

## It's all about education

The Shimabukuro family's video about their son's epilepsy is meant to help others

By [Cindy Luis](#)

POSTED: 01:30 a.m. HST, Jan 25, 2013



Life is one big game of chance.

What are the odds that two brothers would be going up against each other as head coaches in the Super Bowl?

The American Statistical Association puts Jim and John Harbaugh's rare feat at 1-in-255.

What are the odds of someone in the U.S. will be

diagnosed with epilepsy?

A surprising and scary 1-in-26.

Jax Shimabukuro is one of those "1s." The 3-year-old was diagnosed at 17 months after suffering febrile seizures (seizures accompanied by fever).

"It was scary, I didn't know a single person with epilepsy," Jax's mother, Lacey, said. "I had heard of it but didn't know the full spectrum of epilepsy.

"My first thought was what restrictions he'd have. Will he be able to go to school? To play sports? To have a normal life? Now we know he can do everything and anything he wants."

It is all about education when it comes to one of the most misunderstood and misdiagnosed of all diseases. Lacey, husband Gavin and 6-year-old son Ty learned together and, with help from the Epilepsy Foundation of Hawaii, have passed on the information to family, friends and co-workers, as well as teachers and classmates of both Ty and Jax.

The Shimabukuros' message has been simple yet very successful. More than 30 relatives and friends will join them Sunday for the 1-mile walk portion of the annual Sharon's Ride/Run/Walk, a benefit for the Epilepsy Foundation of Hawaii.

The journey does not end there for the young Newtown family. Their video, titled "Now I Know ... Jax," is among a dozen finalists for the Epilepsy Foundation of America's national video contest.

The Shimabukuros' submission shows Jax as the active child he is: swimming, doing gymnastics, playing at the beach, riding his tricycle, on the playground slide.

It also shows him having a seizure because, his parents said, it's part of who he is.

"It has affected our lives," said Lacey Shimabukuro, who works in real estate and with her family's Kabuki restaurants. "We have to remember to bring the medication with us when we go out, always watch him on the playground. It's part of our daily regimen.

"He loves the playground, he loves the water. We knew we couldn't hold him back."

## **SHARON'S RIDE/RUN/WALK**

*Sunday, Kapiolani Community College*

>> **Ride:** 35K, 75K, 100K, 7 a.m.

>> **Run:** 5K, 10K, 7:30 a.m.

>> **Walk:** 1 mile, 8:30 a.m.

>> **Keiki bike and safety course:** 10 a.m.

>> **Online:** [hawaiiepilepsy.com](http://hawaiiepilepsy.com)

"We never dwelled on it," said Gavin Shimabukuro, a project manager at HMSA. "At first, we didn't know too much but we found a lot of information.

"It's part of our life."

The Shimabukuros initially hesitated about making a video that would be posted on Facebook.

"I wasn't sure that I wanted our family photos all over the Internet but it was a good way to share and to educate," Lacey Shimabukuro said. "Jax's story is a story of family love.

"We didn't do it for the prizes. We did it to help people learn about epilepsy."

It's been a commitment almost from the moment of Jax's diagnosis. Sunday will be the family's second "Sharon's" event and they also have participated in the past two Epilepsy Freedom Walks held on the Fourth of July.

In April, the family will travel to Washington, D.C., for the national walk as a way to give back to the organization that has done so much for them.

Currently, Jax's condition is controlled with medication. If he is seizure-free for two years, he will be allowed to go off the medication.

"Jax watches his brother Ty playing sports, flag football, soccer, baseball," Lacey Shimabukuro said. "He is always wanting to go out there.

"He's ready to go and we know, when it's time, he'll be able to do it. Epilepsy is different for everyone and we feel very fortunate that Jax can and will do so much."

Voting for the "Now I Know" video contest runs through Feb. 1 at [www.facebook.com/EpilepsyFoundationofAmerica/app\\_202991206406825](http://www.facebook.com/EpilepsyFoundationofAmerica/app_202991206406825). Click on the "Video Contest" link.

There are two finalists from Hawaii, the Shimabukuros' submission and that from Jari Kaneshiro Sugano's on her daughter MJ Kaneshiro's battle with Dravet Syndrome, a more severe form of epilepsy.

As of Thursday, both Hawaii entries were among the top three receiving votes.

[Mariota says Ducks will have to keep foot on the gas](#)

[Manziel rues conduct: 'I've done this to myself'](#)

[UH basketball team rolls past Southern](#)

[Lions DT Suh suspended for stepping on Packers QB Rodgers' leg](#)

[USC's Leonard Williams declares for NFL draft](#)

[Davis wins AP Female Athlete of the Year honors](#)

[Kiffin says he's staying at Alabama next season](#)

[Falcons fire Mike Smith after 2nd straight losing season](#)

---

*Copyright (c) Honolulu Star-Advertiser*