



After 10-year search, Vancouver family finds cause of son's seizures

10-year-old Emmett one of two people in world diagnosed with Jordan's Syndrome

By [Wyatt Stayner](#), Columbian staff writer

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Elliott, 10, plays in his ball pit at home in Vancouver. Emmett was diagnosed with a rare neurological disorder called Jordan's

Syndrome
earlier this
year. The
disorder can
cause
intellectual
delay,
hypotonia, or
low muscle
tone, impaired
speech,
developmental
delays, autism
spectrum

disorder and
seizures.

(Photos by
Alisha
Jucevic/The
Columbian)

[Photo Gallery](#)

Sharon and Isaac Elliott have become mostly accustomed to the seizures.

They are part of everyday life in the Elliott household in Vancouver. The Elliotts' 10-year-old son Emmett has been experiencing seizures since he was 6 months old. He experiences them two to four times a week generally. Oftentimes, they go away on their own. Sometimes, they don't and Emmett has to visit the hospital or emergency room. One time, he was put in a medically induced coma as his body fought a seizure because the hospital drugs didn't stop it.

"It's just how our life is," Sharon Elliott said.

For about 10 years, the Elliotts searched for a reason for the seizures. They've been to Oregon Health & Science University in Portland for testing. They traveled to Seattle Children's Hospital for years as doctors tested for new causes. Each result came back negative. Each result chipped away at hope.

“I started accepting the current status of not having answers,” Isaac Elliott said. “No one really knowing what was happening for a while.”

“It’s just that the odds start to get worse and worse, lower and lower as the years went by,” his wife Sharon Elliott added.

Then, in March, the Elliotts received a diagnosis. After Emmett’s geneticist pushed their insurance company to cover comprehensive testing, it was discovered that Emmett had Jordan’s Syndrome, a rare neurologic disorder that can cause intellectual delay, low muscle tone, impaired speech, developmental delays, autism spectrum disorder and seizures. Emmett has all those symptoms, plus cortical visual impairment.

IF YOU GO

What: A costume contest for dogs and humans to raise money for Jordan’s Syndrome research

Where: Fido’s, 7700 S.W. Dartmouth St., Tigard, Ore., Suite 110.

When: 6 to 9 p.m. Oct. 5

Website: facebook.com/events/2484487765113647

Donate: jordansguardianangels.org/how-to-help

The disorder was first discovered in a California child named Jordan Margaret Lang. It stems from a mutation on the PPP25RD gene. Emmett’s variation is the PPP25RC gene. Sharon Elliott said that mutation is a cousin in the Jordan’s Syndrome family.

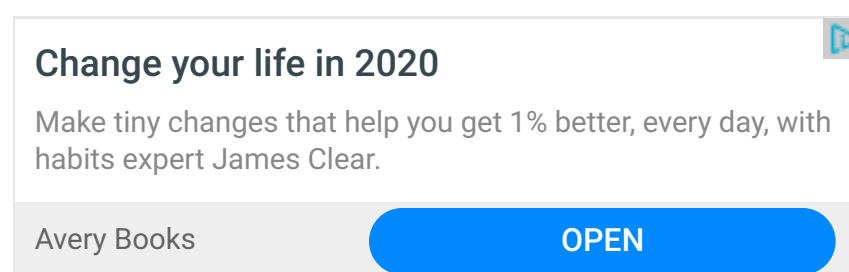
Emmett is one of two diagnosed people with the PPP25RC mutation.

“There’s 3 billion letters in our genetic code and Emmett’s is off by one letter,” Sharon Elliott said.

Now that Emmett has received a diagnosis, the Elliotts have been active in raising awareness about the disorder, fundraising for research and contributing in whatever ways they can. There are more than 100 confirmed cases of Jordan's Syndrome in 19 countries, according to Jordan's Guardian Angels, which leads large-scale research on the disorder. However, Jordan's Guardian Angels believes there's about 250,000 undiagnosed cases of Jordan's Syndrome.

The comprehensive genome sequencing that discovered Emmett's diagnosis is expensive, and not covered by many insurance plans. The Elliotts are advocating for testing that can be more affordable and easier to receive.

"In theory, a lot of people who have some of those symptoms are currently undiagnosed," Isaac Elliott said. "If they can get them onto easier and cheaper panels, we'll start seeing more cases accurately diagnosed Jordan's Syndrome."



While it's difficult to project research breakthroughs, Jordan's Guardian Angels said on its website it believes it can develop treatment for the condition within six to 10 years. The Elliotts are hopeful they can help.

"Our contribution from his experience, what has worked for him, what has not, can go out there to other people when they get diagnosed now, and we can contribute and hopefully help other people's lives be better," Isaac Elliott said.

For now, the Elliotts are attempting to give their son the best possible quality of life. Emmett has self-injurious behaviors, such as hitting his head on his shoulders or hitting his head with his hands because he wants the stimulation. He frequently wears shoulder pads to protect himself.

The Elliotts describe Emmett as sweet and great at connecting with others. He enjoys sensory activities such as playing on swings, in his ball pit or with water beads. Emmett has a younger brother named Sebastian who's now 5 and is neurotypical. He and Sebastian recently started taking private swimming lessons. The teacher remarked it's one of the few things the brothers can enjoy together. The Elliotts like seeing their sons share normal sibling moments.

“I love seeing them connect on anything,” Isaac Elliott said. “Like when Sebastian is sitting next to him playing with a toy, and Emmett just takes it. Stuff kids do all the time. I love seeing those interactions when they connect.”



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