack of Awareness/Knowledge (“Rare” factor)
- Scattered Expertise (few specialized centers, not easily accessible)
- Lack of Coordinated Referrals
- Information Sharing Barriers
- Duplication of Efforts (repeated testing and evaluations)

Diagnosis

Improved Outcomes for the Child

- Targeted Interventions
- Prognosis
- Access to Research/Trials

Empowerment for the Family

- Reduced Stress
- Community and Support
- Planning for the Future
- Reduced Redundancy (repeated testing)

Support

Promoting Access to Genetic Testing

- Increased Awareness for Providers
- Advocacy Training for Parents
- Addressing Insurance Barriers
- Telemedicine/Telehealth for Consultations

Data Collection and Research:

- Tracking Diagnostic Journeys (collecting comprehensive and disaggregated data)
- Collaboration with Research Institutions



My hope is that we can prioritize initiatives that bridge the gaps in our current system, ensuring that every family in Virginia has the support and resources needed to seek testing and answers for their children.