

# DAY FAMILY

SPRING HILL, TN, USA



## **GFPD WARRIOR: ANNA VIOLET**

- She was happy and determined!
- She died at the age of 4 years old.
- She had a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- She was diagnosed at 2 months old via newborn screening.
- She experienced no symptoms at birth other than being jaundice.
- Had PEX 1 variants.



#### **OUR FAMILY INCLUDES**

- Eddie Day Father
- Jennifer Day Mother
- Abby Strader 17 year old Sister

#### **FAVORITE FAMILY ACTIVITIES**

Swimming, we are all part fish!

#### **FAVORITE FAMILY MEMORIES**

Taking Anna Violet swimming and watching her play with her toys.





#### **ACCOMPLISHMENTS**

She was the happiest little girl! Her little giggles could melt any heart of stone!

#### COMMUNICATION

Body Language/Movements

#### **MOST POSITIVE IMPACT**

• Her Palliative Care team. They were absolutely instrumental in helping us give Anna Violet the life she deserved.

The GFPD has helped our family by giving us a family that knew what we were dealing with. Helping us advocate for our warrior both nationally and with her doctors. By helping her medical team when they had questions. By showing us that we weren't alone.



### **CARE TEAM INCLUDED**

- Pediatrician
- Dietician
- Endocrinologist
- Hepatologist
- Geneticist
- Neurologist

- Ophthalmologist
- Audiologist
- Hematologist
- Gastroenterologist Physical Therapist
  - Occupational
    - Therapist
  - Pulmonologist

#### PRIMARY HEALTHCARE SYSTEM

Monroe Carell Jr Children's hospital at Vanderbilt.

#### **SYMPTOMS AND CHALLENGES**

- Cognitive Issues
- Low Muscle Tone
- Kidney Issues
- GI Bleeds
- Reflux
- Adrenal Insufficiency
- Abnormal Liver Function
- Adrenal Insufficiency
- Hearing Loss
- Vision Loss
- Respiratory Difficulties
- GI Bleeds
- Feeding issues that caused Anna Violet to have a central line where she received TP.

Advice to Newly Diagnosed Families: Take it one day at a time. Ask ALL the questions. Give All the love!! Don't hold back when advocating for your warrior.