

NAWAI

**10 YEARS OLD
KEA'AU, HAWAI'I ISLAND**

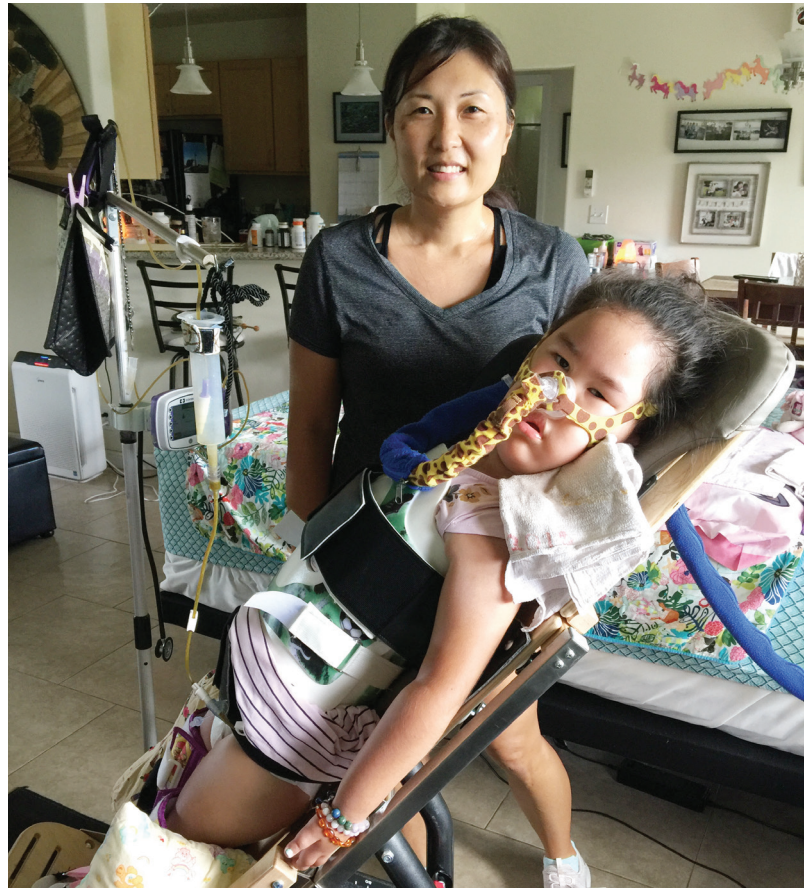
“My hope is that she can live the best life that she can. I hope that more people can see her abilities and not just her disabilities.”

- Wendy, mom



Nawai is a 10-year-old girl living with SMA (Spinal Muscular Atrophy) Type 1. She lives with her parents Jamie and Wendy in Kea'au on the Big Island of Hawai'i. She also has home health nurses.

Nawai is smart, funny, sassy and creative. She loves shopping, art, coloring and reading. At 2 months old, mom's co-workers at Hi'ilani suggested that she had hypotonia. At her two-month checkup, the doctor confirmed that she did have hypotonia and referred her to specialists on O'ahu. At the young age of 3 months, Nawai's diagnosis was found through a genetic blood test. On December 30th, mom received the call from Nawai's pediatrician, confirming her devastating diagnosis. Babies with SMA Type 1 face many physical challenges, including muscle weakness, trouble breathing, sitting, walking and swallowing. Since then, SMA has been put on the newborn screening in Hawai'i and there now are treatments available for SMA. These were only in trial when she was diagnosed.



I have learned so much over these past 10 years. Nawai was admitted to Kapi'olani MCWC in 2015, where she stayed for three months. I learned a lot of her medical care while she stayed in the PICU. My feelings have changed over the years since her diagnosis. I still pray for a miracle of healing, but I now have a sense of gratitude to God for allowing us to be her parents and embarking on the journey as a family.

A typical day at Nawai's house: dad goes to work and mom stays home. Most days we have a nurse, some days we don't. I help her with online schooling, while the nurse does her daily care, cleans her supplies and makes her formula. When we have nursing, I make time to exercise, do chores, cook dinner and run errands. We love weekends because we can fit in fun activities and outings. Her condition causes us to be cautious of germs and sick people. Ways we have adapted: She does most of her schooling online and goes on campus once a week (mostly for social interactions). We do attend social activities but leave if someone is sick or shows signs of being sick.

Our greatest supports over the years have been: her PCP Dr. Choy, pulmonologist Dr. Wu, Easter Seals, Children with Special Health Needs, home health nursing, Biogen, Shriners, Walter's Electric, Hawaii Sheet Metal, and the Laulima Program. Online resources that are most helpful are the parent support groups for children with disabilities.

My hope is that she can live the best life that she can. I hope that more people can see her abilities and not just her disabilities.

Moments of strength: When she was sick and I wasn't sure if she would make it, but then she recovered! Preparing for a medical procedure is always stressful, but we're so grateful when the recovery goes smoothly.

Moments of joy: When she was approved to begin receiving treatment for SMA. Our community did a fundraiser for our family. We were able to buy a



handicapped accessible van with money raised. She received her wish from Make-A-Wish. Walter's Electric donated and installed a PV system and batteries to run her medical equipment and lower our electric bill. When we appealed HMSA's denial for her medication/treatment, it went to an outside review and was approved!

Accessing healthcare is an issue because all of the pediatric specialists are on O 'ahu. But I feel like projects like this, Our Mo 'olelo, help bring light to the complex lives we live, the struggles we face, and possibly access to more support.

Advice for other families of children with disabilities: I know it's tiring being a mom and extra tiring being a medical mom. Somehow we were chosen for this task. All we can do is our best. You are your child's best advocate, so don't be afraid to fight for what's best for your child. Make time to take care of yourself. If you're not well, you won't be able to care for your child. We need to give ourselves grace as we navigate life.