TORRES FAMILY

NEW YORK, USA



GFPD WARRIOR: ELIJAH

- He is currently 27 years old.
- He has a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD).
- He was seen by Dr. Hugo Moser and Dr. Gerald Raymond and diagnosed around seven months of age.
- It took almost another 10 years to confirm PEX 1 variants.
- He is loving, a fighter and an inspiration.



OUR FAMILY INCLUDES

- GFPD Warrior, Elijah
- Elijah's 11-year-old sister, Melina.
- Dad, Erasmo and Mom, Melinda
- Three special people in Elijah's life that are no longer with us are
 - Elijah's Nana, Margarita
 - His Great Aunt Thelma
 - His Great Grandma Ernesta.

We've been blessed to have a tremendous support from family and friends.

- Elijah's Aunt, Christina, has been by our side all of Elijah's life. The bond they share is unique and special.
- Maylene has been an excellent cousin to Elijah. Their bond is also special. She has helped us with Elijah's care, and we consider her Elijah's little big cousin.



HEARING AND VISION

• He lost his hearing gradually and is now deaf and near total blind.

COMMUNICATION

• Created his own way through his body language and movements.

MOBILITY

• Went from a walker to a wheelchair.

SYMPTOMS EXPERIENCED

Seizures, Abnormal Liver Function, Low Muscle Tone, Dental Symptoms (enamel hypoplasia, delayed eruption, etc.), Adrenal Insufficiency, Hearing Loss, Vision Loss, and more.

ACCOMPLISHMENTS

- Elijah's biggest accomplishment is that he is still here with us.
- He learned to sit up on his own and scoot to move around.
- Named Prom King!
- 2021 GFPD Patient Ambassador.
- NY State Resolution for Peroxisomal Awareness Day in 2020.

CHALLENGES

 Dealing with neuropathic pain and not being able to sleep at times because of the pain.

The GFPD has helped our family by opening up the doors to access a lot more information about this disorder, giving us an extended family, and knowing that we are not alone in this difficult journey.



ELIJAH AND MELINA

Melina is a sweet, loving and amazing sister to her brother. To everyone she is Elijah's little big sister. She helps us with everything and has found a way to create a special bond with him. She loves to hug and kiss him even though he doesn't like it much. One of her favorite things she likes to do with him is hold both his hands and walk around the living room.



Advice to Professionals: When relaying a difficult diagnosis to parents, do it with empathy and support. Speak to them not in full medical terminology but instead with common words they can understand.