MAAG FAMILY

JERSEYVILLE, IL, USA

GFPD WARRIOR: KENNA

- Kenna is currently 15 years old.
- After failing her newborn hearing screening and noticing her not tracking visually, we met with a Pediatrician who sent us to see Genetics. She was then diagnosed at age 1 with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- PEX 1 (2098insT and 2528G>A)

PRIMARY HEALTHCARE SYSTEM

St. Louis Children's Hospital

OUR FAMILY INCLUDES

- Big Sister, Clancy
- Mom, Vicky
- Dad, Shannon

FAMILY VALUES

- Faith
- Kindess
- Compassion

OUR FAVORITE THING ABOUT KENNA

The pure joy of her seeing Mommy, Daddy and Sissy. Her face lights up every time she knows we are near.

CHALLENGES

Current challenge is standing and walking. At age 2, she began walking independently and had no problems until she fell in December 2019. After this injury, we noticed her feet were no longer stable and she did not walk for 3 years until she had surgery on both feet in March 2023.

ACCOMPLISHMENTS

Despite 10 weeks in casts on both legs, she smiled through it all.

MOST POSITIVE IMPACT

Going to school!

CARE TEAM INCLUDES

- Otolaryngologist
- Physical Therapist
- Occupational Therapist
- Teacher for the Visually Impaired
- Orientation and Mobility Specialist
- Teacher of the Deaf
- Special Education Teacher
- Ophthalmologist
- Audiologist
- Pediatrician
- Dietician and/or Nutritionist
- Endocrinologist
- Gastroenterologist
- Geneticist
- Speech and Language Pathologist
- Neurologist
- Orthopedic Surgeon

The GFPD has helped my family by connecting me with other people who "get it" and giving our family hope.

GFPD GLOBAL FOUNDATION for PEROXISOMAL DISORDERS
FAMILY • RESEARCH • HOPE

SUPPORT SYSTEM INCLUDES

Kimberly Bauer, cousin, helps our family by attending many doctor appointments when Dad is not able to attend. She helps take care of Kenna as her anxiety increases as we enter the parking garage. She is also another ear to listen to the doctors and her health care background is a huge asset. Kim has attended many conferences with us as well and helps take care of Kenna so we can help with the needs of the conference.

Advice to Newly Diagnosed Families:

Lean on the GFPD for support and don't be afraid to ask for help.