Carolyn Hill

From: diana lejins <dianalejins@yahoo.com>

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Cc: Diana Lejins

Subject: Family moves to save daughters life.......

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Wisconsin Family to Move to Colorado So Daughter, 4, Has Access to Marijuana

Elise SoléSenior WriterApril 23, 2015





A Wisconsin family who's desperately seeking medical marijuana to treat their young daughter who suffers from a seizure disorder is raising money to move to Colorado to legally access the drug.

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Vicky Pletka's 4-year-old daughter, Lily Pletka-Wirth, who suffers from autism and several other developmental delays, also has a rare disease called **Dravet syndrome**, a severe form of epilepsy that can't be controlled by medicine and leads to death in 1 out of 5 cases. Pletka says Lily would likely benefit from using medicinal marijuana, but she says it's not easy to get in Wisconsin.

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Currently 23 states have legalized cannabis for medicinal use for a variety of diseases and conditions, including epilepsy, glaucoma, cancer, and HIV. Studies suggest that THC, the chemical that triggers the psychological effects of marijuana, and a chemical called CBD may inhibit areas of the brain connected to epileptic seizures, although some experts say more research is needed. Anecdotally, though, the drug appears to be helpful.



Lily Pletka-Wirth suffers from Dravet syndrome, a severe form of epilepsy. Her parents are trying to move to Colorado, where they can get medical marijuana to ease her symptoms. (Photo: Courtesy of Vicki Pletka)

In Wisconsin, Lydia's Law (named for Lydia Schaeffer, who suffered and died from seizures at age 7) was signed into effect by Gov. Scott Walker in 2014. In theory, the law permits epileptic children to be treated with cannabis oil, but it's riddled with roadblocks. For starters, it's illegal to grow marijuana in Wisconsin and to bring it in from other states. The law also requires doctors to obtain an investigational drug permit from the FDA, but according to a story published by the Wisconsin State Journal, many hospitals don't have the time or resources to begin the FDA process. On Thursday, Wisconsin state Sen. Van Wanggaard asked for support for a proposal to decriminalize the possession of CBD, but that's not enough for the families who are desperate for solutions right now.

"Lily is one seizure away from possible death," Pletka, 35, a mother of four in Milwaukee, tells Yahoo Parenting. While pregnant, Pletka and her partner, Rosie Wirth, 30, discovered that Lily was missing part of her brain, and doctors explained that if the girl did survive the birth, she would likely be in a vegetative state or suffer from lifelong seizures. Lily's seizures occur almost daily and can last as long as a few seconds to a few hours. "Lily needs around-the-clock care and cannot be left alone, even for a minute," says Pletka, a stay-at-home mom. "When we use the bathroom, we just take her with us."

When Lily leaves the house, she uses a wheelchair, but her immunity is so low (a common cold can trigger seizures) that she's prevented from being that active. Other triggers for Lily include bathwater that's too hot or cold, or flashing lights. If she were able to use medicinal marijuana, she would use cannabis oil in a dropper or through her feeding tube, which she uses to treat a swallowing disorder.

In Colorado, Lily can obtain cannabis oil and be treated by a doctor who specializes in Dravet syndrome. She can also have a seizure response dog regardless of her age, and her parents can be certified as nursing assistants so that one or both can care for Lily full-time while earning wages from the state. To fund their moving expenses and Lily's medical care, the family is currently selling their belongings (they also launched a GoFundMe page in 2013 that's raised \$1,600) and between the two endeavors, they've raised \$3,800. "We need \$5,000 to move to Colorado," says Pletka. "We'll figure out the rest when we get there."

Lily's story is a common one, Chris Brown, spokesperson at Americans for Safe Access, a grassroots movement that aims to provide safe and legal access to medical marijuana, tells Yahoo Parenting. "The FDA hasn't approved marijuana for medicinal purposes because it's a schedule I drug, and a primary concern for opponents is that there's no system in place to monitor its use," he says. What's more, controlled studies are needed to prove its effectiveness, and there's concern that medicinal use will lead to recreational use.

For now, families like the Pletka-Wirths will do whatever they can to care for their children. "When you look at Lily, she looks like any other normal kid — she laugh, sings, and talks," says Pletka. "You would never guess she's a ticking time bomb."

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