CLOUSE FAMILY

CEDAR RAPIDS, IA, USA

GFPD WARRIOR: GWENDOLYN

- She is currently 5 years old.
  - Celebrating her 6th birthday on May 28th!
- She has a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- Gwendolyn was born full term but had a large fontanelle, was "floppy" and had a hard time eating.
- She was diagnosed at 4 months old.

OUR FAMILY INCLUDES

- Natalie, Gwendolyn's Mom
- Phillip, Gwendolyn's Dad
- Gideon Clouse, Brother
- Lucy Clouse, Half-Sister
- Maxwell Clouse, Half-Brother

FAVORITE MEMORY

Every morning when I put her "ears" on, I say "Good Morning Gwendolyn Iris. Mommy loves you!" and I watch her eyes light up...it is the best way to start the day!

FAVORITE ACTIVITIES

Gwendolyn LOVES to go to the pool. She is a pool rat in the summer time. She lays in the zero entry and splashes until she's exhausted!

ACCOMPLISHMENTS

- She took steps in her kid walk.
- She is learning to use tactile symbols to communicate.
- She goes to school!

CARE TEAM INCLUDES

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

The GFPD has helped our family by providing information when we first got Gwendolyn's diagnosis, providing equipment through the equipment exchange, putting me in contact with other families so that I don't feel alone, and putting me in contact with medical experts in the field. **Honestly, the GFPD is the best club I never wanted to be a part of!**

GFPD GLOBAL FOUNDATION for PEROXISOMAL DISORDERS
FAMILY • RESEARCH • HOPE

CHALLENGES

- She is blind and deaf (with cochlear implants).
- She has esophageal varices due to liver damage.
- She has a small airway.

ADVICE FOR PROFESSIONALS

My warrior is more than her diagnosis. She is my little girl, she has a personality, she has a soul, she laughs, she loves and she deserves the best you have to give!

Advice to New Families: Breathe. Enjoy your child because he/she is your child. Remember that your child is here for a purpose, just like the rest of us. Your child is a miracle just like the rest of us. Reach out for help. Don't be afraid or too proud to accept help. Enjoy every moment.