

BURDICK FAMILY

FLAGSTAFF, ARIZONA, USA



GFPD WARRIOR: EZRA GRACE

- She is currently 15 years old.
- Ezra has PEX 1 variants causing her peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- She was diagnosed at 2 years old.
- Diagnosed after having both hearing and vision deficits lead to a very long chain fatty acid test.

FAVORITE THING ABOUT EZRA

She loves to snuggle and hold hands.



FAVORITE FAMILY MEMORIES

Our Make-a-Wish trip to Hawaii when Ezra was 5. Playing in the park near our house on the swings. Going to Disneyland with Family in California. Going to Washington state to visit family.

OUR FAMILY INCLUDES

Jeremy is Ezra's dad, and Noah is Ezra's big brother, Granny Vicki, Poppy Norman, Grandpa Paul, Uncle Jonah, and cousins Sadie, Reese, and Silas.



FUN FACT: Ezra loves to go out for ice cream and French fries!

GOALS: Self feeding and using the toilet.

EZRA'S COMMUNICATION METHODS

- Communication Device
- Body Language and Movements
- American Sign Language
- Object/Tactile cards

Social, strong, and happy.

CARE TEAM INCLUDES

- Audiologist
- Dentist
- Pediatrician
- Endocrinologist
- Geneticist
- Cardiologist
- Psychiatrist
- Neurologist
- Ophthalmologist
- Physical Therapist
- Intervener
- Speech and Language Pathologist
- Occupational Therapist
- Teacher for the Visually Impaired
- Orientation and Mobility Specialist
- Teacher of the Deaf
- Special Education Teacher

The GFPD has helped our family by connecting us with other families who “get it”.



ACCOMPLISHMENTS

- Ezra is still weight bearing and can walk independently and she also continues to eat orally.
- Ezra is also very social and loves to be around other kids/adults.

POSITIVE IMPACT IN EZRA'S LIFE

Her Cochlear Implants

SYMPTOMS EXPERIENCED

- Dental Symptoms
- Hearing Loss
- Bone Abnormalities
- Vision Loss
- Cardiac Symptoms
- Low Muscle Tone
- Chronic constipation

Advice for Families: Be flexible, your child will write their own story with this disorder. Professionals will give you a prognosis, but your child will have their own timeline for everything.