

Pot med is life changer for tiny Sadie

By J. Harry Jones April 28, 2015



Sadie Christina Higuera, 1, (will be 2 on May 4th) spends time at home with her parents Damaris (left) and Brian (right) on Friday evening in Ramona, California. Sadie has a rare genetic disorder and a medical marijuana based substance has almost stopped the 300/day seizures she was having. — *Eduardo Contreras*

RAMONA — Sadie Higuera, not quite 2, has a rare and terminal genetic disorder that affects every cell in her body. At 8 months old she was suffering roughly 300 grand mal seizures a day, no matter what medications doctors prescribed, her parents said.

For the past year, however, those seizures have dropped to three or four a week — an astounding transformation that her dad Brian Higuera credits to a liquid form of medical marijuana.

Medical marijuana has its skeptics and researchers warn that the long-term effects — and potential side effects — of the drug have not been studied fully.

But the Higuera family said the drug's benefits for their daughter have been undeniable.

Sadie has Schinzel-Giedion Syndrome, a condition so rare that there have been less than 60 cases diagnosed worldwide since 1975. The syndrome causes severe retardation, horrible kidney problems and myriad other issues. Seizures can be relentless.

"You can't really do much but sit and watch and hope it stops," said Brian Higuera, a plant engineer at Qualcomm. He and his wife Damaris, live in San Diego Country Estates in southern Ramona with Sadie, and two other healthy daughters, Dina, 5 and Sophie, 3.

Nobody knows what causes Schinzel-Giedion. Sadie was medically fragile from the moment she was born. She spent the first 2 1/2 months of her life in the hospital. She was born with numerous skeletal anomalies and

kidney problems, and without critical neural fibers in the brain that connect the left and right cerebral hemispheres. Doctors knew she was very sick, but didn't know exactly what was wrong with her.

When she was finally discharged, the family boarded a plane bound for the Mayo Clinic in Minnesota "because we didn't have any answers about what her diagnosis was," said her father.

Doctors at the Mayo Clinic identified her disorder as Schinzel-Giedion and gave her less than a year to live, her parents said.

"Her whole life she had this twitching thing and while we were at the clinic she had her first grand mal seizure. From there it got seriously worse fast," Higuera said.

Over the next six months six different types of anti-seizure medications and steroids were given to Sadie. The results made things only worse. The seizures continued, and tumors grew in her body.

"She was intubated all the time," her mother said. "She didn't open her eyes. She was having seizure all the time and yet was sedated all the time." None of the doctors — and Sadie had a plethora of specialists — had solutions, Higuera said. The steroids were making her body shut down and bloat. The Higueras were told they could put her on a different medicine which would ease her pain but would likely kill her within a couple months.

"We were in shock," Higuera said. "What do you mean we don't have any more options for our baby?"

When Sadie was about 9 months old, following a visit with another local doctor who told them there was little to do, Brian began researching medical marijuana. That night he stayed up until 2 a.m. on the Internet and the next morning started calling around seeking a doctor who would help. Several doctors' offices hung up on him after hearing he was looking for a marijuana prescription for a 9-month old girl.

"I don't think they believed me," he said.



Sadie Christina Higuera, 1, (will be 2 on May 4th) spends time at home with her mother Damaris on Friday evening in Ramona, California. Sadie has a rare genetic disorder and with a medical marijuana based substance has almost stopped the 300/day seizures she was having.

– Eduardo Contreras

He eventually found Centric Wellness in San Diego, a holistic and alternative healing clinic, who gave him a prescription for a medical marijuana oil. Sadie's mother was so nervous that she had to leave the house the first time Higuera placed two drops of the medicine into his daughter's mouth.

"After about 10 minutes I noticed her eyes weren't twitching," he said. "I was like, Oh my God, are you really focused on me? She was actually looking at me and her arms weren't twitching."

When Damaris came home she took one look and started to cry.

"My baby was back," she said. "She was swinging on the swing, her eyes were open. I was talking to her and she was pulling me. She was squeezing my finger."

Sadie is fed and receives her medication — a product called Real Scientific Hemp Oil, made by Poway-based HempMeds — through a tube in her stomach. The oil contains very low levels of THC — the compound in marijuana that produces its psychotropic high — and high levels of cannabidiol, a chemical that some studies have shown to produce positive effects on certain illnesses.

Dr. Mark Rabe, of Centric Wellness, said in Sadie's case, medical marijuana oil has been life saving.

"While on multiple pharmaceutical drugs, Sadie was getting hundreds of seizures per week and was having dangerous side effects. Her condition was deteriorating," Rabe said. "Now off the drugs — and with treatment that is high in the non-psychoactive cannabinoid — Sadie is almost seizure-free," Rabe said.

"She is also much more alert and responsive, and she has achieved developmental milestones that were previously thought not possible," Rabe added. "On top of that, she is having no side effects from her herbal-based treatment."

Sadie coos like a 3-month old baby, when before she barely made any noise, her father said.

"It's a quality of life thing," he said.

There is still resistance in the United States to marijuana and hemp based medication. But the tide is turning as research continues and legislation is proposed, said HempMeds spokesman Andrew Hard.

"To me this should be a national health story," Hard said. "There is a stigma and opposition to this. But out there, through all the BS, you have Sadie and (other) children. You have these parents who have been through this and have their stories."

Rabe said doctors and scientists don't know exactly how the cannabinoid components of the marijuana plant make seizures go away.



Brian Higuera (left) removes the feeding tube of his daughter Sadie Christina Higuera, 1, (will be 2 on May 4th) on Friday evening in Ramona, California. Sadie is being held by her great grandmother Candy Barrows.

– Eduardo Contreras

"As seen in cases like Sadie's, though, the end-results are often quite remarkable," he said.

The hemp-based drug does not have a THC base, the chemical that gets people stoned. The medication is very expensive — between \$1,200 and \$1,400 a month.

"It's worth every penny to us," said Brian Higuera.

The family's insurance company won't reimburse the cost of the hemp product because it is not recognized as medicine by the Federal Drug Administration.

Brian Higuera has become a medical marijuana advocate. He is often put into contact with other parents seeking help for epileptic children and in some cases children with autism.

"After what's happened to us, how could I not be an advocate?" he said.

© Copyright 2015 The San Diego Union-Tribune, LLC. An MLIM LLC Company. All rights reserved.