

Inquiring Minds topic for 28 February 2014

Dick Rockstroh, Moderator

Families move to Colo. for 'miracle' marijuana

Greta Botker has been through more adversity in her short life than most adults. At the age of 7, she's sampled a host of medications for her epilepsy: Onfi, Depakote, Felbatol, Keppra and Prednisone.

She's been on strict diets.

She's had brain surgery.

Nothing reduced the 15 or so seizures she had every day since she was 5 months old that kept her from walking steadily, feeding herself or talking. Her parents, Maria and Mark, had run out of options.

Then they heard about a strain of marijuana grown in Colorado that reduced the number of seizures in children with severe epilepsy.

"We really tried everything with Greta," says Maria Botker, a nurse. "We put our child through brain surgery, so a plant like marijuana was not going to scare me."

In November, Maria and Greta headed west to find a miracle. Mark and the couple's two other daughters, 13 and 10, stayed on the family's farm in Minnesota.

Maria and Greta joined a migration of parents who, after trying countless methods to ease their children's crippling seizures, are packing up their families and moving to Colorado.

The state has become a refuge for those families for two reasons: Colorado has the most liberal laws for use of marijuana, and it has opened a market for a strain called Charlotte's Web that is believed to be effective for people with severe epilepsy.

At the beginning of the year, Colorado became the first state to allow recreational marijuana use for adults. It has permitted medical marijuana since 2000. Twenty states and the District of Columbia allow medical use of marijuana, but the diseases for which it is allowed vary. Washington state also has legalized recreational marijuana, but the law hasn't gone into effect.

Realm of Caring, a Colorado foundation started by the family that grows Charlotte's Web, has 100 patients whose families have moved to Colorado from 43 states and two countries, says executive director Heather Jackson. It has a waiting list of more than 2,000 people, she says.

In all, the foundation has more than 300 medical marijuana patients, 200 of them children, Jackson says.

It's the latest development in a movement that began in 1996, when California became the first state to legalize medical marijuana, says Allen St. Pierre, executive director of the National Organization for the Reform of Marijuana Laws, a pro-marijuana group. Since then, he says, NORML has fielded thousands of calls from people who want to move to states with medical marijuana.

"Our advice is ... if you can do it, literally get on a plane and fly west," he says.

Diane Fornbacher, 36, an advocate for legalizing marijuana, will move next month with her husband and two sons from Collingswood, N.J., to the Denver area, so she can use marijuana to manage her post-traumatic stress disorder. She says the condition was brought on by a turbulent childhood in which her mother killed her stepfather, then herself.

Although New Jersey is one of the states that allow medical marijuana, it does not consider PTSD a qualifying condition for its use.

Many of the Colorado newcomers have settled along Interstate 25 between Denver and Colorado Springs, where Charlotte's Web is grown.

The strain is high in cannabidiol, an ingredient in marijuana considered to have medical applications, and low in tetrahydrocannabinol, or THC, which causes people to get high. The strain is taken in liquid form, not smoked.

Charlotte's Web is named after Charlotte Figi, the first child to try the strain two years ago. Charlotte, who was 5 at the time, suffered 60 seizures a day. Now, her parents say, she has none.

Cannabidiol is believed to act as a brake on parts of the brain that cause epileptic seizures and as a stimulant in other parts that help reduce them, says Igor Grant, director of the University of California's Center for Medicinal Cannabis Research.

The science behind it remains unproven, so the Botkers are relocating on a gamble.

The Epilepsy Foundation and the American Epilepsy Society do not expressly tell families not to use medical marijuana, but they warn there is not enough research to show whether it is safe and effective. They urge patients to work with a doctor to determine the best treatment.

Sharon Levy, a pediatrician who directs the Adolescent Substance Abuse Program at Boston Children's Hospital, warns against using marijuana for any purpose. She says it has been proved to have negative long-term effects on children, such as impaired brain function and addiction. Though cannabidiol has shown some success in suppressing seizures, she says, there is no research to guide parents on dosages or long-term effects.

"Marijuana is not a medicine," she says.

Joel Stanley, one of the six brothers who grow Charlotte's Web, says 85% of people taking it have seen reductions in seizures.

A handful of patients have seen their seizures end altogether. In 2012, Jackson's son Zaki, who is 10, was the second child to use Charlotte's Web. Jackson says he has gone almost two years without a seizure.

The successes are anecdotal, but Stanley says the foundation is working with chemists and researchers to document the drug's effectiveness.

Families say the unknown is worth the risk. The alternative, they say, is their child's death.

The Botkers wasted no time getting to Colorado. They bought a house. Maria obtained a Colorado driver's license. Following state requirements, they took Greta to two doctors who signed off on medical marijuana for her and got on Realm of Caring's waiting list. By November, they had settled just south of Denver.

It is the latest chapter in an odyssey that began when Greta was 5 months old and her mother noticed the first seizures. The couple took her to specialist after specialist until one diagnosed her with infantile spasms, which evolved into a rare genetic disease called Lennox Gastaut syndrome, a severe form of epilepsy. The doctor told them Greta would have developmental delays, difficulty with basic functions such as walking and feeding herself, and extreme seizures that would be hard to control.

She was 7 months old.

An array of medications didn't cut the number of seizures. When she was almost 5, Greta had brain surgery. It didn't work.

When they heard about Charlotte's Web on CNN, the Botkers saw it as a lifeline.

Leaving the tightknit western Minnesota community of Clinton and splitting up the family was something they had to do, Maria Botker says.

She telecommutes for her job as an administrative nurse at a Minnesota hospital. Greta, who has the developmental capacity of a 2-year-old, goes to first grade. Mark and the older girls visited during the holidays. The parents switch off every few months, so each can spend time with all their daughters.

"We are a close family, and we love our community," Botker says, "so being away has been really hard."

But they've formed another community with families who are also grasping for hope.

Anna and Biagio Burriesci live four blocks from the Botkers with their 6- and 4-year-old sons and 2-year-old daughter, Grace. In November, the family moved to Colorado from New York City, where they grew up, to find help for their daughter.

Grace is a friendly toddler with a sweet smile and curly black hair. Like Greta, she was born healthy. She began having seizures when she was a year old, her father says — as many as 300 a day.

"She'd be walking and just drop to the floor," Biagio Burriesci says. She was diagnosed with Dravet syndrome, a rare condition with seizures that are difficult to control, cause physical and cognitive delays and can lead to death.

When the family learned on Facebook about a family moving to Colorado last summer, "hoping for a miracle," Burriesci, a former paramedic, says they began researching.

"This condition ultimately meant death for our kid, so we were going to war for her," he says. "Families are desperate."

By the end of the summer, Grace was on Realm of Caring's waiting list for the drug.

The family sold their house in Queens, losing about \$200,000, Burriesci says. He left his job as a New York City police officer and hasn't been able to find work in Colorado.

"We gave up everything," he says. Anna, an emergency room nurse, found work in a hospital. He stays home with the children.

The sacrifice pales in the face of the upside, Burriesci says. Gracie, as she's known to her family, receives 0.7 milliliters of liquid marijuana three times a day. Her seizures are down to five a day, her father says. She is walking better and learning to speak.

"We feel like we found our miracle," Burriesci says.

For the Botkers, hope costs \$600 a month, which is not covered by insurance. It is worth it, Maria Botker says. Greta is down to four to six seizures a day. She's on two of the five medications she used to take.

Botker is fighting to get medical marijuana approved in Minnesota. Then she and Greta could go home.

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Next page: article from the Tampa Bay Times 28 January 2014:

Questions and answers about medical marijuana in Florida



Stephen Nohlgren, Times Staff Writer

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Monday's Florida Supreme Court ruling puts medical marijuana on the November general election ballot. If the proposed constitutional amendment passes by at least 60 percent of the vote, state health officials will have to sort out many details before patients can legally obtain pot. Some specifics, however, are outlined in the proposed amendment. Here is what is known about how medical marijuana would work in Florida:

Who could use medical marijuana?

A person with a doctor's certificate stating that the patient qualifies for medical marijuana. The Florida Department of Health would issue an identification card to be shown at purchase. The card would let law enforcement know the patient can possess amounts set by law.

What medical conditions would qualify?

Specific diseases or other "debilitating" conditions for which the doctor thinks benefits of use would outweigh risk. Cancer, glaucoma, HIV/AIDS, hepatitis C, ALS, multiple sclerosis, Parkinson's disease and Crohn's disease are all specified.

When could a patient start legally using marijuana?

The effective date of the amendment is Jan. 6. After that date, the Department of Health must implement regulations within six months and begin issuing identification cards within nine months. If the department fails to issue cards within nine months, the doctor's certification will serve as identification.

How much marijuana could a patient possess?

That will be determined by the Department of Health, based on what is "reasonably presumed to be an adequate supply." Patients who think they need more could appeal. Marijuana, oil, tinctures and cannabis-laced food products would be allowed.

How would a patient fill a prescription?

There will be no prescriptions because marijuana is not an FDA-approved medicine with controlled doses. It would be more like an over-the-counter herb. Certifying doctors must be licensed in Florida and perform a physical exam and "full assessment of a patient's history," but the amendment does not require doctors and patients to have an ongoing relationship.

Where would medical marijuana be sold?

Only at state-licensed dispensaries called "Medical Treatment Centers." Growers would also be licensed as treatment centers. The Department of Health would issue rules about how dispensaries would be monitored. Growing your own pot would remain illegal, as it is under current law.

What if the Department of Health writes regulations so restrictive that usage is effectively banned?

The department must issue "timely" and "reasonable" rules that "ensure the availability and safe use of medical marijuana by qualifying patients." If the regulations are too restrictive, any Florida citizen could sue to enforce constitutional intent.

Can caregivers possess marijuana?

A person over 21 can buy and handle the marijuana on behalf of up to five patients. Caregivers would have an identification card issued by the state.

How old must a patient be?

The amendment does not set age limits. In other states, use by minors requires parental consent, as with traditional medicinal treatments.

Would insurance cover it?

That would be up to the insurer. The amendment does not require coverage. Medicare does not cover nonprescription drugs and supplements.

What about using it at work or in schools?

Schools and employers would be free to prohibit on-site use. The amendment does not prohibit employers from requiring drug tests or imposing sanctions for positive results.

Would information on identification cards be public?

No. The Department of Health must keep records confidential, even from employers or family members. But the information could be disclosed for "valid medical or law enforcement purposes."

Could the Legislature set up its own system to regulate medical marijuana?

Yes, but it could not contradict the amendment. For example, the Legislature could not make dispensaries illegal. However, it could permit home cultivation, which is now banned by statute.

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https://www.floridapublicaccess.com/press-releases/2014/01/28/questions-and-answers-about-medical-marijuana-in-florida/2163031

Could the Florida Supreme Court ruling on the ballot language be appealed?

Not successfully. Federal courts leave interpretation of state constitutions to state courts.

Could pot-smoking in public be regulated just as cigarette smoking is regulated?

Yes. Calling it medicine does not confer the right to use pot anywhere.

What about DUI?