

# DRAAYER FAMILY

DES MOINES, IA. USA



## GFPD WARRIOR: WARREN

- Warren is currently 2 years old.
- Diagnosed at 11 months.
- He has a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- PEX 1 variants c.2528 G>A p.(G843D)
- Symptoms leading up to diagnosis included respiratory issues, missed milestones, growth development, and nystagmus.

## OUR FAMILY INCLUDES

- Adam Draayer (dad)
- Shannon Draayer (mom)
- Theo Draayer (brother)

## OUR FAMILY VALUES

- Kindness
- Loyalty
- Curiosity
- Optimism



## FAVORITE FAMILY MEMORIES

We love to be outside together. Pushing both boys on swings affixed to our old oak tree in the backyard, playing with light-up toys (especially light sabers), and enjoying time with our grandparents and friends.



**Silly  
Happy  
Strong  
Strong-Willed**

## ACCOMPLISHMENTS

- Eats by mouth.
- Drinking water through a straw.
- Improving in Physical Therapy.
- Using his Nimbo Walker.

## GOALS

- Standing and walking independently.
- Communicating with us through various signs and communication devices.

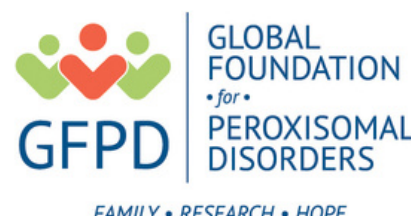
## ALL ABOUT WARREN

- Warren is very happy, smiley, and loves to laugh.
- Happiest when mom is holding him.
- He is resilient.
- Loves to explore his environment.
- He loves being outside- swinging and playing with his ride-on toys.

## SUPPORT SYSTEM INCLUDES

Immediate Family, Grandparents, Friends, My School, Unity Point Health Team

The GFPD has helped our family by connecting us with other parents and helping us understand the scope, risks, and challenges of this diagnosis. We regularly consult the posts within the Facebook group and have reached out to other parents in the group. It's helped us better understand Warren and the variety of journeys associated with his condition. It has helped us not feel alone.



## CHALLENGES

- Respiratory issues
- Hypotonia
- Unable to stand or walk on his own
- Severe hearing loss
- Does NOT like to wear his hearing aids



Advice to Professionals: Consider the whole family and balance of all the appointments, therapies, and decisions the caregivers are weighing.