

# PYPER

**8 YEARS OLD  
KAPA'A, KAUA'I**

“Pyper is a cheerful 8-year-old who loves playing on the playground, swimming and dancing. Despite her challenges, Pyper’s mom Kelsie hopes that she will be able to live an independent life.”



**Pyper** is a cheerful 8-year-old girl who lives with her mom Kelsie and her older sister on the beautiful island of Kaua'i. Pyper was born full term but was found to be weak and did not eat or cry. This prompted mom to question that something may be wrong and an IV was placed. Three days after birth, the decision was made to medivac Pyper to Kapi'olani Medical Center for further evaluation. However, she had a seizure before she got on the plane and had to be stabilized prior to flying.

Upon arriving at Kapi'olani, Pyper was found to have no gag reflex and was unable to swallow, so an NG tube was placed. Mom recalls many procedures were done, including blood cultures and genetic testing and assessments. At 5 days old, Pyper received speech therapy to help with her swallowing and physical therapy to increase her strength. She was never able to nurse or drink from a bottle, so when she was a month old, Pyper had a G tube placed, which she had for three years. Pyper wasn't diagnosed with Prader Willi Syndrome until a day before she was discharged.



At 11 months old, Pyper started taking growth hormone shots, which is now a standard of care for individuals with Prader Willi Syndrome. The shots were working well but were stopped twice, once when she was a toddler and another time a few years later. These episodes caused setbacks that they have never been able to recover from since the growth hormone was





controlling everything. Pyper sees multiple specialists on O'ahu, including an endocrinologist and Michelle through the Children with Special Health Needs Program for nutrition support.

Mom recalls feelings of helplessness and denial. She did not want to acknowledge that her child had an incurable medical condition. However, mom persevered and realized that she needed to learn what she needed to do in order to care for Pyper. She took child CPR classes and learned how to feed Pyper by using the feeding machine and prepping her formula. Pyper received early intervention services, and when she aged out at 3 years old, mom met a woman who was familiar with the diagnosis and opened doors to resources. She was also diagnosed with autism and global delay at age 7 years old.

Pyper's mom credits her support team, which includes Pyper's three older siblings and their families and

numerous aunties and uncles who step in to help. Pyper attends elementary school through the Department of Education. Her hobbies include playing on the playground, swimming, dancing, singing, and walking. She also enjoys playing with dinosaurs, Spider-Man, and her baby dolls.

Mom states Pyper's biggest challenges are her behaviors and inability to feel full. Eating is always at the forefront of her mind, so mom has had to take measures in the home to prevent overeating and distract her. Mom hopes that Pyper will be able to live an independent life one day and that by sharing her story she is able to help others. Mom also hopes there will be more resources and programs for Pyper on Kaua'i.

Mom credits social media and two online resources: **fpwr.org** and **pwsausa.org**.