

2020

Annual Impact Report

Executive Director's Message

When the world COVID-19 pandemic created crisis and change in our daily lives, HUGS was affected as well. Our staff worked remotely for most of the year, changed our operations and service delivery, and cancelled many events. But our major concern was the impact of the pandemic on our HUGS families. We immediately ramped up our calls to our families to find out how they were doing and found that many were furloughed or unemployed, needed a variety of resources to fill basic needs, learned to manage distance learning with their children, and felt overwhelmed and stressed about their economic situation and potential COVID-19 exposure to their ill child – on top of dealing with their ill child's medical issues – all at the same time.

True to our mission of improving the quality of life of Hawaii's families as they face the emotional and financial hardships of caring for a seriously ill child, our staff and Board of Directors quickly pivoted to a different way of continuing our services for our families while keeping safety in mind. Our peer support programs for Moms, Dads, and families have been conducted monthly on Zoom, offering fun opportunities for them to keep connected, relieve some stress and find support from each other during hard times. We changed our normal in-person Respite activities to Kids Nights via Zoom as well. We nearly doubled distribution of food from our small food pantry and connected families with needed COVID-related updates and other community resources through our Ho'okele program to help them pay for utilities, rent or other needs.

I'd like to extend a giant Mahalo to our Board of Directors, staff, donors, community partners, and volunteers who stood by us during this period of great change. You kept HUGS and our families going as we continually met new challenges over the past 15 months. You have brought joy and hope to Hawaii's seriously ill children, their parents and siblings during these tough times. We are grateful for your compassion and generous support, and hope that we can continue to count on you to be our HUGS Champions for our families.

With warm aloha,



Joan Naguwa
HUGS Executive Director

"When we learned of our son's diagnosis, we were devastated, could not believe this could even happen to a little kid who was very healthy up until now. It was such a blessing to get together with other parents (without kids) who get us and understand how complicated and stressful life is having a child with a medical condition... We appreciate knowing that we are not alone, that has been a blessing of HUGS."

– HUGS family from Hawaii Island



96590



84333

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HUGS Impact Overview

457

Families statewide received HUGS' services

2,099

Family members served

52

New HUGS families

15,242

Total touchpoints or interactions with families

168

Hospital visits made by HUGS staff and volunteers

228

Boxes of food distributed

47

Family members received emergency airfare assistance

114

Family members received case management services

31

Neighbor Island families received a stipend for daily living expenses with a hospitalized child on Oahu

\$0

Amount families pay for services

3,049

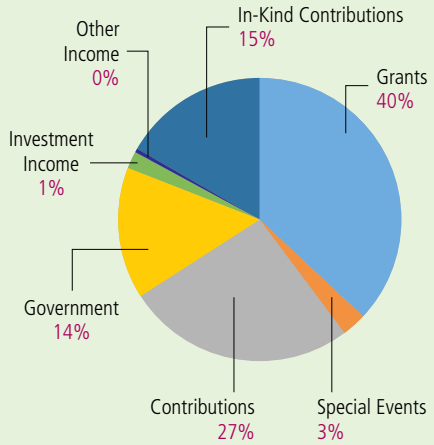
Total Volunteer Hours

\$824,251

Raised

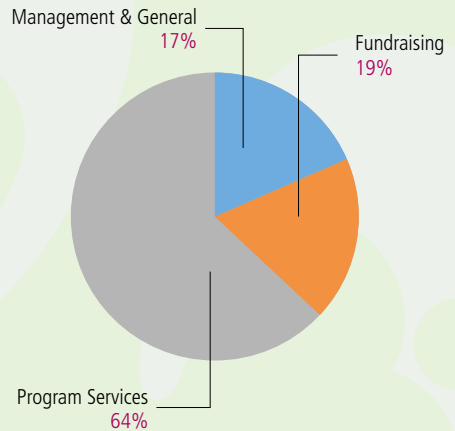
Revenue & Other Support

\$824,251



Expenses

\$727,863



*Unaudited Financials

"We are truly thankful for all that HUGS has done for us! We consider HUGS family as you all have simulated that family component that can only be defined, as an Ohana. Our aina/aiga/ohana, will always know in our hearts, that HUGS is family!"

– HUGS dad from Oahu

The Hurst-Naranjo Family's Story



The Hurst-Naranjo Family

Roselani and Royce Hurst-Naranjo live in Kāhala'u with their four sons, Keaka (15 y.o.), Sage (4 y.o.), Cameron (3 y.o.), and Noah (9 m.o.). As a family, they enjoy going to beaches, parks, and on special adventures, like fishing in Haleiwa.

Two summers ago, Roselani and Royce had noticed that their second oldest, Sage, was not acting like his usual self, but they thought he was only having temper tantrums. Those tantrums however turned out to be seizures, and after several EEGs, MRIs, and visits to the doctor, in October

2019, Sage was diagnosed with Medically Refractory Epilepsy. The Hurst-Naranjo family found out that Sage has actually four areas of damage in his brain. Even more crushing, because of these permanent damages, his parents have been told that he will not be able to grow out of his seizures. The diagnosis shocked the entire family, as Roselani shared, "When I got that news I was scared and devastated. I felt guilty. It took me a while to explain Sage's condition with family without crying about it." Though these feelings may never fully disappear, Sage's family now advocates for him, and they are continually learning about and finding ways for him to be independent and live a high-quality life.

Along with the fear and sadness that the Hurst-Naranjo's felt at the beginning of Sage's medical journey, it was difficult for them, because they couldn't find anyone comfortable with watching Sage while they worked. The family has had to change their lifestyle to ensure that they can still do things as a family that are safe and enjoyable for Sage. As Roselani puts it, "We conform our life around Sage and his safety." To ensure that Sage is staying safe, the family went to Lucile-Packard Children's Hospital-Stanford for treatment this past November. Since then, Sage has been able to return back to school, which he absolutely loves! Although distance learning has been challenging, he still enjoys it and does well with his education.

Aside from learning in school, Roselani also shared that she has been teaching her sons new concepts herself during the COVID-19 pandemic, and says that she loves watching them grow. Although the pandemic has taken a toll on their family, they have also been "afforded the opportunity to grow as a family and really connect to each other."

The Hurst-Naranjo family is thankful for the help HUGS has given them so far since joining our HUGS family, sharing "HUGS has been a huge support to our family. Helping with our trip to California. I don't know what we would have done. We are so grateful." They had a great time at the Christmas event and look forward to joining more events as a family in the future. As grateful as they are, one thing that Sage's family would like to advocate for more, in terms of support, is education. They want public school staff to learn more about seizures and ways to help when a child is having one. Roselani shares that she would feel a lot safer with Sage in school, if staff had more education on the matter.

Despite the hardships he's going through, Sage continues to be a happy little boy and his optimism gives his family strength. He is helpful, compassionate, and a great brother to his three siblings. "He loves life and his family and doesn't let his epilepsy get in the way of his happiness", shared mom. The family looks forward to getting a seizure assist dog later on this fall, which will be another safety net to help Sage continue to thrive in his extraordinary life!

Your support of HUGS makes a big impact on families like Sage's.

2020 Gifts to HUGS

With heartfelt gratitude, we recognize the following individuals and organizations who generously supported HUGS with gifts valued at \$500 or more in 2020. Your gifts are truly making an impact on Hawaii's families on their journey of caring for a child with a life-threatening illness.

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To strengthen Hawaii's families and improve their quality of life as they face the emotional and financial hardships of caring for a seriously ill child.

