OUR MO‘OLELO
STORIES OF
STRENGTH, LOVE & RESILIENCE

KO KĀKOU MO‘OLELO:
NĀ MO‘OLELO O KA
IKAIKA, KE ALOHA, A ME KA ‘ŌPŪ ALI‘I

PĀ'ANA KA LĀ NO NĀ KEIKI
SUNSHINE FOR CHILDREN

HAWAI‘I STATE DEPARTMENT OF HEALTH
CHILDREN WITH SPECIAL HEALTH NEEDS BRANCH
JULY 2025

JULY 15, 2025

Aloha,
Navigating the journey of caring for a child with special health needs is a path filled with many challenges, triumphs, and profound moments of growth. Each family's experience is unique, yet they all share a common thread of love, resilience, and hope.

This booklet is a collection of moʻolelo shared by families of children with special health needs throughout Hawaiʻi. Some families shared their moʻolelo in their family's heritage language, honoring the rich and vibrant expressions of culture within our community. Within these pages, you'll find honest reflections, hard-won insights, and moments of both struggle and strength. Each moʻolelo is a powerful reminder of the strength found in ʻohana and in the connections we build along the way. To celebrate these stories, families also participated in a joyful photoshoot, capturing the spirit of their ʻohana.

We hope these moʻolelo bring comfort, nurture connection, and deepen understanding—whether you're a fellow parent or caregiver, a healthcare provider or agency, a community organization, an advocate, a government agency serving children, or simply someone who wants to learn.

Mahalo to the families who so courageously opened their hearts to share their moʻolelo. May their stories inspire empathy, spark dialogue, and remind us all that we are never alone on this journey.

With lots of aloha,
The CSHNB ʻOhana

IULAI 15, 2025

Aloha,
ʻO ka huakaʻi o ka mālama ʻana i ke keiki me nā pono olakino kūikawā he ala piha i nā pilikia, nā lanakila, a me nā manawa hohonu o ka ulu ʻana. He kū hoʻokahi ka ʻike o kēlā me kēia ʻohana, akā, ʻoukou a pau e paʻa ana i ke kaula like o ke aloha, ka ʻōʻōpū aliʻi, a me ka manaʻolana.

He hōʻiliʻili kēia puke liʻiliʻi o nā moʻolelo i kaʻana ʻia e nā ʻohana o nā keiki me nā pono olakino kūikawā ma Hawaiʻi a puni. Ua kaʻana kekahi mau ʻohana i kā lākou moʻolelo ma ka ʻōlelo hoʻoilina o ko lākou ʻohana, e hoʻohanohano ana i ka waiwai a me ka nohona ʻōlelo o loko o ko kākou kaiāulu. I loko o kēia mau ʻaoʻao, e ʻike ana ʻoukou i nā noʻonoʻo kūpaʻa, nā ʻike i loaʻa me ka paʻakikī, a me nā manawa o ka pilikia a me ka ikaika. He hoʻomanaʻo ikaika kēlā me kēia moʻolelo o ka ikaika i loaʻa i loko o ka ʻohana a me nā pilina a mākou e kūkulu ai ma ke ala. No ka hoʻolauleʻa ʻana i kēia mau moʻolelo, ua komo pū nā ʻohana i kahi pana kiʻi hauʻoli, e hopu ana i ka ʻuhane o ko lākou ʻohana.

Manaʻo mākou e lawe mai kēia mau moʻolelo i ka ʻoluʻolu, e hānai i ka pilina, a hohonu i ka ʻike—ina paha he makua ʻē aʻe ʻoe a he kahu mālama paha, he mea lawelawe olakino a he keʻena paha, he hui kaiāulu, he mea kākoʻo, he keʻena aupuni e lawelawe ana i nā keiki, a i ʻole he kanaka wale nō e makemake ana e aʻo.

Mahalo i nā ʻohana i wehe wiwo ʻole i ko lākou mau naʻau e kaʻana i kā lākou moʻolelo. Na kā lākou moʻolelo e hoʻoulu i ka naʻauao, e hoʻā i ke kūkākūkā, a e hoʻomanaʻo iā kākou a pau ʻaʻole mākou e hoʻokahi wale nō ma kēia huakaʻi.

Me ke aloha nui,
Ka ʻOhana CSHNB

JOSH GREEN, M.D.
GOVERNOR OF HAWAIʻI
KE KIAʻĀINA O KA MOKUʻĀINA ʻO HAWAIʻI

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In reply, please refer to:
File:

July 15, 2025

Aloha mai kākou,

It is with heartfelt aloha that I invite you to immerse yourself in the *Moʻolelo* Story Book.

In Hawaiian culture, *moʻolelo*—from *moʻo* (succession) and *ʻōlelo* (speech or language)—is more than storytelling. It is how generations have passed down knowledge, preserved family history, and strengthened identity. These stories are vital—they teach, heal, and connect us.

In this book, you will find 12 powerful *moʻolelo* shared by Hawaiʻi families of children and youth with special health needs. Through their voices and images, they invite us into their lives—to witness their resilience, love, and the everyday challenges and triumphs they experience.

These stories do more than inform. They open our hearts and minds. They help service providers like us better understand the real experiences families face when navigating care and support systems. They remind us that each child's journey is unique, and each family's wisdom is invaluable.

Storytelling in this context is not simply about reflection—it's a tool for change. It encourages compassion, reveals gaps in systems, and points us toward more responsive and respectful care. It honors the lived experiences that other data alone cannot capture.

As you read these 12 family *moʻolelo*, I invite you to be open to learn, being mindful of their respective journey, and always with aloha. May their shared experience inform your work, inspire your spirit, and deepen your commitment to supporting Hawaiʻi keiki and their ʻohana.

Me ke aloha pumehana,

Ruben Frescas, Jr., MD, MPH, FAAFP
Chief, Children with Special Health Needs Branch
Hawaiʻi State Department of Health

SIGNIFICANCE OF MO‘OLELO

The word Mo‘olelo comes from:

Mo‘o – meaning succession or series
‘Ōlelo – meaning speech or language

In Hawaiian culture, Mo‘olelo served as the primary way to pass on knowledge through oral history. ‘Ohana shared their **mo‘okū‘auhau** (genealogies), historical events, and other stories through oral storytelling to ensure their lineage and traditions were never forgotten. Mo‘olelo is more than just storytelling—it's a way to preserve family history, share wisdom and values, and strengthen a family's identity.

* * *

‘O ka hua‘ōlelo Mo‘olelo mai:

Mo‘o – ke ‘ano o ka ho‘oilina a i ‘ole ka mo‘okū‘auhau
‘Ōlelo – ke ‘ano o ka ‘ōlelo a i ‘ole ka ‘ōlelo ‘ana

Ma ka mo‘omeheu Hawai‘i, ua lilo ka Mo‘olelo i ala nui e ho‘oili ai i ka ‘ike ma o ka mo‘olelo waha. Ua ka‘ana ‘ia e ka ‘ohana ko lākou **mo‘okū‘auhau** (mo‘okū‘auhau), nā hanana mō‘aukala, a me nā mo‘olelo ‘ē a‘e ma o ka mo‘olelo waha e hō‘oia i ko lākou lāhui a me nā loina ‘a‘ole e poina. ‘Oi aku ka nui o ka Mo‘olelo ma mua o ka mo‘olelo wale nō—he ala ia e mālama ai i ka mō‘aukala ‘ohana, e ka‘ana i ka na‘auao a me nā waiwai, a e ho‘oikaika i ka ‘ike o ka ‘ohana.

Hiki i ka ka‘ana ‘ana i nā mo‘olelo o nā ‘ohana ke loa‘a ka hopena hohonu a me ka mana‘o nui, ‘a‘ole wale ma luna o nā ‘ohana iho, akā, ma luna pū nō ho‘i o ke kaiāulu ākea. Ke ka‘ana aku nā ‘ohana i ko lākou ‘ike, hiki ke hana i nā pilina, e kūkulu i ka na‘auao, a e hā‘awi i ke kāko‘o.

INTRODUCTION/PURPOSE

Sharing families’ mo‘olelo can have a deep and meaningful impact, not just on the families themselves, but also on the broader community. When families share their experiences, it can create connections, build understanding, and provide support.

Here’s how sharing your story makes a difference:

- Help inform and educate service providers (who may or may not have firsthand knowledge) about families’ experiences with accessing services for children and youth with special health needs.
- Help bring people together to heal and to create understanding.
- Teach others about the love and challenges of caring for children and youth with special health needs.
- Show children and youth with special health needs a way to see their own strengths.
- Guide other ‘ohana who are on a similar journey.

In the next few pages, you will read the mo‘olelo of families. These stories—told in their own words and accompanied by photos—give you a glimpse into their journeys. As you read, we invite you to share in their aloha and reflect on the strength and wisdom they have gained along the way. May their stories and photos inform, inspire, and uplift you.

Eia kekahi mau ala e hana ai ka ka‘ana ‘ana i kāu mo‘olelo i ka ‘oko‘a:

- Kōkua i ka ho‘omaopopo a me ka ho‘ona‘auao ‘ana i nā mea lawelawe (nā mea hiki ke ‘ike maka ‘ole) e pili ana i ka ‘ike o nā ‘ohana me ka loa‘a ‘ana o nā lawelawe no nā keiki a me nā ‘ōpio me nā pono olakino kūikawā.
- Kōkua i ka ho‘ohui ‘ana i nā kānaka, e ho‘ōla, a e hana i ka na‘auao.
- E a‘o i nā mea ‘ē a‘e e pili ana i ke aloha a me nā pilikia o ka mālama ‘ana i nā keiki a me nā ‘ōpio me nā pono olakino kūikawā.
- Hō‘ike i nā keiki a me nā ‘ōpio me nā pono olakino kūikawā i ala e ‘ike ai i ko lākou mau ikaika iho.
- Alaka‘i i nā ‘ohana ‘ē a‘e e hele ana ma ka huaka‘i like.

Ma nā ‘ao‘ao e hiki mai ana, e heluhelu ana ‘oukou i nā mo‘olelo o nā ‘ohana. E hō‘ike ana kēia mau mo‘olelo—i ha‘i ‘ia ma ko lākou mau ‘ōlelo pono‘ī a me nā ki‘i pū—i kahi nānā i ko lākou mau huaka‘i. Iā ‘oukou e heluhelu ai, ke kono aku nei mākou iā ‘oukou e ka‘ana i ke aloha a me ka no‘ono‘o i ka ikaika a me ka na‘auao i loa‘a iā lākou ma ke ala. Na kā lākou mo‘olelo a me nā ki‘i e ho‘omaopopo, e ho‘oulu, a e ho‘āla iā ‘oukou.

JAXSTON DRAI

15 YEARS OLD
KAUMAKANI, KAUAʻI

> "Jaxston Drai has the biggest, most infectious smile that lights up any room he enters. He loves to go to school, be surrounded by his classmates, and listen to Steve Harvey from the Family Feud."
>
> - Jackie, mom

Jaxston Drai is a 15-year-old who lives with his mother Jackie and maternal grandparents on the beautiful island of Kauaʻi. Jaxston Drai was born with cerebral palsy and epilepsy. When he was very little, he had a hard time gaining weight and was constantly getting pneumonia. He was eventually diagnosed with severe Gastroesophageal Reflux and changed from gastrostomy feedings to jejunostomy feedings, which helped tremendously. He also needed to get a tracheostomy to assist with his work of breathing. Jaxston Drai has the biggest, most infectious smile that lights up any room he enters. He loves to go to school, be surrounded by his classmates, and listen to Steve Harvey from the Family Feud. In 2016, Jaxston Drai got his Make-A-Wish granted and had his entire family (along with cousins) go to Maui and visit the Maui Ocean Center!

Jackie is a single mom and remembers the shock of learning that her unborn son was going to have a disability. Through the years after Jaxston Drai was born, Jackie has felt that trying to get the services and help that he needs has been a nonstop roller coaster. However, Jackie has not been daunted and rose to the occasion multiple times, thinking out of the box when Jaxston Drai needed items that she could not get help with, specifically a wheelchair van and a wheelchair ramp. Jackie did some online research and was blessed to meet Bob and Pam Serr from the Paisley Mae

Foundation, who helped her start a GoFundMe and a nonprofit charity to raise funds for the wheelchair van. They finally got their van on July 2023! Jackie and Jaxston Drai's home on Kaua'i did not have a wheelchair ramp, and Jackie serendipitously came across a wheelchair ramp on Facebook, where a family generously donated the ramp to Jaxston Drai.

Jackie admits that the journey with Jaxston Drai has been hard but acknowledges help that she received along the way…like from Holly Pickens from the Aloha Independent Living Hawai'i Program, who helped her get paid from his insurance company to be his caretaker, and from the various workers from the Hawai'i Department of Health Children with Special Health Needs Program. Jackie doesn't really know what the future holds, but she knows that with the help of her family and friends, things will work out in the end.

* * *

Ni Jaxston Drai ket 15 anios ken kabbalay ni Jackie a nanangna ken ti lolo ken lolana iti ina iti nagpintas nga isla ti Kaua'i. Nayanak ni Jaxston Drai nga addaan cerebral palsy ken epilepsy (kissiw). Idi bassit pay, saan a lumuklukmeg ken kanayon nga ag-pneumonia. Idi agangay, nadayagnos nga adda nakaro a Gastroesophageal Reflux-na isu a nagbaliw ti kankanenna manipud pang-gastrostomy a nagbalin a pang-jejunostomy, ket dakkel ti naitulong dayta. Kinasapulanna met ti agpa-tracheostomy tapno matulongan nga aganges. Ngem nakais-isem ni Jaxston Drai ket dayta ti mangparagsak iti aniaman a klase a sumrekanna. Magusgustuanna ti ageskuela, makikadua kadagiti klasmeytna, ken agbuya iti show ni Steve Harvey iti Family Feud. Idi 2016, gapu ta napatgan ti Make-A-Wish ni Jaxston Drai, nakapan isuna ken ti intero a pamiliana (agraman dagiti kasinsinna) iti Maui ket binisitada ti Maui Ocean Center!

Agsolsolo nga ina ni Jackie ket malagipna a nakigtot idi naammuanna nga adda diperensia ti di pay naipasngay nga anakna. Bayat ti tawtawen kalpasan a nayanak ni Jaxston Drai, kasla di agsarsardeng ti panagdanag ni Jackie iti panangikagumaanna a mangala kadagiti serbisio ken tulong a kasapulan ni Jaxston Drai. Ngem saan a nagbuteng ni Jackie ket namin-adu a sinangona ti problema, isu a nangpanunot iti posible a pamay-an no adda bambanag a kasapulan ni Jaxston Drai nga awan ti pagpatulongan ni Jackie, nangnangruna iti van ken rampa para iti wheelchair. Nag-research ni Jackie iti online ket nagsayaat ta naam-ammona da Bob ken Pam Serr manipud Paisley Mae Foundation, nga isuda ti timmulong kenkuana a mangirugi iti GoFundMe ken di-aggangganansia a charity nga agkalap iti pondo para iti van ken rampa ti wheelchair. Naaddaanda met laeng iti van idi Hulio 2023! Awan ti rampa ti wheelchair iti pagtaengan da Jackie ken Jaxston Drai iti Kaua'i. Nagasat ni Jackie ta nakabirok iti rampa ti wheelchair iti Facebook, isu a naited kas donasion ken Jaxston Drai dayta a rampa.

Inamin ni Jackie a narigat ti situasion ni Jaxston Drai ngem agyamyaman kadagiti tulong a naawatna …kas ti tulong ni Holly Pickens manipud Aloha Independent Living Hawai'i Program, a timmulong kenkuana nga agbayad iti insurance company ni Jaxston Drai ken agbalin nga agaywan kenkuana, ken ti nadumaduma nga empleado ti Children with Special Health Needs Program ti Hawai'i Department of Health. Di ammo ni Jackie no anianto pay dagiti mapasamak, ngem ammona a babaen ti tulong ti pamilia ken gagayyemna, addanto met laeng solusion ti bambanag.

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**.

AKONI

3 YEARS OLD
MĀ'ILI, O'AHU

> "All of the people we encountered on our journey and their compassion for our family gave me strength to be a strong advocate for our children, which aided in their success."
>
> - Asahel, mom

My name is Asahel, and I am the mother of a 3-year-old boy named **Akoni**. When he was around 5 months old, I began to notice signs that he wasn't developing at the same level of his peers. Since my other two children had special needs, this likely made me more aware that Akoni wasn't meeting his milestones on time. Being this wasn't my first experience, I already knew what was to come. At least that's what I thought at the time.

My other children were close in age, so I was able to navigate the second child's process quicker. If I'm being honest, I had no clue with my firstborn. I had only heard the word "autism" a few times and didn't even understand that fully. Multiple people began saying, "Have you ever considered he may be autistic?" I then began to research the topic and started to believe the possibility but still had some doubts. Later, I was told by another mom to call Early Intervention. This was a program I had never heard of before.

My oldest son started with Early Intervention in California at 2 years old and was diagnosed as autistic with speech delay by the psychologist. Through the EI program, we were enrolled in a center-based special needs school. There, I attended with him three days a week for four hours. So, when I started to notice signs of delay with my daughter, I immediately began the same process. She was later diagnosed with Global Developmental Delay. We were also enrolled at the same school as my son by the EI program. There, both my children excelled and were later transferred to the school district. As you can see, I just assumed it would be the same process with Akoni.

I seemingly forgot the main rule of thumb of being a parent of a special needs child: “Each child is different and don’t compare.” See, I just thought I would walk through this process easy as I had done prior. I assumed Akoni would be diagnosed with autism with speech delay as my other son. I knew there were different levels of autism, but nothing could have prepared me for the challenges I would face with Akoni’s symptoms and behaviors. He had a unique set of needs that would require me to do a lot of research and get way more services than I had done with my other children. However, I was now in a different state and had different insurance. The process and programs were different.

Navigating the process for services for Akoni here in Hawaiʻi was difficult at first. I was initially denied by Early Intervention. I experienced long wait periods due to limited staffing and had gaps in services. Nevertheless, it all came together slowly but surely. By staying determined to help my youngest succeed, he eventually received EI Services, which included: speech, SPED, nutrition, psychology, and later PBS. He also received OT and ABA services through Kaiser. Unfortunately, there was no center-based program in Waiʻanae. So, utilizing the experience I had received in California with my other children, Dexter and Noelani, I was able to replicate a system of a center-based program with Keiki Steps and Ka Paʻalana Preschool. Fortunately, with their kindness and sympathy for our situation, I was able to have our RBT (Registered Behavior Technician) attend daily with us at both programs. In using all of my experience and knowledge and remaining determined, I truly believe this is what helped our children succeed. All of the people we encountered on our journey and their compassion for our family gave me strength to be a strong advocate for our children, which aided in their success.

NAWAI

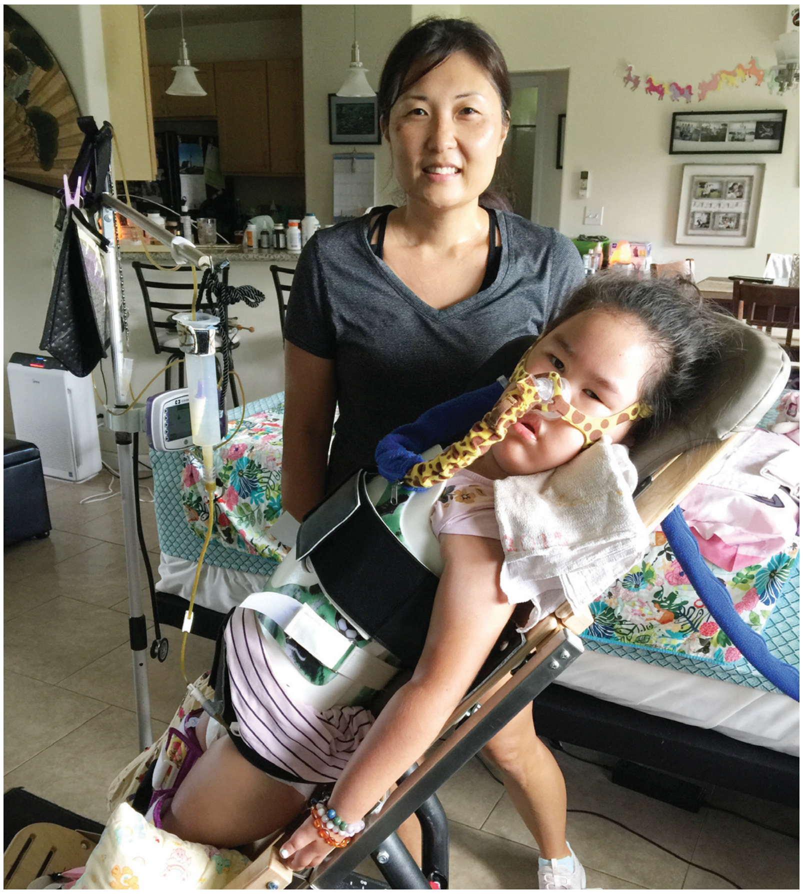
10 YEARS OLD
KEA'AU, HAWAI'I ISLAND

"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 Kapiʻolani 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 ʻahu. But I feel like projects like this, Our Mo ʻolelo, 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.

MICKY

7 YEARS OLD
‘ĀINALOA, HAWAI‘I ISLAND

“Assistive technology is being introduced, and our hope is that a tablet he controls with his eyes, in addition to a wheelchair he controls with his head movements, will let him speak for himself in all moments with all people. Watching Micky learn to use this tech and realize he can participate in his environment are the best parts of our day.”

- Grace & Eamon, mom & dad

Our story is one of confluence. We, Grace and Eamon, had our story, and **Micky** had his, until we found each other.

We came to Hawai’i to teach in 2019, only months before the COVID-19 Pandemic. We knew we wanted to adopt a child with a disability at some point but needed time to settle in. We hadn’t yet registered with the state of Hawai’i to be Resource Caregivers—a foster family—when a friend who knew our eventual goal of adoption forwarded us a phone call. There was a child, 2 years old, who needed placement as soon as possible, but the severity of his disability and the absence of a capable and willing biological family were making it difficult to find him a home. We told the state we’d like to meet him.

Micky was born at 24 weeks, three months premature, with a Level II brain bleed and addictions to the drugs his birth mother had been taking while pregnant. She had no interest in keeping him. After four months in the NICU, he was released into the care of the people we now call Mama Gina and Papa Jamie, a foster family with 25 years of experience in caring for infants with disabilities. Micky was loved from their first minute together. Gina and Jamie gave him every opportunity to grow and learn and love. By the age of 2 years, Micky’s physical disability and global cognitive delay were clear, along with his need for a permanent home.

The first time we saw Micky was on a screen alongside several other faces, members of his care team, all Zooming in from home. Gina held the camera above Micky’s face as he lay on a pile of blankets. The conversation was about all of us in turn—Micky and his capabilities and needs, us and our capabilities and needs, and the legal team from the state and their matchmaking. At our house, we were already imagining a life with this beautiful child. It took a year for us to save money and find a place to live where Micky could join us. It then took another year of fostering before we could adopt him, which was one of the greatest days of our lives and an anniversary we still celebrate.

As an adoptive family, we didn't go through the shock of learning a diagnosis after we met our child; we knew his diagnosis first and never hoped for another situation. But on the Big Island, we are isolated away from family, from prompt medical care, and from the community that would otherwise rise around kids like ours and their families. Instead, we have found online forums for parents of kids with CP to be valuable and connective sources of hope and normalcy from around the world. We get tips and resources from them, trade used equipment, and offer services, like the family that makes custom washable adult-size swim diapers or the family that offered us a nebulizer to borrow when we forgot ours when traveling in their area. They give advice on recovery from surgeries, celebrate birthdays, and boost morale when one of us doesn't know how to keep going. We would not have as healthy an experience as parents as we have without these online havens.

Today, Micky is 7 years old, tall and big for his age, with a booming voice that fills the room. He loves swimming, reading, joyriding, and listening to music. He especially loves going to school, where he socializes with other kids with and without disabilities and learns to navigate his world. He loves circle time and singing and dancing, focuses hard in English and reading, and often cries through math. He is accepted by his peers and pushed to learn alongside them. The key to his education has been unlocking his communication with those around him. Micky is nonverbal and has only slight control of his hands, making sign language impossible. Instead, he uses his eye gaze to direct others' attention to what he wants or chooses or understands. Assistive technology is being introduced, and our hope is that a tablet he controls with his eyes, in addition to a wheelchair he controls with his head movements, will let him speak for himself in all moments with all people. Watching Micky learn to use this tech and realize he can participate in his environment are the best parts of our day.

ANGEL

19 YEARS OLD
PUKALANI, MAUI

> “Our kids depend on us. They show us how strong we truly are.”
>
> - Margarita, mom

“I’m ready to take my photo!” 19-year-old Angel exclaims with the enthusiasm of a young child. He carefully uses his walker to approach his mother Margarita at the table and transfers to his wheelchair. “What’s taking so long?” Angel asks. Margarita laughs, “You’re ready, but you have to wait for everyone else.”

Angel was born in Guatemala. In 2006, 17-year-old Margarita fled to the United States with her infant Angel, seeking asylum to escape war. They joined family members living in Maui, Hawai‘i. Margarita didn’t speak any English and worked hard cleaning homes. She found immigration guidance from community organizations that had language access.

In 2007, Margarita had another child. This brought public health services into their home. A bilingual social worker, visiting for her newborn, noticed Angel’s developmental delays—he wasn’t yet walking or talking at 2 years old. Angel was diagnosed with Cerebral Palsy. As an immigrant, Angel did not qualify for federal health insurance. Margarita could sometimes pay for health insurance for basic care.

Margarita credits the aloha spirit for supporting their family. School and nonprofit programs like Special Olympics connected them with other special needs families for social activities and sharing of resources, like diapers, outgrown wheelchairs and childcare. A connection to others and a space for social activities brought joy and inclusion into Angel’s life. Margarita shared, “Angel’s first language was English! To help him and to help those professionals trying to help us, I had to learn English, too.”

Access to specialty medical care was a challenge. Fortunately, a couple of outreach clinics like Shriners Children’s Hospital and Kapi‘olani Medical Center specialists came to Maui a few times a year, but most of Angel’s appointments required travel to the island of O‘ahu. It typically took his parents a whole day of travel to get Angel, his wheelchair, his walker, and his supplies onto the plane and into a taxi to complete an appointment and then return home. His mother also needed to be prepared for possible travel delays due to weather or airport security delays due to their immigration status.

Margarita reflects, “For families still in the dark days of caregiving, don’t give up. Our kids depend on us. They show us how strong we truly are.”

Nearly 20 years after arriving in Hawai‘i, Margarita earned her Certified Nurses Aid license. She diligently kept detailed records of Angel's health and education to submit to U.S. immigration. In 2023, both she and Angel became U.S. citizens. Now, Angel can access benefits that may help him as an adult with special needs.

"What's taking so long?" Angel asks. Margarita laughs, "You're ready, but you have to wait for everyone else."

Finally, the family gathers for their proud picture day.

"¡Estoy listo para tomar mi foto!" Ángel de 19 años exclama con el entusiasmo de un niño pequeño. Usa cuidadosamente su andador para acercarse a su madre Margarita en la mesa y se traslada a su silla de ruedas. —¿Por qué tarda tanto? —pregunta Ángel. Margarita se ríe: "Estás lista, pero tienes que esperar a todos los demás".

Ángel nació en Guatemala. En 2006, Margarita, de 17 años, huyó a Estados Unidos con su pequeño Ángel, en busca de asilo para escapar de la guerra. Se unieron a familiares que vivían en Maui, Hawái. Margarita no hablaba nada de inglés y trabajaba duro limpiando casas. Encontró orientación de inmigración de organizaciones comunitarias que tenían acceso al idioma.

En 2007, Margarita tuvo otro hijo. Esto llevó los servicios de salud pública a su hogar. Una trabajadora social bilingüe, que visitó a su recién nacido, notó los retrasos en el desarrollo de Ángel: aún no caminaba ni hablaba a los dos años. Ángel fue diagnosticado con Parálisis Cerebral. Como inmigrante, Ángel no calificó para el seguro médico federal. Margarita a veces podía pagar un seguro médico para la atención básica.

Margarita le da crédito al espíritu aloha por apoyar a su familia. Los programas escolares y sin fines de lucro, como las Olimpiadas Especiales, los conectaron con otras familias con necesidades especiales para realizar actividades sociales y compartir recursos, como pañales, sillas de ruedas pequeñas y cuidado de niños. Una conexión con los demás y un espacio para actividades sociales, trajeron alegría e inclusión a la vida de Ángel. "¡El primer idioma de Ángel fue el inglés! Para ayudarlo, y para ayudar a los profesionales que intentaban ayudarnos, también tuve que aprender inglés".

El acceso a la atención médica especializada fue un desafío. Afortunadamente, un par de clínicas de extensión como el Hospital Shriners para Niños y los especialistas del Centro Médico Kapi‘olani venían a Maui varias veces al año, pero la mayoría de las citas de Angel requerían viajar a la isla de Oahu. Por lo general, a sus padres les tomaba un día entero de viaje llevar a Ángel, su silla de ruedas, su andador, sus suministros, al avión, a un taxi, para completar una cita y regresar a casa. Su madre también necesitaba estar preparada para posibles retrasos en el viaje debido al clima o retrasos en la seguridad del aeropuerto debido a su estatus migratorio.

Margarita reflexiona: "Para las familias que todavía están en los días oscuros del cuidado, no se rindan. Nuestros hijos dependen de nosotros. Nos muestran lo fuertes que somos realmente".

Casi 20 años después de llegar a Hawái, Margarita obtuvo su licencia de Auxiliar de Enfermería Certificada. Mantuvo diligentemente registros detallados de la salud y la educación de Ángel para presentarlos a la inmigración de los EE. UU. En 2023, tanto ella como Ángel se convirtieron en ciudadanos estadounidenses. Ahora, Ángel puede acceder a beneficios que pueden ayudarlo como adulto con necesidades especiales.

—¿Por qué tarda tanto? —pregunta Ángel. Margarita se ríe: "Estás lista, pero tienes que esperar a todos los demás".

REN

4 YEARS OLD
KAIMUKĪ, O‘AHU

Ren, who just turned 4 years old in April, is bright and joyful. He lives in Honolulu with his loving parents, Rez and Emi. Diagnosed with Coffin-Lowry Syndrome, Ren has faced many medical challenges since birth—from clubfeet and hearing loss to surgeries and developmental hurdles. Yet, through it all, he shines with an incredible spirit. His wide, contagious smile lights up every room, and his laughter reminds everyone around him of life's beautiful moments.

Ren finds joy in watching his favorite movies—Studio Ghibli classics, Moana, and Finding Nemo—and loves diving into his beloved animal and fish books.

From the very beginning, Rez and Emi embraced their journey with unwavering love and gratitude. Every challenge has deepened their appreciation for the gift of having Ren in their lives. While navigating medical systems and securing the care Ren needs hasn't been easy, they remain determined and hopeful.

Though Emi had to step away from her career to care for Ren full time, both parents continue to face each day with perseverance and optimism. They are thankful for the support of programs like Early Intervention and Children with Special Health Needs, and they continue to build a strong network of advocates and allies, including connections like Kate Ducheneau from Hawai‘i Hands and Voices.

Rez and Emi are actively seeking ways to balance their work and care for Ren, aiming to ensure his needs are met while building a sustainable future. They've encountered roadblocks, but their resolve never wavers. When the path forward seems steep, all it takes is a glance at Ren's radiant smile to be reminded of what truly matters—and to find the strength to keep going.

ハワイ・ホノルルのあたたかな陽ざしの下、4歳になったばかりの明るく陽気な男の子、Ren（レン）くんは、愛情深いご両親のRez（レズ）さんとEmi（エミ）さんと共に暮らしています。

レンくんは、「コフィン・ローリー症候群」という、約4万人から5万人に一人の割合で発症する希少疾患を抱えて生まれてきました。日本では難病にも指定されており、この病気の影響で、生まれつきの重度の聴覚障害、先天性内反足、低筋緊張、頭蓋骨縫合早期融合症、そして発達の遅れなど、さまざまな症状を抱えています。

そのため、小さな体で何度も大きな手術を受けるなど、数えきれないほどの困難に立ち向かってきました。それでもレンくんは、いつも目を輝かせ、驚くほど前向きなエネルギーと笑顔で、周囲の人々に「生きることの喜び」を伝えてくれる存在です。

そんなレンくんの楽しみは、スタジオジブリの名作『となりのトトロ』や『千と千尋の神隠し』、そして『モアナ』や『ファインディング・ニモ』といった大好きな映画を観ること。また、動物や魚の絵本を読むのも大のお気に入りです。

IKAIKA

21 YEARS OLD
‘ĀINALOA, HAWAI‘I ISLAND

> “It takes a village made up of professionals and other families encouraging us to grow our advocacy skills and learn how to care for a medically fragile and deaf child.”
>
> - Amanda, mom

Aloha! We are the Ka‘ahanui ‘Ohana, a family of three, living on the Big Island of Hawai‘i. Our son, **Ikaika**, is now 21 years old, and it has been quite the journey getting him to this point. When you hear the old adage “it takes a village,” for us, that was not a cute saying. That was how we lived, especially in those early years, with a village surrounding and supporting us. From doctors and nurses to social workers and agencies, so many helping professionals and other families encouraged us to grow our advocacy skills, learn how to care for a medically fragile and deaf child, and navigate the health and educational systems.

In Ikaika’s first four months of life, he received the first 4 of 13 surgeries before he left the Pediatric ICU at Kapi‘olani Hospital. His first was to repair a hole between his trachea and esophagus when he was 10 days old. He was unable to breastfeed or drink from a bottle in those first few weeks because he was drowning every time he tried to eat. His G-tube was placed when he was 1 month old, and I kept pumping so he’d have breastmilk to help him strengthen his immune system. By 2 months old, he was not breathing well and had a trach tube placed. That was the hardest decision to make, but we had to do what would help him, even though it was scary. We were able to meet with other parents who had similar medical needs in the PICU, and that was the first time we realized the value of parent-to-parent support and connections.

We enrolled Ikaika in Early Intervention and had an interdisciplinary team, including a Deaf Educator, Speech and OT Therapist, and a Deaf Mentor. It was so important for us to meet and interact with adults who were deaf and other parents who had a deaf child. It was from these interactions that we learned how to advocate for his rights and that our hopes and dreams for him were still reachable.

When Ikaika entered school, his first language was American Sign Language (ASL). But over time, he learned to use his hearing aids and upgraded to a

bone-anchored hearing aid, which improved his hearing significantly, and he started to talk more and sign less. His trach tube was removed when he was 8 years old, and he no longer needed nursing services at home or at school. That was a game changer. In the beginning, we didn't want nurses in our home, but after eight years, they became part of our family. It was a hard to transition to life without them.

Over the years, I (mom) presented at different conferences and workshops, sharing the parent perspective on raising a deaf, medically fragile child and our educational advocacy along the way. This helped me to see how far we'd come, to appreciate our own journey, and allowed me to give back to the village who nurtured us over the years.

After a lot of hard work and support, Ikaika graduated from Kalaheo High School on O'ahu. If you'd asked us in elementary school if he would graduate, we would have honestly said, "I don't know." But with the right supports, in inclusive settings, he was able to not only graduate, but he also did so with honors!

Even though Ikaika is now taking classes at Hawai'i Community College and we are looking for him to work in the community, we still rely on our village for support. Last year, the dietician from the Children with Special Health Needs Program helped us transition from canned, processed milk to a blended food diet, working with his doctor and insurance to make this healthier change. Transitioning to adult life, we know the need for continued supports and services has not changed, but with the connections we've made over the years, we know Ikaika's Village will be there for support when he needs them.

JEREMIAH

9 YEARS OLD
HILO, HAWAIʻI ISLAND

> "More than anything, I saw my son's resilience. He was the one who taught us how to be brave. He has been holding us up as an ʻohana."
>
> - Leilani, mom

Our family lives on Hawaiʻi Island. Before our son **Jeremiah** was born, I stayed on Oʻahu at Kapiʻolani Medical Center for Women and Children, where he was hospitalized in the Neonatal Intensive Care Unit (NICU) for seven months. About six weeks before he was born, the doctors noticed that Jeremiah was smaller than expected and began weekly monitoring. It was a very difficult time—I had to be away from my husband and our two older sons, Joseph and Kawika, who were just 9 and 11 years old.

At 34 weeks, during a routine checkup, doctors noticed something was wrong with Jeremiah's heartbeat. That Monday afternoon, they told me he had to be delivered right away. My husband, working in Kohala—about an hour from the airport—rushed to Oʻahu but arrived 30 minutes after Jeremiah's birth.

Jeremiah weighed just two and a half pounds. A week later, my husband returned home to work and care for our sons while Jeremiah and I remained at the hospital. When Jeremiah was 10 days old, I went to his bedside, hoping to finally nurse him for the first time. But the nurse gently told me that his belly looked swollen. An emergency X-ray was done and my husband was told that Jeremiah needed emergency surgery. Since it was spring break, he brought our boys to Oʻahu so we could all be together. During surgery, doctors discovered volvulus—a dangerous twisting of the intestines-—and removed more than half of Jeremiah's small intestines. After many months in the NICU, Jeremiah finally came home in October 2016.

When I first learned he'd need a feeding tube, my heart sank. It was a mix of fear, grief, and guilt. Fear of the unknown. Grief, because I was terrified to place the tube in his nose if it came out. And guilt, wondering if I somehow failed him, even though I knew deep down that wasn't true.

I quickly realized that feeding a child through a tube isn't just about nutrition—it's about trust, patience, and acceptance. It's about learning a new language of care. I had to grieve the loss of "normal" and then redefine what our normal would look like. More than anything, I saw my son's resilience. He taught us how to be brave. He has been holding us up as an ʻohana.

At 9 years old, he has been diagnosed with pediatric feeding disorder, failure to thrive, ADHD, dyslexia, dysgraphia, dyscalculia, mild hearing loss in both ears, and mild vision impairment.

But none of that has stopped him from being Mr. Aloha. He has a smile that lights up the room—and it's wonderfully contagious! With a playful sense of humor and a big heart, he loves chatting with friends and grown-ups alike. He enjoys playing with cars and video games like Roblox and Farming Simulator with his dad. He's always curious, always learning, and always trying his very best. But what he loves most of all is when his whole family is together—laughing, talking, and simply enjoying each other's company.

* * *

No ko mākou ʻohana e noho ana ma ka mokupuni ʻo Hawai ʻi. Ma mua o ka hānau ʻia ʻana o kā mākou keiki kāne ʻo Jeremiah, ua ho ʻokomo ʻia au ma Kapiʻolani Medical Center for Women and Children ma O ʻahu no ka mea ua ʻike nā kauka he ʻu ʻuku a ʻe ʻo Jeremiah ma mua o ka mea i mana ʻo ʻia, a ho ʻomaka lākou i ka nānā ʻana i kēlā me kēia pule ma O ʻahu. He wā pa ʻakikī loa ia—pono au e ka ʻawale mai ka ʻu kāne a me kā māua mau keiki kāne ʻelua, ʻo Joseph lāua ʻo Kawika, he 9 a me 11 wale nō.

I ka 34 o nā pule, i ka wā o ka nānā ma ʻamau, ua ʻike nā kauka he mea ʻino i loko o ka pu ʻuwai o Jeremiah. I kēlā ahiahi Pō ʻakahi, ua ha ʻi mai lākou ia ʻu e pono e hānau koke ʻia ʻo ia. Ua holo wikiwiki ka ʻu kāne, e hana ana ma Kohala—he hola ho ʻokahi mai ke kahua mokulele—i Oʻahu akā ua hō ʻea ʻo ia 30 minuke ma hope o ka hānau ʻia ʻana o Jeremiah.

Ua kaumaha ʻo Jeremiah he ʻelua a me ka hapalua paona wale nō. Ua noho ʻo ia ma ka Neonatal Intensive Care Unit (NICU) no ʻehiku mahina.

I ho ʻokahi pule ma hope o ka hānau ʻana o Jeremiah, ua ho ʻi ka ʻu kāne i ka hale e hana a mālama i kā māua mau keiki kāne i ka wā e noho ana ʻo Jeremiah a me a ʻu ma ka haukapila. I ka wā he 10 mau lā o Jeremiah, ua hele au i kona moe, me ka mana ʻolana e hānai iā ia no ka manawa mua. Akā, ua ha ʻi mālie mai ke kahu ma ʻi ia ʻu ua ʻōpu ʻupu ʻu kona ʻōpū. Ua kauoha ʻia kahi x-ray pilikia.

Ma hope koke iho, ua ha ʻi ʻia ka ʻu kāne e pono ʻo Jeremiah i ka ʻoki pilikia. No ka mea he wā ho ʻomaha pua, ua lawe ʻo ia i kā māua mau keiki kāne i Oʻahu i hiki iā mākou a pau ke hui pū. I ka wā o ka ʻoki ʻana, ua ʻike nā kauka i ka volvulus—he ʻano ʻino o ka wili ʻana o nā ʻōpū--a ua hemo lākou i ʻoi aku ma mua o ka hapalua o nā ʻōpū li ʻili ʻi o Jeremiah.

Ma hope o nā mahina he nui ma ka NICU, ua ho ʻi mai ʻo Jeremiah i ka home i ʻOkakopa 2016.

I ka wā mua a ʻu i a ʻo ai e pono ʻo ia i ka paipu hānai, ua kaumaha ko ʻu na ʻau. He hui pū ʻana o ka maka ʻu, ka ʻeha, a me ka hewa. Maka ʻu i ka mea ʻike ʻole ʻia. ʻEha, no ka mea ua maka ʻu au e ho ʻokomo i ka paipu i kona ihu inā puka mai ia. A me ka hewa, me ka no ʻono ʻo ʻana inā ua hā ʻule wau iā ia, ʻoiai ua ʻike au i loko o ko ʻu na ʻau ʻa ʻole ʻo ia he ʻoia ʻi ʻo.

Ua ʻike koke au ʻa ʻole wale nō ka hānai ʻana i ke keiki ma o ka paipu e pili ana i ka hānai ʻana—e pili ana ia i ka hilina ʻi, ka ho ʻomanawanui, a me ka ʻae ʻana. He mea e a ʻo ʻia i ka ʻōlelo hou o ka mālama ʻana. Ua pono ia ʻu e kaumaha i ka lilo ʻana o ka "ma ʻamau" a laila e ho ʻoholo hou i ka mea e like me kā mākou ma ʻamau. Ma mua o nā mea āpau, ʻike au i ka ikaika o ko ʻu keiki. Ua a ʻo mai ʻo ia iā mākou pehea e kia ʻi ikaika ai. Ua pāpa ʻa nō ʻo ia i ko mākou ʻohana.

I kona makahiki 9, ua ʻike ʻia ʻo ia me ka ma ʻi Pediatric Feeding Disorder, Failure to Thrive, ADHD, dyslexia, dysgraphia, dyscalculia, loa ʻa pū kekahi ka lohi ʻōlelo iki ma nā pepeiao ʻelua a me ka lohi maka iki.

Akā, ʻa ʻole i ho ʻopau ia i kona ʻano ʻo Mr. Aloha.

Loa ʻa iā ia kahi mino ʻaka e ho ʻomālamalama i ke lumi—a he mea ho ʻopunipuni maika ʻi nō! Me kahi mana ʻo ʻaka ʻaka pā ʻani a me ka na ʻau nui, makemake ʻo ia e kama ʻilio me nā hoa a me nā kūpuna pū kekahi. Makemake ʻo ia e pā ʻani me nā ka ʻa a me nā pā ʻani wikiō e like me Roblox a me Farming Simulator me kāna makuakāne. ʻO ia mau manawa makemake nō, a ʻo mau, a ho ʻā ʻo mau ʻo ia i kona maika ʻi loa.

Akā, ʻo ka mea āna e aloha loa ai, ʻo ia ka manawa e hui pū ai kāna ʻohana holo ʻoko ʻa—e ʻaka ʻaka, e kama ʻilio, a e hau ʻoli wale pū me kekahi i ka wā like.

UHIWAI

23 MONTHS OLD
KAHALU'U, O'AHU

"Please remember to thank yourself. You are resilient. Your mental health is your family's wealth."

- Jessie, mom

We are the ʻohana of **Uhiwai**. He was born with a rare condition called a midline volvulus and underwent his first surgery—the Ladd's Procedure—at just one day old. At five months, we learned he had developed lysis adhesions, requiring a second surgery. Sadly, this time, recovery didn't go well. Uhiwai suffered a massive epileptic episode, and for months, we were uncertain if he would regain motor functions.

As a third-time mother, I sensed something was wrong when he couldn't keep feedings down. I urged the pediatrician to recheck him before we left the hospital. Hours later, we heard the words no parent expects: "It looks like there's a blockage." I nervously joked, "But not surgery, right?" Moments later, our baby was in the OR. We rode waves of fear, grief, numbness, and hope—not once, but twice. Those early days were dark. But God is so good. Today, Uhiwai is happy, healthy, walking, talking, and keeping up with his big brothers. He loves dancing, playing ball, going to the park, and copying everything his siblings do. While medical challenges still arise, we hold tight to the joy of God's grace and are grateful for every step forward.

We owe immense gratitude to the entire team at Kapiʻolani Medical Center: Dr. Justin Hino, Dr. Angela Pratt, Dr. Russell Woo, Dr. Michale Sofer, Dr. Jared Su, Dr. River Kim, Dr. John Harrington, Dr. Marissa Fakaosita, Dr. Konstantine Xoinis, Dr. Jason Brown, Dr. Prashant Purohit, Dr. Marianne Melish, Dr. Mohamed Kandil, Dr. Jeremy King, and many more. The NICU, PICU, and pediatric nurses—John, Lorien, Kas, Renette, Dom, Kolea—were truly angels. Physical therapist Kelly Meyer and our Department of Health Early Intervention team, Auntie Heather and Auntie Jen, were essential in Uhiwai's healing journey.

To anyone walking a similar path: hold on tight. To your baby—remind them they're strong and life is waiting. To your faith—pray, gather, believe. To your support system—lean on them when you're in survival mode. Mahalo to our brother Ikaika Nihipali, who anchored us physically, mentally, and emotionally when we needed it most.

Care for yourself. Eat when you can—protein shakes saved us. Pack warm clothes, socks, and a good pillow when you stay bedside. Sleep in snatches. Breathe deeply. You can't help your child if you fall apart.

When there's a break to go home—whether to rotate shifts with other family members, to hug and kiss your other children, replenish supplies, or to take a well-deserved break—let go. Cry, laugh, dance, scream. When you're ready, find a therapist or cultural practitioner. You are navigating uncharted waters, advocating for your child, working, parenting, surviving—and you are doing it.

Please remember to thank yourself. You are resilient. Your mental health is your family's wealth. Mālama.

* * *

ʻO mākou ka ʻohana o Uhiwai. Ua hānau ʻia ʻo ia me kahi maʻi kūʻē loa i kapa ʻia ʻo midline volvulus a ua hoʻōla ʻia ʻo ia i kāna hana mua—the Ladd's Procedure—i kona lā mua o ka hānau ʻana. I ka ʻelima mahina, ʻike mākou ua hoʻomāhuahua ʻo ia i nā lysis adhesions, no laila pono ʻo ia i kahi hana ʻelua. Aloha ʻole, ʻaʻole maikaʻi ka hoʻihoʻi ʻana i ka manawa ʻelua. Ua loaʻa iā Uhiwai kahi hōʻailona epileptic nui, a no nā mahina he nui, ʻaʻole mākou i ʻike inā e hoʻi hou ana nā hana kino.

Ma ke ʻano he makuahine ʻekolu, ʻike au he hewa ke manaʻo ʻana ʻaʻole hiki iā ia ke mālama i nā mea ʻai. Ua paipai au i ka pediatrician e nānā hou iā ia ma mua o ko mākou haʻalele ʻana i ka hōkele. I loko o nā hola, ua lohe mākou i nā ʻōlelo ʻaʻole i manaʻo ʻia e nā mākua: "Ke nānā nei he obstructed." Ua ʻakaʻaka au me ka naʻau mālie, "Akā ʻaʻole hana ʻē aʻe, ʻae?" Ma hope koke iho, aia kā mākou keiki i ka LUMI HANA LAPAʻAU.

Ua holo mākou ma nā nalu o ka makaʻu, kaumaha, pōʻeleʻele, a me ka manaʻoʻiʻo—ʻaʻole hoʻokahi manawa, akā ʻelua manawa. Ua pouli loa nā lā mua. Akā, maikaʻi loa ke Akua. I kēia lā, hauʻoli ʻo Uhiwai, maʻi ʻole, hele wāwae, kamaʻilio, a e hahai pū me kāna mau kaikunāne nui. Makemake ʻo ia e ʻauʻau, pāʻani pila, hele i ka pāka, a hoʻopiha i nā mea āpau a hana nā kānaka o kona ʻohana. ʻOiai aia nō nā pilikia olakino e ala mai, paʻa mākou i ka hauʻoli o ke kūpaʻa o ke Akua a mahalo i kēlā me kēia ʻanuʻu mua.

Ua paʻa mākou i ka mahalo nui i ka hui holoʻokoʻa ma Kapiʻolani Medical Center: Dr. Justin Hino, Dr. Angela Pratt, Dr. Russell Woo, Dr. Michale Sofer, Dr. Jared Su, Dr. River Kim, Dr. John Harrington, Dr. Marissa Fakaosita, Dr. Konstantine Xoinis, Dr. Jason Brown, Dr. Prashant Purohit, Dr. Marianne Melish, Dr. Mohamed Kandil, Dr. Jeremy King, a me nā poʻe ʻē aʻe he nui. ʻO ka NICU, PICU, a me nā kahu mālama pediatric—ʻo John, Lorien, Kas, Renette, Dom, Kolea—ʻo lākou nō nā ʻanela maoli. ʻO ka physical therapist ʻo Kelly Meyer a me kā mākou hui Department of Health Early Intervention, Auntie Heather a me Auntie Jen, he mea koʻikoʻi loa i ka hoʻomaha ʻana o Uhiwai.

I kekahi mea e hele ana ma kahi ala like: paʻa mau i ka paʻa. I kāu keiki—hoʻomaopopo iā lākou he ikaika lākou a aia ke ola e kali ana. I kou manaʻoʻiʻo— pule, hui, a manaʻoʻiʻo. I kāu pūʻulu kākoʻo—e kūkulu i kēlā me kēia manawa ʻoe e ola ai. Mahalo nui iā kā kākou hoahānau ʻo Ikaika Nihipali, nona i paʻa i kā kākou kino, manaʻo, a me ka naʻau i ka wā i pono ai.

E mālama pono iā ʻoe iho. ʻAi i kou hiki—nā kāmole paʻakikī nā mea i mālama iā kākou. Hoʻopili i nā lole wela, nā makau wāwae, a me kahi poʻi maikaʻi ke noho ʻoe ma ka ʻaoʻao o ke keiki. Hiamoe i nā ʻāpana liʻiliʻi. Hanu hohonu. ʻAʻole hiki iā ʻoe ke kōkua i kou keiki inā paʻakikī ʻoe.

I ka wā loaʻa kahi wā hoʻomaha e hoʻi i ka hale—ma ke ʻano e hoʻololi mau i nā haʻawina me nā ʻohana ʻē aʻe, e hūnā i kou mau keiki ʻē aʻe, e hoʻihoʻi i nā pono, a i ʻole e kiʻi i kahi wā hoʻomaha kūpono—e ʻae. Kanaka waimaka, ʻakaʻaka, hulahula, ʻūa. I kou mākaukau ʻana, e ʻimi i kahi kauka no ka naʻau a i ʻole ka mea mālama moʻomeheu. Ke holo nei ʻoe i nā kai hou ʻole i ʻike ʻia, e kūkulu no kou keiki, e hana, e mālama keiki, e ola— a ke hoʻokō nei ʻoe.

E hoʻomanaʻo mau e mahalo iā ʻoe iho. ʻO ʻoe ka ikaika. ʻO kou olakino noʻonoʻo ka waiwai o kou ʻohana. Mālama.

KALAIMOKU

33 MONTHS OLD
KAHALU‘U, O‘AHU

“Kalaimoku’s parents appreciate that early intervention services are provided at home, allowing them to incorporate activities and strategies within their daily routines like having a meal, playing in the backyard, playing with their toys, or making a lei together. “

The Revilla family deeply values time rooted in culture, physical activities, and family tradition. Marie and Kahekili strive to provide their children with all the tools and opportunities to help them become successful and happy in life. Lililehua (8 years old), Kahekili (6 years old), La‘akea (4 years old), and **Kalaimoku** (33 months old) enjoy playing with their toys and games as any other child but are also becoming well-versed in ‘Ōlelo Hawai‘i and developing their knowledge of practices in Hawaiian tradition, like hula, farming (mahi‘ai) and lei making.

The Revilla family’s journey with early intervention services began with their oldest child, Lililehua, who was born with a condition known as torticollis, where a baby’s neck muscles cause the head to tilt or turn towards one side. Their pediatrician, Dr. Robin Lynch at Reis Pediatrics, referred Lililehua to the Department of Health – Windward Early Childhood Services program for early intervention services. Unfortunately, their family had to seek out private physical therapy services for Lililehua in town for her condition due to staffing shortages at the program. This unfortunate circumstance, however, allowed the Revilla family to greatly appreciate the early intervention services available when their two youngest children, La‘akea and Kalaimoku, were referred by their pediatrician to the Department of Health – Windward Early Childhood Services program for early intervention services.

Being able to receive the support needed for their children in the convenience and comfort of their own home setting that took into account the resources available in the home made implementing the recommended strategies doable. La‘akea received support through early intervention for her communication delay until she was 3 years old. While La‘akea continues to receive some services for her articulation skills today, she successfully enjoys having many conversations with her family now. Kalaimoku has received services since he was an infant for torticolis, the same condition his older sister Lililehua has, and more recently for speech/language therapy support. His parents have been grateful to receive support through early intervention that considers the complete social and physical development of the child. Marie and Kahekili delight in seeing the aunties from early intervention pulling up to their house to visit and being welcomed by their children like any other family members coming for a visit!

Marie and Kahekili most appreciated how early intervention services were provided for them at home. They were able to incorporate activities and strategies within their daily routines like having a meal, playing in the backyard, playing with their toys, or making a lei together. They loved knowing they had access to a full team of professionals for any concerns they may have had related to their children. Marie and Kehekili felt empowered as parents becoming more knowledgeable of their children's developmental needs and knowing more about the resources available through early intervention and beyond that can support them. Their hopes and dreams are for their children to be healthy, grateful, appreciative of what they have, and always respectful.

◆

Hoʻonui ka ʻohana Revilla i ka manawa i hoʻokumu ʻia ma ka moʻomeheu, nā hana kino, a me nā loina ʻohana. E hoʻoikaika nei ʻo Marie lāua ʻo Kahekili i ka hoʻolako ʻana i kā lāua mau keiki i nā mea hana a me nā manawa kūpono e kōkua iā lākou e lilo i poʻe holomua a hauʻoli i ke ola. Hoʻohauʻoli ʻo Lililehua (8), ʻo Kahekili (6), ʻo Laʻakea (4), a me Kalaimoku (2) i ka pāʻani ʻana me kā lākou mau mea pāʻani a me nā pāʻani e like me nā keiki ʻē aʻe, akā ke aʻo nei hoʻi lākou i ka ʻŌlelo Hawaiʻi a ke hoʻomohala nei i ko lākou ʻike i nā hana kuʻuna Hawaiʻi e like me ka hula, ka mahi ʻai, a me ka hana lei.

Ua hoʻomaka ka huakaʻi a ka ʻohana Revilla me nā lawelawe ākea i ke wā kamaliʻi me kā lāua keiki mua, ʻo Lililehua, ka mea i hānau ʻia me kekahi maʻi i kapa ʻia ʻo torticollis, kahi kūlana i ʻeʻe ai nā ʻiʻo ʻāʻī o ke keiki a hoʻohuli ai i ke poʻo i hoʻokahi ʻaoʻao. Ua kuhikuhi kā lākou kauka keiki, ʻo Dr. Robin Lynch mai Reis Pediatrics, iā Lililehua i ka papahana Department of Health – Windward Early Childhood Services no nā lawelawe ākea i ke wā kamaliʻi. No ka nele o ka limahana i ka papahana, ua koi ʻia kā lākou ʻohana e ʻimi i nā lawelawe lomilomi kino pilikino no Lililehua ma ke kūlanakauhale no kona kūlana. Ua lawe pinepine ʻia kēia kūlana ʻeha i mea e mahalo nui ai ka ʻohana Revilla i nā lawelawe ākea i ke wā kamaliʻi i loaʻa i kā lāua mau keiki ʻelua ʻuʻuku, ʻo Laʻakea lāua ʻo Kalaimoku, i kuhikuhi ʻia e kā lāua kauka keiki i ka papahana Department of Health – Windward Early Childhood Services no nā lawelawe ākea i ke wā kamaliʻi.

E hiki ke loaʻa ka kākoʻo e pono ai no kā lākou mau keiki i ka ʻoluʻolu a me ka ʻoluʻolu o ko lākou wahi noho ponoʻī, me ka noʻonoʻo ʻana i nā kumuwaiwai i loaʻa i ka home, ua maʻalahi ka hoʻokō ʻana i nā hoʻolālā i paipai ʻia. Ua loaʻa iā Laʻakea ke kākoʻo ma o ka hoʻomaka ʻana o ka wā kamaliʻi no kona lohi ʻana i ka kamaʻilio a hiki i kona makahiki ʻekolu. I kēia manawa, ʻoiai ke loaʻa nei iā Laʻakea kekahi mau lawelawe no kona mākau haʻi ʻōlelo, hauʻoli ʻo ia i ka hoʻolauna ʻana me kona ʻohana. Ua loaʻa iā Kalaimoku nā lawelawe mai kona wā kamaliʻi. Ma mua no ke kūpikipikiʻō, ka pilikia like me kona kaikuaʻana ʻo Lililehua, a ma hope aku no ke kākoʻo haʻiōlelo/ʻōlelo. Ua mahalo nui kona mau mākua i ke kākoʻo i loaʻa mai i ka lawelawe wā kamaliʻi, i ka nānā ʻana i ka ulu ʻana o ke keiki ma ke ʻano kino a me ke kaiāulu holoʻokoʻa. Hoʻokipa ʻia ka hele ʻana mai o nā ʻanakē mai ka papahana lawelawe wā kamaliʻi e Marie lāua ʻo Kahekili, me ka hauʻoli hoʻi o kā lāua mau keiki, me he ʻohana ʻē aʻe e kipa ana!

ʻO ka mea i mahalo nui ʻia e Marie lāua ʻo Kahekili, ʻo ia hoʻi ka hiki ʻana mai o nā lawelawe i ko lāua hale ponoʻī. Ua hiki iā lāua ke hoʻokomo i nā hana a me nā ʻano hana i loko o ko lāua mau hana maʻamau i kēlā me kēia lā, e like me ka ʻai ʻana, ka pāʻani ʻana ma ke kua ʻāina, ka pāʻani me nā mea pāʻani, a me ka hana pū ʻana i ka lei. Ua makemake nui lāua i ka ʻike ʻana he hui piha o nā loea i loaʻa no nā hopohopo pili i kā lāua mau keiki. Ua loaʻa ka mana iā Marie lāua ʻo Kahekili ma ke ʻano he mau mākua, ma o ka ʻike hou ʻana i nā pono ulu o kā lāua mau keiki, a me ka ʻike ʻana i nā kumuwaiwai i loaʻa ma o ka lawelawe wā kamaliʻi a i ʻole. ʻO ko lāua mau manaʻo a me nā moeʻuhane, ʻo ia hoʻi e ola ka lāua mau keiki me ke olakino, me ka mahalo, a me ka ʻike ʻana i ka waiwai o nā mea i loaʻa iā lākou. E hoʻomau i ka mahalo a me ka haʻahaʻa i nā mea ʻē aʻe.

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 Rezentes ‘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.

REFLECTION PAGE: SHARING YOUR MO‘OLELO

This is your chance to share your mo‘olelo. Every journey is woven with moments of joy, challenge, resilience, and love. The stories you share not only honor your experiences but also strengthen your connections and inspire others. Your mo‘olelo is a gift—a testament to the strength and beauty of your journey.

Find a quiet moment and take some time to settle into a peaceful space. Whether it’s on your lanai, by the beach, or at your kitchen table, find a place where you feel at ease to think and reflect. No rush—just take a breath and be ready to dive into your mo‘olelo.

Consider these questions as you think about your experiences:

- What moment in your journey has shaped you the most?
- How have your experiences strengthened your connections or reshaped your perspective?
- What message would you share with someone on a similar path?
- What traditions, values, or lessons do you want to pass on to future generations?

We encourage you to document your mo‘olelo in a way that feels right for you—through writing, oral storytelling, art, poetry, music, or any other form of expression. By preserving and sharing your mo‘olelo, you ensure that your lived experiences are never forgotten. Your mo‘olelo matters.

This reflection is all about you, your journey, and the memories that have shaped you. Take your time and be kind to yourself. Mahalo for being a part of this collective journey of love, resilience, and shared wisdom.

‘AO‘AO NOHO MANA‘O: KA‘ANA I KOU MO‘OLELO

He manawa kēia no ‘oe e ka‘ana aku ai i kou mo‘olelo. Ua ulana ‘ia kēlā me kēia huaka‘i me nā manawa o ka hau‘oli, nā pilikia, ka pa‘akikī, a me ke aloha. Nā mo‘olelo āu e ka‘ana ai, ‘a‘ole wale nō e ho‘ohanohano i kou mau ‘ike, akā e ho‘oikaika ho‘i i kou mau pilina a ho‘oulu i nā kānaka ‘ē a‘e. He makana kou mo‘olelo—he hō‘oia no ka ikaika a me ka nani o kou huaka‘i.

E ‘imi i kekahi manawa mālie a e noho i kahi e mālie ai kou na‘au. Inā ma kou lanai, kokoke i ke kahakai, a i ‘ole ma kou papa ‘aina kuke, e ‘imi i kahi e ho‘omaha ai kou kino a me kou na‘au no ka no‘ono‘o ‘ana. ‘A‘ohe koi—e hanu mālie a e mākaukau no ke komo ‘ana i loko o kou mo‘olelo.

E no‘ono‘o i kēia mau nīnau i kou huli ‘ana i kāu mau ‘ike:

- He aha ka manawa i kou huaka‘i i ho‘ohālike loa iā ‘oe?
- Pehea i ho‘oikaika ‘ia ai kou mau pilina e kou mau ‘ike, a i ‘ole i ho‘ololi ‘ia ai kou ‘ike?
- He aha kāu leka e makemake ai e hā‘awi aku i kekahi mea i hele i ke ala like?
- He aha nā loina, nā waiwai, a i ‘ole nā ha‘awina āu e makemake ai e ho‘oili aku i nā hanauna e hiki mai ana?

Ke paipai mākou iā ‘oe e palapala i kou mo‘olelo ma ke ‘ano e pono ai iā ‘oe—ma o ka kākau ‘ana, ka ha‘i mo‘olelo ‘ana ma ka waha, ke ki‘i, ka haku mele, ka haku oli, a i ‘ole kekahi ‘ano ‘ē a‘e o ka hō‘ike. Ma ka mālama ‘ana a me ka ka‘ana ‘ana i kou mo‘olelo, e hō‘oia ‘oe ‘a‘ole e poina loa ‘ia kāu mau ‘ike i noho maoli ai. He mea nui kou mo‘olelo.

No ‘oe kēia no‘ono‘o ‘ana, no kou huaka‘i, a no nā ho‘omana‘o i ho‘oikaika iā ‘oe. E mālama i kou manawa a e aloha iā ‘oe iho. Mahalo no kou lilo ‘ana i māhele o kēia huaka‘i aloha, kūpa‘a, a me ka na‘auao i ka‘ana ‘ia.

WRITE OR DRAW YOUR MO‘OLELO HERE.

KĀKAU A KAHA PAHA I KOU MO‘OLELO MA ‘ANE‘I.

MAHALO!

Mahalo to all the incredible family contributors, editors, photographers, designers, and the CSHNB ‘ohana. Your creativity, dedication, and heart brought this project to life. It truly couldn’t have been possible without each and every one of you. It takes a TEAM!

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APPENDIX A:

CONTACT INFORMATION AND WEBSITE

CHILDREN WITH SPECIAL HEALTH NEEDS BRANCH

Ruben Frescas, Jr., MD, MPH, FAAFP - Chief

https://health.hawaii.gov/cshcn

Children and Youth with Special Health Needs Section	
Specialty Support Program (SSP)	• Provides care coordination, social work, nutrition, and other services for children with special health needs age 0-21 years with chronic medical conditions. • For more information and to make a referral, see Appendix B. • https://health.hawaii.gov/cshcn/home/communitypage/
Early Childhood Program	• Promoting the health and development of young children. • https://health.hawaii.gov/cshcn/hcch/
Hawai‘i Childhood Lead Poisoning Prevention Program (HI-CLPPP)	• Prevent children from being exposed to lead, identify children already exposed to lead so the source can be removed, link families with recommended services. • https://health.hawaii.gov/cshcn/childhood-lead-poisoning-prevention/
Project LAUNCH:	• Promotes the wellness of young children from birth – age 8 by addressing their physical and mental health needs. The program's goal is to help improve the abilities and skills of adult caregivers of young children to encourage healthy social and emotional development and identify and address behavioral concerns before they develop into serious emotional disturbances (SED). • https://health.hawaii.gov/cshcn/project-launch/

Hi‘ilei Developmental Screening Program	• Free resource for children birth to 5 years old; provides developmental screens and information to families. • https://health.hawaii.gov/cshcn/hiileihawaii/
Hearing and Vision Screening Program	• Provides guidance on hearing and vision screenings conducted in schools. • Website coming soon.

Early Intervention Section

Early Intervention Section	• Provides early intervention services for children ages 0-3 years who are developmentally delayed or biologically at risk for developmental delay. • https://health.hawaii.gov/eis/

Genomics Section

Hawai‘i Birth Defects Program	• Provides population-based surveillance for birth defects in Hawai‘i, monitors major structural and genetic birth defects that adversely affect health and development and provides a surveillance system and data. • https://health.hawaii.gov/genetics/programs/hbdhome/
Newborn Hearing Screening Program	• Coordinates hospital hearing screening programs on all islands; helps families make hearing screening appointments for missed screens and follow-ups; refers families for early intervention services; provides information to families, health care providers, early intervention staff, and the public on hearing and hearing loss; maintains statewide data on hearing screening results and follow-up. • https://health.hawaii.gov/genetics/programs/nhsp/
Newborn Metabolic Screening Program	• Tests babies born in Hawai‘i for metabolic disorders. • https://health.hawaii.gov/genetics/programs/nbshome/

APPENDIX B:

CONTACT INFORMATION AND WEBSITE SPECIALTY SUPPORT PROGRAM (SSP)

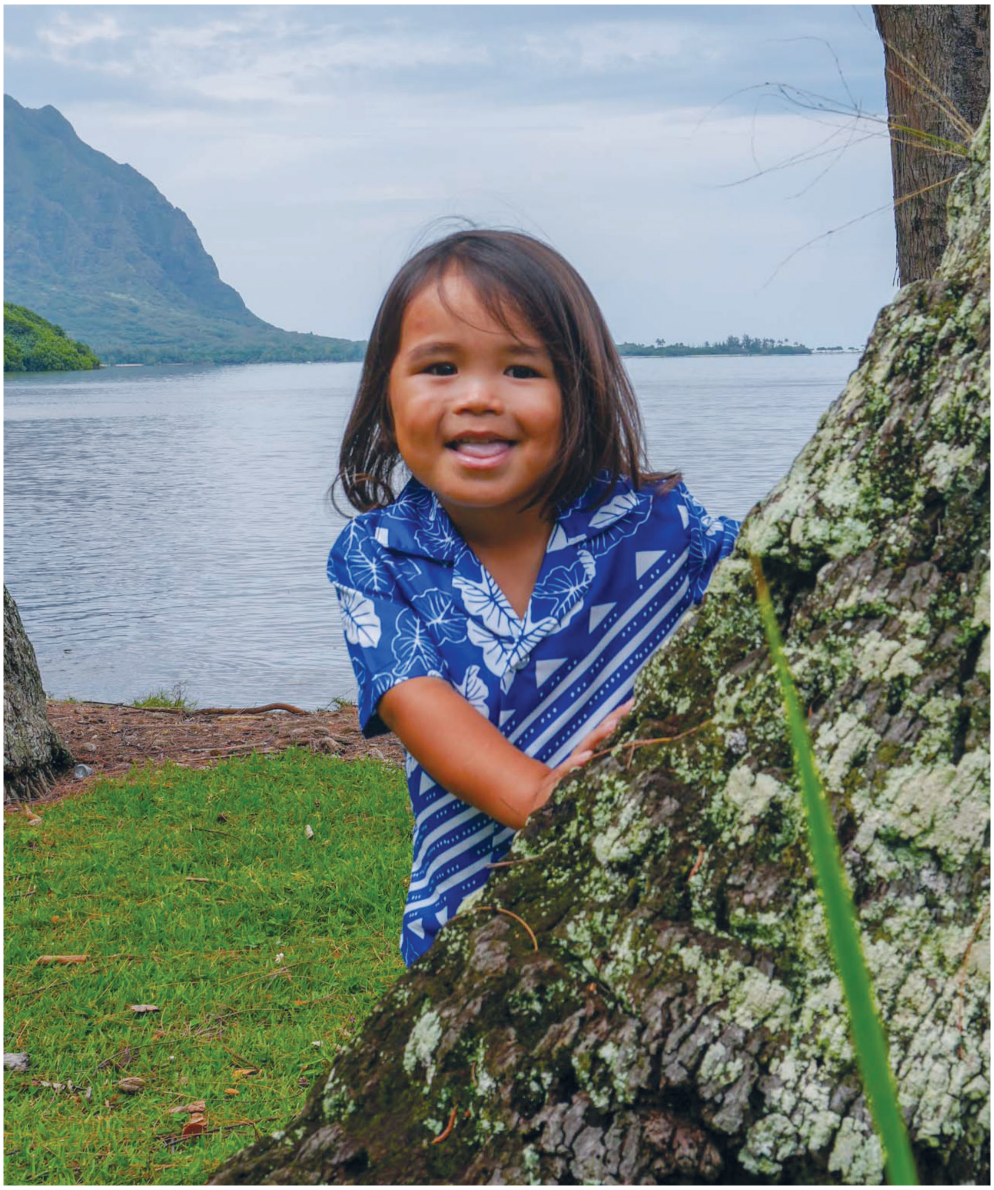
(formerly called Children and Youth with Special Health Needs Program)

https://health.hawaii.gov/cshcn/home/communitypage

Referrals can also be made online.

Contact the office in your area for questions or to make a referral.

Oʻahu	741 Sunset Avenue Honolulu, HI 96816 Phone: (808) 733-9055 Fax: (808) 733-9068
Kauaʻi	3040 Umi Street Līhuʻe, HI 96766 Phone: (808) 241-3376 Fax: (808) 241-3480
Maui	54 High Street, #301 Wailuku, HI 96793 Phone: (808) 984-2130v Fax: (808) 243-5202
Hilo	P. O. Box 916 Hilo, HI 96721 Phone: (808) 974-4288 Fax: (808) 974-4285
Kona	79-1015 Haukapila Road Kealakekua, HI 96750 Phone: (808) 322-4882 Fax: (808) 322-1504



To learn more about “Our Moʻolelo: Stories of Love, Strength & Resilience,” please scan the QR code to our website.

health.hawaii.gov/cshcn/our-moolelo

* * *

To learn more about the CSHNB 5-Year Strategic Plan (2025-2030), please scan the QR code to our website.

health.hawaii.gov/cshcn/cshnb-strategic-plan

CSHNB 5-YEAR STRATEGIC PLAN LOGO DESCRIPTION

The logo for the CSHNB 5-Year Strategic Plan was thoughtfully designed to visually represent the core elements that define the direction and values of the strategic plan. Each element of the logo symbolizes components in the framework for supporting children and youth with special health needs.

People at the center so that CYSHCN “enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health, and emotional needs, ensuring dignity, autonomy, independence, and active participation in their communities.”

The five themes emerging from internal and external reviews help to organize the strategies, while also understanding the interdependent nature of these themes.

The Blueprint for Change Framework helps to guide intended outcomes while also supporting the foundation of how we identify coverage and support for CYSHCN, as well as opportunity for growth.

The need for continuous quality improvement to assess progress among the various strategies and share with partners, including families and the public.

Josh Green, M.D., Governor of Hawaiʻi
Kenneth S. Fink, MD, MGA, MPH, Director of Health

Hawaiʻi State Department of Health
Children with Special Health Needs Branch
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“MĀLAMA OLA PUNAHELE A ʻOHANA”
“TO CARE FOR THE HEALTH OF THE SPECIAL ONE IN THE FAMILY”

PĀ'ANA KA LĀ NO NĀ KEIKI
SUNSHINE FOR CHILDREN

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