

# Medical marijuana: Could pot stop this baby's seizures?

**Toronto parents struggling with baby Kaitlyn's Dravet syndrome call for clinical trials here after miraculous results in Colorado.**



BARRY POGSON

Nine-month-old Kaitlyn Pogson suffers from Dravet syndrome, a severe form of epilepsy that results in frequent seizures - up to 300 per day. Her parents are encouraged by stories out of Colorado, where a special strain of cannabis is reducing the number of seizures suffered by children with otherwise untreatable epilepsy.

**By:** Marco Chown Oved — THE STAR Staff Reporter  
Published on Thu Jul 18 2013

Kaitlyn Pogson has lived through more seizures than calendar months.

The 9-month-old's epilepsy sends her tiny body into convulsions that last up to an hour. Right now they happen every three days, but as she grows the seizures will become more frequent — potentially topping 300 per week.

That's one every 34 minutes.

Every time she has a seizure, Kaitlyn's parents, Barry and Shannon, call 911 and take her to the emergency room, where doctors give her antiseizure drugs that don't work. It's a frighteningly repetitive routine.

Kaitlyn's condition is so severe they have a special name for it: Dravet syndrome. Not only does it grow worse over time, it's notoriously resistant to traditional medication.

But a growing number of doctors and families with Dravet say they've stumbled upon a miracle drug: marijuana.

"Kate is on morphine and three other drugs not normally given to children," and they're not working, Barry said. "Rules are already being broken. So why not this one?"

Dravet syndrome, also known as Severe Myoclonic Epilepsy of Infancy (SMEI), is a catastrophic form of epilepsy that occurs in one in every 30,000 births. Besides leading to developmental delays, the syndrome is also associated with higher rates of sudden unexplained death.

When Kaitlyn had her first seizure at barely 2 months old, Barry didn't even know what a seizure looked like. Now, between hospital visits and work, he's been researching online and discovered the story of a little girl in Colorado who was able to reduce her seizures by more than 99 per cent.

With a small dose of marijuana extract administered orally three times a day, little Charlotte went from being "flaccid, lying in her mothers arms and unresponsive," to a walking, talking little girl, said Dr. Alan Shackelford, who oversaw her treatment.

"The response was instantaneous," Shackelford told the Star by telephone. "After the first dose, the seizures stopped ... and she didn't suffer a seizure for seven days."

Charlotte now suffers one seizure every other week, Shackelford says, "a remarkable and heretofore unprecedented change."

The key is a strain of marijuana that is high in the active substance Cannabidiol (CBD) but very low in THC, the chemical that gets you high.

Shackelford says Colorado's liberal marijuana laws allow doctors like him to perform "valid observational study" and publish their results. But federal regulations are still formidable barriers for any doctor to undertake formal clinical trials with a Schedule 1 controlled substance like cannabis.

“We need to study this to know what’s going on, what dosages work best and develop treatment for children and adults alike,” said Shackelford.

At New York University, Dr. Orrin Devinsky has just received FDA approval for a clinical trial to study the safety and tolerability of CBD in children with epilepsy.

“At this point, I think we really lack much data,” said Devinsky, who points to promising results in animals, but says the real push came from the anecdotal evidence provided by parents in Colorado.

“I’ve spoken with these parents, and I think they’re solid, good, loving parents, who’ve had very good experiences. Whether this will be borne out by scientific studies is uncertain,” he said.

If the trials go perfectly and there are no setbacks, Devinsky estimates that CBD could be approved in the U.S. in two to three years.

In that case, parents from across the country — whether in pot-friendly Colorado or pot-hostile Texas — would have access to the drug.

But in Canada, despite our relatively liberal medical marijuana laws, there still isn’t a single trial or study taking place on the use of high-CBD marijuana for juvenile epilepsy.

Health Canada rules allow anyone suffering from epileptic seizures to apply for a licence to possess marijuana for medical purposes. With that licence, you can also apply to grow your own marijuana.

The problem for the Pogsons is that the marijuana available in Canada has far too little CBD and too much THC to treat an infant like Kaitlyn.

“CBD is very difficult to procure. It’s a freak form of marijuana,” said Barry. “You can’t import it to Canada.”

The Pogsons have started [an online petition calling on Health Canada](#) to allow CBD into the country and to sponsor medical trials to study CBD’s benefits and the appropriate dosages.

“There isn’t really any other solid hope for a treatment out there,” said Barry. “All the drugs either don’t work, or start out working and then stop.”

In the past few months, the Pogsons moved out of their new house near Oshawa and into a condo downtown, to be closer to the Hospital for Sick Children. They take shifts watching over Kaitlyn while she sleeps, for fear of a nocturnal seizure. They’re exhausted, irritable and have very little hope things will improve in the near future if they can’t somehow bring CBD into the country.

“This could be what she needs,” Barry said.

### **Medical marijuana without the high**

Marijuana growers in Colorado have developed a special strain of pot with very little THC — the chemical that gets you high — and very high Cannabidiol (CBD), the component believed to reduce seizures. They’ve dubbed it “Charlotte’s Web” in honour of their first patient.

In a [video detailing Charlotte’s turnaround](#), grower Josh Stanley says the strain, which has only 0.5 per cent THC and 17 per cent CBD, is “the future of medical marijuana.”

A similar strain is being developed in Israel, says Dr. Alan Shackelford, who hopes to secure funding to conduct clinical trials there.

GW Pharmaceuticals in the UK is developing a CBD medication to treat epilepsy. The company, which specializes in drugs made from cannabinoids, has a spray that contains a 1:1 ratio of CBD to THC content that’s currently available to multiple sclerosis patients in Canada and holds high hopes for a future CBD-heavy medication.

“There’s been some very promising preclinical work,” said company spokesman Mark Rogerson. “We think that there is definitely scope for clinical trials for a product like this.”