

December 5, 2013

Families See Colorado as New Frontier on Medical Marijuana

By JACK HEALY

FOUNTAIN, Colo. — As their children cooed from wheelchairs and rocked softly in their arms, the marijuana migrants of Colorado clasped hands, bowed their heads and said a prayer of cautious thanks.

They thanked God for the dinner of roast turkey and mashed potatoes, for their children and for the marijuana-based serum that has drawn 100 families to Colorado on a desperate pilgrimage to quell the squalls of seizures inside their children's heads. They have come from Florida and Virginia, South Carolina and New York, lining up to treat their children with a promising but largely untested oil that is considered legal medicine in this cannabis-friendly state.

"Thank you for bringing us together," said Aaron Lightle, whose wife and 9-year-old daughter, Madeleine, moved here after the girl's neurologists suggested removing part of her brain to stop her relentless seizures. "In crazy ways, maybe. But hey, we're here."

Amen, they said.

Their migration is one of myriad ways that a once-illicit drug is reshaping life here in Colorado, which now stands at the forefront of the national debate over legalizing drugs. While these families are seeking treatment through a medical marijuana system that has existed for years, they are arriving at a time when the drug is becoming a mainstream part of public life, made legal for recreational use in a [historic vote](#) last year.

The Justice Department has warily allowed Colorado and Washington State, which passed a similar measure, to go ahead with their plans to regulate recreational marijuana, even though it remains illegal under federal law. The first retail marijuana shops in Colorado are poised to open in January. Strains of sativa and indica plants flourish in basements across the state. This week, the Denver City Council [moved toward allowing](#) people to smoke marijuana on their property, though smoking in public would still be prohibited.

The new arrivals call themselves marijuana refugees. Many have left jobs and family members behind in states where marijuana remains outlawed, or cannot be used to treat children. While some have moved their entire families, others are splintered, paying rent and raising children in two states. During the holidays, they join family gatherings through video chats and swap iPhone pictures of Christmas trees.

But as more arrive to register their children as medical-marijuana patients, they have knitted together a random family here, across the suburbs and foothills of Colorado's Front Range. They are Muslims and conservative Christians, liberal Democrats and conservative Republicans.

Now, they cook dinners and babysit for one another. They meet to compare progress and seizure diaries. They discuss the best ways to feed the oil to their children. They wait, and hope for results that mirror the astonishing successes they have seen in [television reports](#) and online videos.

"I put what fit in my car and drove out here," said Marisa Kiser, whose 19-month-old son, Ezra, has had seizures since he was 3 days old.

The families have hung their hopes on a marijuana oil called Charlotte's Web, which is made by a medical marijuana dispensary in Colorado Springs. The business, called [Indispensary](#), also sells a variety of highly potent marijuana and

edibles. Buyers of the medical marijuana must present certifications from two practicing Colorado doctors.

Charlotte's Web is a rich amber and as thick as cold honey. It smells like marijuana and tastes like raw plants. Joel Stanley, one of five brothers who run the dispensary, says the oil is low in THC, which gets users high, but contains a wealth of a cannabidiol, or CBD, a chemical that provides no buzz, but that marijuana advocates and medical researchers say has a variety of medical uses.

A month's supply of the oil can cost \$150 to \$250, and some families say they receive financial help from a nonprofit group related to the dispensary called the [Realm of Caring Foundation](#). In a [YouTube video](#) produced by Realm of Caring, two mothers describe how their children were transformed after taking the oil for a few months. In one section, Paige Figi recalls how seizures had jolted her daughter Charlotte every 15 minutes, leaving the girl unable to walk or talk. In the next shot, the girl dances in a pink leotard and shouts, "Ballerina!"

The other mother featured in the video, Heather Jackson, was so convinced by the potential of CBD that she is now the executive director of the Realm of Caring Foundation.

Ms. Jackson said her son, Zaki, who once had 200 seizures a day, still faces a host of developmental disabilities, and will probably need help for the rest of his life. But she said he had gone 14 months without a seizure. A pretreatment recording of electrical activity in his brain showed a heaving chaos of huge spikes and deep troughs. A readout taken several months in showed smoother rises and falls.

"It's really incredible," Ms. Jackson said in an interview. "For whatever reason, this has put his syndrome into remission."

There is [only scattered medical research](#) to substantiate the claims, in large part because marijuana's outlaw status has kept it off limits for many scientists in the United States. Studies as far back as 1975 have suggested that cannabidiol can prevent spasms in lab animals, and a few researchers in the United States have conducted limited studies on people.

Dr. Margaret Gedde, a Colorado physician who has recommended medical marijuana to dozens of families with severely epileptic children, recently conducted a small survey that offered promising results. Of 11 families who treated their children with high-CBD oil, eight reported that their children's seizures had fallen by 98 to 100 percent. The other families reported smaller but noticeable declines.

Dr. Gedde and her co-researcher, Dr. Edward H. Maa, an assistant professor of neurology at the University of Colorado School of Medicine, will present their research to the American Epilepsy Society at a meeting next week.

But the clinical trials matter little to parents who have watched their children sustain cracked skulls and broken arms during seizures, who have spent holidays in the emergency room, whose toddlers are taking barbiturates. After years of watching their children slowly vanish behind a firestorm of seizures, or the debilitating side effects of powerful prescription drugs, they said marijuana seemed worth a try. The families' stories have been covered extensively in the local newspaper, [The Gazette](#).

"We really didn't have any other options," said Annie Koozer, whose family left Tennessee in search of help for their 2-year-old daughter, Piper, who has a rare genetic condition called Aicardi syndrome, in which the structure that connects the two hemispheres of the brain is deformed or missing. Since she was 3 months old, the girl has endured 400 seizures a day.

After treatment by five neurologists and nine increasingly debilitating seizure medications, the family moved to Colorado in August. Ms. Koozer's husband, Justin, called it the family's last-ditch effort to help Piper. They signed a lease on an apartment and began giving her the oil about a month ago.

Waves of seizures [still attack her](#), leaving her parents helpless, worried she will stop breathing. But they said Piper sleeps more, seems more alert and appears to have fewer spasms now — sometimes as few as two or three each day. They do not know what will happen, whether the progress is real or sustainable. But they have decided to keep at it. And they have

decided that this place, 1,300 miles away from their extended family, is now home.