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Much-needed HUGS

Help, Understanding and Group Support for Hawai'i's seriously ill children and their families

s Hawai'i 'ohana go through the unimaginable, East O'ahu-based nonprofit HUGS, which stands for Help, Understanding and Group Support, does exactly as their moniker suggests and provides them with a metaphorical embrace when the going gets tough.

The organization, which celebrates its 40th anniversary this year, makes it their mission to empower families and improve their quality of life as they tackle the tremendous adversities of caring for a child with a lifethreatening condition.

A HUGS representative typically meets the 'ohana at Kapi'olani Medical Center for Women & Children shortly after they are told the diagnosis, and provides information on how the nonprofit can be of service.

"It's very devastating," shares executive director Joan Naguwa. "They spend a good amount of time with their child in the hospital feeling panicked out and so much information is in their heads, so we initially meet them (there) and we encourage them to participate. Sometimes they will right away, and sometimes they won't. They can enter at any time throughout their journey.

"Our kids have all kinds of illnesses; we're not disease specific," she explains. "They have cancer, cardiac issues, cystic fibrosis, liver or kidney conditions, and some of them have developmental issues due to seizures. Some are diagnosed at birth and some are diagnosed further down the road."

Its Kīlauea Avenue cottage serves as a hub for the children and families under its care. Prior to the pandemic, the nonprofit would host gatherings, during which the kids could get together and, to put it simply, just be kids.

"A lot of these (children) have visual disabilities ... and there are people who stare at them or ask, 'What's wrong with you?' and that's very difficult for a parent or child to hear," explains Naguwa. "When they come to us, everybody knows that's just normal for them and say things like, 'My brother/sister/child is the same way,' and nobody talks about it — they don't stand out."

Carrying out its mission of looking out for the entire 'ohana, HUGS hosts events for moms and dads, as well as a three-day camp for siblings, too.

"We have mom's nights, where moms can meet other moms in a very relaxed setting, become friends and share stories like, 'My child has a spinal tap and was screaming and I didn't know what to do,' and another mom would say, 'Oh, my child had that. Here's what I did that seemed to work.' It's something they can't necessarily get from doctors and nurses," says Naguwa.

"One mom told me, 'You know, we have a lot of friends and we have

"One mom told me, 'You know, we have a lot of friends and we have a lot of family, but it's other HUGS families that I know who truly understand what we're going through.'

"We do the same for dads ... but dads are different," she continues. "Dads have said, 'I'm the head of the household, I'm supposed to be brave, but all these feelings are going through me and I don't want to share them with my wife because I don't want to make her more worried.' So, dads get together and they get to express some very heartfelt, meaningful fears and challenges that they only want to share with another dad.

"For HUGS families, it's like coming to a second home, and that's what we want."

Being a nonprofit, it's a full community effort to keep the wheels turning at HUGS to support its nearly 350 families that are on the roster. The surrounding East O'ahu neighborhood, in specific, has been instrumental to the operation. For example, Punahou School has a HUGS Club, during which students (prior to the pandemic) would get together with keiki one-on-one in a safe environment; other area schools have made gift baskets and sold lollipops; and a local church provided free landscaping.

"We really enjoy being in the 96816 community and we feel very thankful and blessed to have the support of the community that we do have, and we hope to maintain that."

THOSE WHO WANT TO LEARN MORE ABOUT HUGS OR SEE HOW THEY CAN GET INVOLVED AND/OR DONATE CAN VISIT HUGSHAWAII.ORG.





