

Haleigh's Hope: A Mother's Unexpected Journey to the Front Lines of Marijuana Advocacy



Janea Cox, her husband Brian, their 7-year-old daughter Haleigh and their chocolate Lab Kala left their Forsyth home in December 2016 for their semi-annual trip to Colorado.

They flew into Denver and made their way toward Colorado Springs in a rental car, squeezing the three of them, a wheelchair and the dog into the small, four-door sedan. A handicap-equipped van would have been better, but the economy ride was what they could afford.

The family checked into a budget hotel and went to sleep; not that they ever sleep well, or for very long. Young Haleigh was up through the night, as usual. She has epilepsy so severe she requires constant oversight. For most of her life, her young brain hasn't been seizure-free long enough to develop normally. So she gets around in a wheelchair, receives nourishment through a feeding tube and is barely able to communicate. Haleigh is a prisoner in her own body.

She also has type one diabetes. Kala is a service dog specially trained to check blood sugar levels by smell and alert handlers of spikes — to do what Haleigh cannot do for herself, to speak out when she needs help.

These family trips are not fun. They stretch the Coxes to their financial limit. And they take everything Janea and Brian have just to get to the offices of the Flowering Hope Foundation, where botanist Jason Cranford dispenses his specially formulated cannabis oil, Haleigh's Hope, named after his special client. Janea believes it is the only thing that has kept her daughter alive.

The cannabis oil isn't the only thing named after Janea and Brian's daughter. Her name also appears on the law — Haleigh's Hope Act — enacted in 2015, which permits registered patients in Georgia to possess up to 20 ounces of low-THC oil. But because it remains illegal to produce or dispense the oil in Georgia, the Coxes must go to Colorado to buy it.

The next morning, Brian packed the bags and the chair and the dog back into the rental car and the family returned to the Denver airport where, as calmly as she could, Janea Cox, 35, quietly committed a federal crime by smuggling 10 two-ounce vials of the oil out of Colorado. Her husband eyed the TSA inspectors nervously while Haleigh sat silently in her wheelchair, a floppy red bow on her head, staring out at the world with big brown eyes.

A Life Sentence

Three years earlier, in January 2014, something happened that changed Janea's life forever.

On that particular evening, she did the same thing she did every night. She slipped a medical vibrating vest onto 4-year-old Haleigh's motionless body to loosen up the mucus that routinely built up in her lungs. She plugged one end of a black vacuum hose into the vest and the other end into a boxy plastic machine. When Janea flipped the switch, the machine sprung to life, sucking air up from around its vents and pushing it pressurized into the hose and vest. An instant later, Haleigh began to vibrate.

Haleigh was diagnosed with intractable epilepsy when she was eight months old. Intractable is a doctor's word for untreatable. She took a daily regimen of more tranquilizers and anticonvulsants than is recommended for a grown adult. And still Haleigh suffered more than 200 seizures a day; every five minutes or so, day and night. She was paralyzed by her seizures, unable to build the neural pathways that would allow her young brain to move a leg or an arm, or to speak. All of her baby teeth had to be removed so she wouldn't suck them into her lungs as they loosened or bite her tongue off.

With Haleigh vibrating away in her vest, Janea set about her chores, folding laundry in the next room. A few minutes later, she set down the laundry basket and returned to unhook the tubes and slip off the vest. She'd planned to take Haleigh to the bedroom, change her diaper, put her to sleep. This was Janea's daily routine as her daughter's primary caregiver.

But on that day, for reasons no one knows, something went wrong. Janea froze in her steps at the sight of her daughter, her face purple and her body blue.

Janea shrieked in horror. She'd only been gone two minutes. Maybe three? *It'll be OK*, she told herself as she struggled to remove the vest.

A former EMT and firefighter, Janea had seen this kind of thing before.

“I knew for sure my daughter was going to die,” she recalled.

Janea administered CPR and screamed out for her firefighter husband to call 911. Haleigh’s pulse was beating more than 200 times per minute. Then came the flashing emergency lights. Sirens in the driveway. People in the living room. A hazy blur of activity. Then the emergency room and a chair in a pediatric ICU hallway at the Medical Center of Central Georgia in Macon.

“You never know,” Janea said quietly, reflecting on the worst moment of her life, “how long a minute is until you see your child dying.”

A Plea for Help

Janea grew up an extroverted, fun-loving cheerleader at McEachern High School in Cobb County. After graduation she followed her dream of becoming an EMT and a firefighter.

Janea is strong, physically and mentally. Ask her about what she saw her life becoming, and she talks about a simple love of hanging out with the boys at the fire station. Being on a team. Doing exciting work that helps other people. Being the only girl in the boys club.

She met Brian on the job. They become friends first, talking on the phone and laughing about work. Eventually the pair started dating.

“He kept asking me to marry him, but I would always say no,” she said, a ebullient Southern lilt ever present in her voice. They did eventually marry. And they were both surprised, four years later, after unsuccessful efforts to have children, when Haleigh came along.

“I was always told I couldn’t have kids because of my diabetes, so we’d given up. Well, all of sudden, once we quit trying, here came Haleigh.”

All appeared normal when Haleigh was born in July 2009. It wasn’t until her daughter was six months old that Janea noticed Haleigh’s progress lagged behind other kids her age. She wasn’t trying to sit up or reach for toys. Janea was concerned, but the doctors didn’t seem worried. Nonetheless, CT scans were ordered. Then MRI’s.

That’s when Janea learned Haleigh might have had a stroke. There was frontal lobe damage. Then the seizures started, little ones at first. She went on meds. More seizures followed. Then more meds, more seizures.

Janea quit her job to care full time for Haleigh. She spent what little spare time she had searching online for a miracle. But Haleigh just got worse and worse. Until that day Janea found her lifeless in the vest.

Nobody can say exactly what happened to Haleigh that night, or why she stopped breathing. But the prognosis looked grim. Doctors told Brian and Janea that Haleigh might be brain dead.

As the minutes turned to hours, Janea sat in that hospital hallway and prayed. And she came to a decision. If their daughter made it, she told Brian, she was taking Haleigh to Colorado where

she could receive medical marijuana treatments. They'd argued about that very thing earlier in the day.

Janea had read good things about a cannabis oil that reduced the frequency of convulsions for patients with seizure disorders. It was high in cannabidiol (CBD) and low in tetrahydrocannabinol (THC), which means it doesn't induce the psychoactive "high" most commonly associated with marijuana use.

But Brian didn't want them to leave Georgia. He didn't want to place false hope in some Colorado weed scheme. And he didn't want to take the chance of something happening to Haleigh while she was so far away from him.

"But we had tried every other thing that every other doctor had ever suggested, and none of it had done anything at all," Janea said. "After that night, it felt like it was our last resort."

Brian finally agreed.

That same night, Janea sent an email to State Rep. Allen Peake (R-Macon), pleading for him to help change the law in Georgia and legalize medical marijuana.

Peake was a sixth-term representative and the owner of dozens of restaurant franchises — among them Cheddars, Fasoli's and Captain D's — in Georgia. He had helped author legislation related to historic home rehabilitation, adoption laws and Alzheimer's patients, but never marijuana legalization.

"I answered her that very night to tell her I'd look into it," Peake recalled. He didn't know her plea was written from the hallway outside a dying girl's hospital room, but he understood the urgency.

A few days later, Peake arrived at the PICU and met the Cox family for the first time.

Meanwhile, Haleigh had begun to stir, and Janea's fears of permanent brain damage began to diminish. When Peake arrived, Haleigh's big beautiful brown eyes looked up at him and she almost smiled.

"Haleigh reminded me of my own granddaughter," Peake said. "I empathized with the family in pain."

And so he said yes to Janea's request.

Finding the Formula

While Brian stayed behind to continue working, Janea and Haleigh moved to Colorado Springs in March 2014 and rented a duplex. They couldn't have managed it without support from their community, including \$21,000 raised on Haleigh's behalf by Ride to Give, a cycling nonprofit that benefits medically fragile children.

Thus began a “really lonely” period of life for Janea. It was just the two of them. If Haleigh didn’t sleep, neither did Janea. If Haleigh had a bad day, so did Janea. There was no relief from the care-giving duties.

“Brian would come out for a week every month, then later it became more like once every two months because he couldn’t find the time to get off work,” she said. Other than those occasional visits, Brian’s daily phone calls were Janea’s only lifeline to an outside world.

But soon the Colorado marijuana community came to embrace the Coxes, beginning with Jason Cranford, executive director of Flowering Hope Foundation. The organization promotes accessibility to medical marijuana for those whom he believes benefit from it, including sufferers of epilepsy, multiple sclerosis, Crohn’s disease and cancer.

Cranford, who also owns a marijuana dispensary in Rifle, Colorado, connected Janea and Haleigh with doctors and provided them with free cannabis oil as they worked together to come up with the right formula for Haleigh. It was a trial-and-error process because marijuana is classified as a Schedule 1 drug with no medical value, so it can’t legally be tested and analyzed by researchers.

“There are no broader studies on this stuff,” said Janea. “It took a year to understand the best dose for Haleigh. There are so many variables to figure out. We were constantly getting blood work done, and then left to interpret the results for ourselves. Sometimes Haleigh would have more seizures, and we just didn’t know if that was a function of medical marijuana changes, or changes elsewhere in weaning her off seizure medicines.”

How the oil works to alleviate seizures is not quite clear, said Dr. Bryan Doner, a board certified emergency medicine physician and CEO for Compassionate Certification Centers, a medical marijuana consulting company.

“We know for sure that the body has an endogenous endocannabinoid system; a system inside your body right now, already, that exists to process cannabinoids. We understand that those endocannabinoids work on the neurotransmitter system of the brain, that there is some sort of utility there. And we know that these medical cannabis oils bind to the receptors to produce physiological effects. In cases like Haleigh’s, those physiological effects include a reduction in the number and severity of seizures taking place.”

Meanwhile back in Georgia, Peake introduced a medical marijuana bill during the 2014 Georgia legislative session that was shot down. As a result, other families like the Coxes began to move west.

“We became sort of friends with everyone in the cannabis community; they looked out for Haleigh like one of their own,” Janea said. “Others started making the trek, too. People would see our story and all of a sudden they’d be out there in Colorado, calling me up. They’d pack up their entire lives and just move.”

And eventually Janea and her team hit upon the right combination to help Haleigh. She was orally administered a blend of two oils that reduced the number of her seizures from 200 a day to one or two. And she greatly reduced the number of other pharmaceuticals she was taking.

“Medical marijuana is saving Haleigh’s life,” said Janea.

Historic Legislation

Back in Georgia, Peake would not be deterred. During the 2015 legislative session, he introduced House Bill 1, called Haleigh's Hope Act. It was similar to the bill that failed the previous year, but it was amended so that cultivation and sale in Georgia was not legalized. It passed both the House and Senate with ease, and in April 2015, Gov. Nathan Deal signed the bill into law while Peake and the Cox family looked on. The law permits registered patients to possess up to 20 ounces of oil containing no more than 5 percent THC.

The family rejoiced, but Janea and Haleigh had to bide their time in Colorado while the law was put into place, the logistics for the registry worked out and temporary registration cards distributed.

Then last August, the Cox family's Forsyth home burned down. Brian was doing yard work at the time, so no one was injured, but every possession the family owned was lost. Following an investigation, the fire was attributed to an electrical malfunction near an air conditioning unit.

"That was, next to Haleigh's fight, the hardest thing I've ever had to handle," said Janea.

Today the family lives in Brian's late grandparents' house in Forsyth while a new house is under construction, thanks in part to contributions from the Young Leadership Program of the Associated General Contractors of Georgia Inc.

In that home, the Cox family will continue to serve as the most visible medical marijuana advocates in the state. Janea wants to see cultivation legalized in Georgia so parents aren't forced to break the law transporting the oil from states where it can be purchased legally. According to its website, TSA does not search passengers for marijuana or other drugs, but if it's found they turn the matter over to local law enforcement.

Several bills have been introduced during the current legislative session that, if passed, could affect Haleigh's Hope Act. House Bill 65 and House Resolution 36 would expand the law, but according to Peake, "none of the legislation that has a chance of passage this year addresses cultivation."

And Senate Bill 16, which was introduced by state Sen. Ben Watson (R-Savannah) and has already passed the Senate, would limit the amount of THC present in cannabis oil to 3 percent.

Watson, who is a medical doctor, has also called for federal officials to reduce the classification of marijuana from a schedule 1 drug so it can be subjected to research studies.

"To say cannabidiol has no medicinal value is just not true," Watson told the AJC last month.

"It's politicized, sure," said Peake. "And that's too bad. Because real families are losing their children. At least four kids have died just since the law was enacted. It's real-life."

But for all the politics, it's also an opportunity.

"Look, this happens once in our history, right?" said Doner. "When we look back in 10 or 20 years, we in the broader medical and political arenas aren't going to look at cannabis with the

same stigmas as we did before. This has been a movement initiated on the patient front, and it has gained traction because by and large there are tremendous medical gains to be had. We don't understand nearly as much as we could, but we do understand that medical marijuana is, in many cases, working to produce great outcomes for patients."

Haleigh, now 7 and three years removed from the seizure that sent her mom on a collision course with history, is finally emerging from the nightmare that once gripped her. In January, Haleigh sat up for the first time. A few weeks later, she went two days in a row without a single seizure.

"Now that we are solving the seizures, she is getting so much better," said Janea. "She is able to express herself. For four straight years she couldn't tell us if her stomach hurt or that she was about to have a seizure. She had no communication at all. Now she can answer yes or no questions. And it's amazing how much she knows."

Janea never meant to be a spokesperson for medical marijuana; she says she's never even tried it. But people stop her in the grocery store to ask if she's the "weed lady," and she patiently explains that, yes, she was in the AJC, or on CNN yesterday, but no, she is not the "pot mom." She's Janea Cox, Haleigh's mom.

And then, just the other day, it happened, the moment Janea had prayed for since the seizures first began. She and Haleigh were watching "Gilmore Girls" on TV and having lunch. Haleigh, wearing her signature hair bow, looked up at her mother with those big brown eyes and she smiled.

Hi mamma! Haleigh said, speaking a sentence for the first time in her life.

Stunned, Janea smiled and cried and took her daughter's hand.

Hi honey, she replied.

ABOUT THE STORY

Half-baked is the word that comes to mind when considering Georgia's medical marijuana law, which permits registered patients to possess cannabis oil but doesn't permit them to legally obtain it. That catch-22 inspired freelance writer Adam Kincaid to tell the story of Janea Cox and her daughter Haleigh Cox, for whom the law is named. To report this story he talked to Georgia lawmakers, lobbyists, law enforcement officials, marijuana growers in Colorado, a Georgia company hoping to provide cannabis oil locally someday, individuals who provide alternative means of procurement, as well as the Cox family. It is a complex story with a happy ending, at least for one family whose daughter's health has been improved by cannabis oil.

Suzanne Van Atten

Personal Journeys editor
personaljourneys@ajc.com

ABOUT THE REPORTER

Adam Kincaid is a freelance writer for The Atlanta Journal-Constitution, The Bitter Southerner and others. He wants a good literary agent and a verified twitter badge [@adamjkincaid](https://twitter.com/adamjkincaid).

ABOUT THE PHOTOGRAPHER

Bitá Honarvar is an Atlanta-based photographer whose work has appeared in the New York Times, Guardian US, Chicago Tribune and The Atlanta Journal-Constitution, where she was a staff photojournalist and photo editor for 16 years. Her work has taken her around the United States and abroad, including stints in Afghanistan, Iraq and Iran.