

AVA

**21 YEARS OLD
'EWA BEACH, O'AHU**

“Ohana means family...family means
no one gets left behind or forgotten.”

- Lilo and Stitch (2002)



Meet **Ava-Isabel**, Mom Kau'i and Daddy Jason...We are the Rezentos 'Ohana.

Beautiful and spunky, Ava is an almost 22-year-old diagnosed with Spinal Muscular Atrophy, Type I (SMA, Type I) or Werdnig-Hoffmann Disease. When she was born, we knew she would do great things but life had not prepared us for the ride we were on. Ava was diagnosed at the age of 5 1/2 months, and at the time, we were told it was basically a death sentence. She would not live to see her second birthday and possibly her first birthday. We were devastated. This beautiful little human we created could soon be taken away from us. A few days after her diagnosis, we ended up in the hospital battling her first cold and spending the next six months navigating the healthcare system, trying to figure out how to pay our mortgage and survive in Hawai'i on just one income. I, mom, was already staying home from work to learn all aspects of Ava's care. Dad slept in the car at night to be near us, then headed to work in the mornings and gigs on the weekends.

We were connected to the right Case Manager who helped us create a care map and care plan that would guide Ava to excellence. She liked the way I spoke with the doctors and advocated for Ava's needs while in the hospital. She introduced me to another Mama, another Advocate Warrior, that was writing for a grant to help others navigate the healthcare system for our medically fragile kiddos. I was fortunate to work with these awesome Mana Wahine (Strong Women) and continue to help other families navigate the system. Being surrounded by amazing leaders and making contacts in our State Programs helped us to know exactly what we NEEDED, what we WANTED, and HOW we could BEST advocate for Ava's needs.

As Ava transitions to adulthood, although we have been preparing for these moments for years, it has not come without its hurdles. We have made some mistakes along the way, but with the help of our case managers and some programs, we are once again navigating to see how we can BEST advocate for her needs in this new season of her life. We are figuring out slowly what she NEEDS now and what we WANT for her to achieve an amazing quality of life.

One of the biggest hurdles has been trying to rebuild our nursing team. Since COVID, we have lost most of our team due to scheduling conflicts and the demand for staffing in hospitals has increased. Working outside the home has been difficult, but Mom and Dad have made it work by tag teaming.

As a family, we realize life is always changing. There are many moving parts to making it work, and we know the importance of communication and compromise will be what pulls us through the many more obstacles we may face.



E hālāwai me Ava-Isabel, ka makuahine 'o Kau'i a me ka makua kāne 'o Jason... 'O mākou ka 'Ohana Rezentes.

He u'i a ikaika 'o Ava, kokoke i ka 22 o kona makahiki, ua loa'a iā ia ka ma'i Spinal Muscular Atrophy, Type I (SMA, Type I) a i 'ole Werdnig-Hoffmann Disease. I kona hānau 'ana, ua mana'o mākou e hana 'o ia i nā hana nui, akā 'a'ole mākou i mākaukau no kēia huaka'i. Ua loa'a ka 'ike ma'i iā Ava i kona 5 1/2 mahina, a ua ha'i 'ia mai iā mākou, he ho'ohālikelike ia i ka make koke 'ana. 'A'ole e ola 'o ia a hiki i ka lā hānau 'elua, a paha i ka lā hānau mua. Ua ho'owahāwahā loa mākou. Ua loa'a iā mākou he keiki u'i, a ua hiki ke lawe 'ia akula mai iā mākou. I kekahi mau lā ma hope o ka 'ike ma'i 'ana, ua komo mākou i ka haukapila no kona ma'i anu'u mua, a noho mākou i laila no nā mahina 'eono, e ho'okele ana i ke 'ōnaehana olakino, a e nānā pehea e uku ai i ka uku home a e ola ana i Hawai'i me ho'okahi wale nō loa'a kālā. 'O wau nō ka makuahine, ua noho au i ka home e a'o i nā mea a pau e pili ana i ka mālama 'ana iā Ava. Ua hiamoe ka makua kāne i loko o ke ka'a i ka pō e noho kokoke iā māua, a hele i ka hana i ke kakahiaka, a hana i nā hana 'ē a'e i nā hopena pule.

Ua ho'okomo 'ia mākou i ke kahu mana kūpono nāna i kōkua iā mākou e hana i palapala mālama a palapala alaka'i e ho'okō ai i ka maika'i loa no Ava. Ua makemake 'o ia i ka 'ano o ko'u kama'ilio 'ana me nā kauka, a me ka kūpa'a 'ana no nā pono o Ava i ka haukapila. Ua ho'okomo 'o ia ia'u i kekahi makuahine 'ē a'e, he koa ho'i, e kākau ana no ka kālā kōkua e kōkua i nā 'ohana 'ē a'e e ho'okele i ke 'ōnaehana olakino no kā mākou mau keiki palupalu.

Ua pōmaika'i wau i ka hana pū 'ana me kēia mau Mana Wahine kupaianaha a ho'omau i ke kōkua 'ana i nā 'ohana 'ē a'e. Ma ka noho 'ana me nā alaka'i kupaianaha a me ka hana pū 'ana me nā papahana aupuni, ua 'ike mākou i nā mea i PONO AI mākou, nā mea i MAKEMAKE AI mākou, a PEHEA e kūpa'a AI mākou no nā PONO o Ava.



Ke ne'e aku nei 'o Ava i ke 'ano o ka nui 'ana, a 'oiai ua ho'omākaukau mākou no kēia manawa no nā makahiki he nui, 'a'ole i hala 'ole kēia hele 'ana me nā pilikia. Ua hana mākou i kekahi mau hewa i ke ala, akā me ke kōkua o kā mākou mau kahu mana a me kekahi mau papahana, ke ho'ā'o hou nei mākou e 'ike i ke ALA kūpono no kāna pono i kēia wā hou o kona ola. Ke ho'omaopopo mālie nei mākou i nā mea e PONO AI 'o ia i kēia manawa, a me nā mea makemake mākou e ho'okō ai i ka nohona maika'i loa nona.

'O kekahi o nā pilikia nui loa, 'o ia ka ho'ā'o hou 'ana e kūkulu hou i kā mākou hui nursi. Mai ka wā o ka ma'i ahulau COVID, ua nalowale ka hapanui o kā mākou hui no ka pilikia o nā papa manawa a me ka pi'i 'ana o ka makemake no nā limahana i nā haukapila. Ua pa'akikī ka hana 'ana i waho o ka home, akā ua hiki iā Māmā lāua 'o Pāpā ke mālama i ka hana me ka 'apo pū 'ana.

Ma ke 'ano he 'ohana, ke ho'omaopopo nei mākou he mau loli ke ola. He nui nā mea e ne'e ana e ho'okō ai i kēia mea, a 'ike mākou 'o ka pili kama'ilio 'ana a me ka 'ae 'ana kekahi i kekahi ka mea e huki ai iā mākou i nā pilikia e hiki mai ana.