

# When You Advocate For Your Needs

Kaui R. - Ewa Beach, Oahu, Hawaii



*"We would not be able to do this without Medicaid."*

*That's Medicaid shares stories of people covered by Medicaid at critical points in their lives, underscoring the importance of stable health insurance coverage in building a Culture of Health.*

**Kaui's** daughter is 17 years old now, but shortly after being born she was diagnosed with type-1 spinal muscular atrophy (SMA), a rare disease in which children often die within two years because of weakness and wasting in the voluntary muscles.

According to the Cleveland Clinic it is one of the most common genetic conditions affecting children and it is estimated that one in every 6,000 to 10,000 babies worldwide is born with SMA.

While the news of their daughter's disability was devastating in itself, Kaui and her husband feared the needed care would be beyond their means. They soon applied for Medicaid but were denied the first time because of their assets. After a follow-up effort they were approved for

a waiver because of the nature of the disease under Hawaii's program, which provides case management, habilitation and a health aide, as well as specialized food, a ventilator, and a wheelchair.

Kaui now uses that persistence as a parent-advocate for a local organization, helping others obtain crucial health services and, as she says, "do what is best for their child."

The job also offers relief during the pandemic because she and her husband are able to work from home, care for their daughter, and manage telehealth visits. It is all part of the support the federal-state program has provided her family.

"We would not be able to do this without Medicaid," she says.