



Alexander Repetski cuddles with his 16-month-old daughter Gwenevere in their Toronto home on November 6, 2013. (Jennifer Roberts for The Globe and Mail)

Is medical marijuana safe for kids?

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At 16 months old, Gwenevere Repetski cannot walk or say “mama” and “dada.”

Her father, Alexander Repetski, hopes that cannabidiol (CBD) – an ingredient in medical marijuana – will help Gwenevere recover from infantile spasms, a rare form of epilepsy that has delayed her development by at least six months.

Repetski, who lives in Thornhill, Ont., said he has read news reports about oil of cannabidiol and spoken to more than 60 parents who say CBD oil has helped reduce their children's seizures. And he is frustrated that CBD oil has not been approved by Health Canada.

"There's very little, to no chance, it could hurt [Gwenevere]," Repetski said, but "it could have great beneficial effects for her."

When conventional medicine fails, resorting to experimental treatments is a gamble that many critically ill patients and their families are willing to take, even if it means putting faith in anecdotal reports instead of clinical trials – and taking unknown risks.

But unlike many untested treatments for serious diseases, concentrated CBD may soon be available to Canadians in the form of dried marijuana.

In April, Health Canada enacts new medical marijuana rules that will allow licensed commercial producers to sell marijuana strains that have been genetically modified to contain high levels of CBD and low levels of the plant's psychoactive ingredient, THC.

Already, companies such as Toronto-based MediJean have applied for licences to produce medical marijuana similar to Charlotte's Web, a high-CBD strain bred by the Stanley brothers of Colorado and named for a young epileptic patient named Charlotte.

"We will be creating a special formulation for children," said MediJean's chief strategy officer, Anton Mattadeen. Children will use the product in a vaporizer instead of smoking the plant, Mattadeen said.

Demand for CBD is high. More than 7,500 people have signed a petition urging Health Canada to overturn its decision to exclude CBD oil from its Special Access Program, which allows patients with life-threatening conditions to obtain drugs that are not authorized for use in Canada.

The urgent call for an experimental treatment is understandable among parents whose children are very ill, said Dr. Kerry Bowman, a bioethicist at the University of Toronto.

But whether they obtain CBD oil illegally or get a doctor's prescription to give medical marijuana to their kids, parents will be taking chances with potential risks, he added.

Anecdotal reports suggest that CBD may reduce children's seizures and even help restore cognitive abilities. "But we've been down this road with other things, like [liberation therapy] for multiple sclerosis," Bowman said. "You had people swearing that this has changed their lives and then it really did not hold up to randomized clinical trials," he said.

In this case, however, the patients are children who cannot give their own consent, he pointed out. Normally, the best way to make medical decisions for children "is a risk-benefit equation," Bowman explained. In the absence of medical data for CBD, substitute consent is on shaky ethical ground, he said.

The only evidence to support the use of CBD to date consists of anecdotal reports and rat studies. Neither provides a basis for medical treatment, said

Dr. Mary Connolly, director of the epilepsy program at BC Children's Hospital in Vancouver.

"We have lots of parents who would like to take their children off medication and try CBD, without having all the facts," she said.

As media hype outpaces medical progress, researchers are scrambling to find answers for parents of children with treatment-resistant epilepsy, which affects 30 to 40 per cent of children with seizure disorders.

A clinical trial of CBD in children with epilepsy is under way at New York University. In Calgary, a pediatric neurologist has a proposed study of CBD (but declined an interview request). Another Canadian team is looking into the feasibility of conducting a clinical trial at the Hospital for Sick Children in Toronto.

Setting up a randomized controlled trial would require access to a source of medical-grade CBD, funding for the study and approval from an ethics board and Health Canada, among other steps, said Dr. Shelly Weiss, a neurologist at the Hospital for Sick Children who is part of the team considering a clinical trial.

Even if CBD is proven to reduce seizures, rigorous study would be needed to determine the proper dosage, potential interactions with other medications and possible short- and long-term side effects, Weiss said.

A scientifically validated CBD treatment is “not something that’s going to be available in the near future,” she added.

But the pace of medical research may be too slow for children such as Gwenevere, who may suffer irreversible damage from her form of epilepsy, Repetski said. For most of her life, Gwenevere has been on potent medications with dangerous side effects to control her disorder, which causes chaotic brain waves and clusters of up to 100 spasms at a time.

Repetski said he hopes to get a doctor’s prescription for high-CBD medical marijuana to give to his daughter. But he acknowledged that “if I’m baking it in cookies or making it into butter, I can’t control the dosage.” Repetski added he will either hire a private lab to analyze the CBD levels of a medical marijuana product, or move his family to Colorado to obtain CBD oil from the Charlotte’s Web strain.

The clock is ticking on Gwenevere’s chances of making cognitive improvements, he said. The longer she has uncontrolled brainwave patterns, he said, “the more damage is being done.”

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