

KAUFMAN FAMILY

COLUMBUS, OH, USA



GFPD WARRIOR: LOLA 'LO'

- Lola is currently 4 years old.
- At 9 months, Lo had nystagmus which led to Ophthalmology, resulting in a brain MRI and neurology.
- She was then diagnosed at age 1 with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- PEX 1 variants.

PRIMARY HEALTHCARE SYSTEM

Nationwide Children's Hospital



ABOUT US

We're a very typical family who's world was rocked by ZSD-PBD. While we would remove this disorder from existence in a heartbeat, we are so in awe of our daughter every day, and SO, SO thankful for who she is.

OUR FAMILY INCLUDES

Jake (dad), Sara (mom), Mills (little brother), Nana, Papa, Mamaw, Pappy, lots of aunts, uncles, and cousins

FAVORITE ACTIVITIES

- Taking walks together
- Going to the park to swing
- Reading books in the morning and following a very specific routine, and MUSIC.

ALL ABOUT LOLA

- She is a huge fan of sound books and loves laughing at the sounds as she turns and bends the pages.
- Loves to dance to fast-paced music.
- Reputation by Taylor Swift is her favorite album.
- Lo is not a fan of Mills, her 15-month-old brother but Mills is a fan of Lola, especially her cochlear implants!



CARE TEAM INCLUDES

- Audiologist
- Pediatrician
- Dietician and/or Nutritionist
- Dentist
- Endocrinologist
- Gastroenterologist
- Geneticist
- Neurologist
- Otolaryngologist
- Orientation and Mobility Specialist
- Ophthalmologist
- Vision Specialist
- Physical Therapist
- Occupational Therapist
- Speech and Language Pathologist
- Teacher for the Visually Impaired
- Hematologist

The GFPD is always a source of helpful perspective. For us, the group has been a wealth of information—from learning what to expect, to tips managing certain conditions, to advice on schools, toys, and equipment.



SYMPTOMS AND CHALLENGES

Deaf (now has cochlear implants), Visual Impairment, Cognitive Delays, Muscle Weakness, Peripheral Neuropathy, Adrenal Insufficiency, and a bleeding disorder. Our Lo is not yet able to walk, talk, or feed herself.

ACCOMPLISHMENTS

Selecting and touching an object upon request, Turning pages of a book, Navigating around the school playground in her kid walker, Splashing during bath time, Transitioning to a 'big kid' bed, Using a "more" button, Taking steps while wearing SMO braces.

**Every day, we're praying for GFPD Warriors and families.
Alone we are rare, together we are strong.**