



Kailey's Story

TOLD BY MOM



Presented By: *Mary Anne Hammond*

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PCORI EAIN-3885



Something is not quite right.....

- Normal pregnancy, delivered at 37 weeks (spontaneous labor)
- At 2 days of age, diagnosed with a moderately large VSD
- Never required surgery
- Started having major concerns by 6-9 months, not meeting milestones
- Began therapy (PT, OT) between 12-18 months of age
- Evaluated between age of 2-3 and given diagnosis of mental retardation
- At 8 years, 10 1/2 months, re-evaluated by the Autism Team and given Autism Diagnosis
- Global Developmental Delay, Profound Intellectual Disability and Severe Autism

Medications Currently Taking

1. Birth Control Pill to stop menses (skips placebo, goes to new pack @ 3 weeks)
2. Prozac – 30mg (Anxiety)
3. Nexium (Reflux)
4. Culturelle Probiotic
5. Singulair – 10mg (EG)
6. Linzess (Irritable Bowel-Constipation)
7. Intuniv – 3 mg. in morning; 1mg at bedtime (ADHD)
8. Melatonin
9. Allegra (seasonally for allergies)

Medical Diagnosis

- Severe Autism
- Ventricular Septal Defect – Cured btw ages 20-24
- Bruxism
- Eosinophilic Gastroenteritis
- Irritable Bowel – Constipation
- Reflux
- Dysphagia (requires all liquids thickened to Nectar Consistency)
- ADHD/Anxiety

What would be the benefit of Genetic studies?

1. Parents find themselves in a difficult situation especially in the case of the **non-verbal child/adult**, who has no reporting capabilities. If there could be genetic testing/indicators that would accurately determine what the best medicines to consider would be for a specific condition – that would be incredibly beneficial.
2. As it stands now, the only way we can **determine side effects** is simply behavior. This feels dangerous and risky at times.
3. If there was a way to **study drug side effects** in kids with **severe autism (e.g., nonverbal)** that would be a great relief. Or, if there was a way to **determine by genetic information what medicines they may respond to best**, so you are not simply trying and guessing.

My role as Parent led to my job as Education Coordinator for Autism at CMH

- **Kailey got me my job!** I had no desire to qualify for it, but am so happy to come to my job everyday.
- I **coordinate trainings** for professionals at Children's Mercy, professionals in the community at large, for families that have received the diagnosis of ASD, schools, etc. Sometimes I am the presenter, often I coordinate one of our professionals to speak on a specific topic.
- We cover everything from Solving the Medication Puzzle to Sleeping 101, Eating and Enjoying It, Applied Behavior Analysis, Safety, Sexuality, Dealing with Rigid and Repetitive Behavior, Transition to Adulthood, to name some.

Missouri Autism Centers (MO ACs)

1. Children's Mercy (Developmental and Behavioral Sciences), Kansas City, MO
(LEAD PI, Michele Kilo, MD)
2. MU-Thompson Center for Autism & Neurodevelopmental Disorders,
Columbia, MO
3. Knights of Columbus Developmental Center
SSM Cardinal Glennon Children's Medical Center, St. Louis, MO
4. Southeast Missouri State University Autism Center for Diagnosis and
Treatment, Cape Girardeau, MO
5. Washington University Autism Clinical Center, St. Louis, MO

2008-Present (Funded by the Missouri Department of Health)

Overall Goals (MO ACs)-Children's Mercy

1. Improve patient access to our diagnostic services
2. Enhance educational programs and community awareness

Diagnostics

- Year 1: 161
- Year 9: 494 (206% increase from Y1)
- Total Years 1-9 (2008-2016): 3,452

Education & Training

- Trainings to Students/Professional Staff (Total Served: 11,537)
- Trainings to Families (Total Served: 1,885)
- Family Resource Coordinator (2,282 Referrals/11,165 Contacts Made)

**Education
Coordinator**

