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Reid and Jari Kaneshiro meet the challenge of keeping their children active. No small feat when one has Asperger syndrome and the other a rare form of epilepsy

By Cindy Luis

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*cindy ellen russell / crussell@staradvertiser.com*Jari Sagan Kaneshiro, left, and Reid Kaneshiro will walk with their children, "MJ" and Austen, at Sharon's Ride, Run, Walk for Epilepsy on Jan. 26.

Love is complex in its simplicity.

It is patient. It is kind. It never fails.

It is the core of parenting for Jari Sugano Kaneshiro and Reid Kaneshiro, whose two children have medical conditions that have been challenging and beyond.

Son Austen, who turns 8 next Tuesday, was diagnosed with Asperger syndrome, considered a highly functioning form of autism. He is smart, a bit hyperactive and loving life as a second grader at Mililani Mauka Elementary.

Daughter MaileJen "MJ" turned 5 on Jan. 2. She has Dravet Syndrome, a catastrophic form of epilepsy so rare that she is the only one in Hawaii known to have what is also called Severe Myoclonic Epilepsy.

Her days are different, where a seizure can be triggered at any time and by something as simple as being in the sun for too long. She's in kindergarten at Mililani Waena, which offers a medically fragile classroom.

Sharon's Ride, Run, Walk for Epilepsy At Kapiolani Community College >> When: Sunday, Jan. 26 >>

Bike rides: 35K, 75K and 100K, 7 a.m. >> **Runs:** 5K and 10K, 7:30 a.m. >> **Walk:** 1 mile, 8:30 a.m. >>

Also: Keiki bike safety and obstacle course, 10:30 a.m. >> **Cost:** Entry fees vary >> **Online:**

hawaiiilepsy.com

"It is challenging," said Reid, a Handi-Van driver. "With Austen, we didn't know what he had until maybe he was 4 or 5. With the right diagnosis, it's gotten way better.

"MJ had her first seizure when she was four months. It used to be she could have hundreds of small subtle seizures daily and now maybe she has 20 in a week. It's been trial and error to find the right combination of medicine.

"In the beginning, it was rough but we've adapted. We have our routine."

One thing that has become part of the family's routine is the annual Sharon's Ride, Run, Walk, a fundraiser and awareness event for the Epilepsy Foundation of Hawaii. The family is entered for the second time and will participate in the 5K run.

"It's a run but we'll walk it," said Jari, who works for the University of Hawaii's College of Tropical Agriculture. "My brother has had T-shirts made and our families and friends will be with us for 'Team MJ.'

"It's nice to be able to share what you're going through and refreshing to meet people who are walking in the same shoes. Otherwise you end up living in your little bubble."

It was difficult for the Kaneshiros to share their story about MJ because "as much as you want people to know, it's hard to open up," Jari said.

But she did it so successfully in the 2012 national "Now I Know" video contest, taking top honors in the West region.

As she said in the video voiceover, "Strangers can become family through shared experiences."

Still, it is difficult. Ask what constitutes a normal day and there is laughter.

"It's always hectic," Reid said. "MJ is so active, she wants to go, go, go. And over-exertion can trigger seizures.

"There is help out there but her condition is so rare there's only so much doctors can do right now. They're still doing research.

"My wish for her is to be able to start walking and to be able to interact with other children without us worrying that she'll hurt herself or them. She doesn't talk so she does things like pulling hair to get attention. ... It is challenging."

So they try to find a new normal, especially when it comes to sports. Reid, a self-described band geek at Farrington, enjoys playing volleyball. Jari played soccer at Aiea.

"We are sports people," she said. "We find our own ways to get the kids exercise and keep them active. We tried a lot of things with Austen and now it's swimming and singing. And MJ loves the water.

"We do have support from family and friends. My co-workers will bring us dinner or dessert, someone will offer to take Austen to a movie, do little things that make a big difference. As the years go by, people are understanding the challenges."

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