

Sebastien Cotte

March 11th, 2019

Atlanta, Georgia

Dear Kansas Legislators,

My name is Sebastien Cotte and my wife Annett and I are the blessed parents of an amazing little boy called Jagger.

Jagger suffers from a rare, progressive, terminal form of mitochondrial disease called Leigh's disease. There is no cure for Leigh's disease and 95% of the kids that are diagnosed before age 2 never get to see their 5th birthday. We received Jagger's diagnosis shortly after his first birthday, which meant that his symptoms are severe and life expectancy short.

Having a child with a terminal progressive disease with little to no hope for the future is obviously something more challenging and difficult than words could ever express. We searched everywhere, reached out to dozen of doctors all over the country to find someone or something that could help Jagger. We were eventually able to get in a FDA drug trial specifically for Leigh's disease which helped to slow down disease progression for a while, but over time due to controlled dosing the drug became less effective.

On night in late 2013 while watching a documentary on CNN called Weed, I realized that maybe medical cannabis could help Jagger reduce his seizures and severe pain, some of the many symptoms of Leigh's disease. Unfortunately for us, we live in Georgia where medical cannabis was not legal at that time. So we joined forces with other parents to create an advocacy group called Georgia's Hope with the goal of passing a medical cannabis bill during the 2014 session. Sadly, we were not able to pass the bill and after a lot of research and reflection, we decided to move to Colorado in August of 2014. We became what is known as "medical refugees", but our situation was certainly not unique as thousands of families from all over the country had to make the same decision and move to a legal state in order to save their children or loved ones. I cannot even put into words how incredibly difficult it is to leave everything behind (family, friends, support systems, medical team etc.) and start over in a new state while caring for a terminally ill child.

Jagger's hospice team warned us that he had a 50/50 chance of not surviving the trip to Denver. (Due to Jagger's weakened respiratory function, he cannot fly commercial so we had no other option but to drive.) It took us 6 days to make the trip (aka the trip from hell) from Atlanta to Denver. We had to stop at a hotel every 2-4 hours because Jagger was so agitated and in so much pain that his breathing was getting labored and we had to calm him down to make sure he didn't stop breathing.

Fortunately we made to Colorado and on August 20th 2014, Jagger received his very first dose of medical cannabis. We saw a difference almost right away. Jagger's demeanor changed, he became more alert and made great cognitive improvements such as keeping better eye contact and tracking us around the room. Then a few days later he smiled. I know that might not sound like a big deal, but when your child has stopped smiling months before and having all joy sucked out of him, seeing a smile again made the entire trip from hell worth it.

As time went on and after some tweaking of Jagger's medical cannabis regimen, which includes both CBD and THC oils, his seizures decreased and his muscle pain was finally under control. He stopped screaming and arching in pain something he had done almost daily up until this point. We were also able to wean him slowly (with doctor supervision) of some of the dangerous opioids and seizure medicines. As of today, Jagger has not used Oxycodone in over 4 years and Morphine in almost 3 years.

In the meantime, I was travelling back and forth to Georgia to help the local parent advocacy group with a second attempt to pass a medical cannabis bill. Finally, on April 16th 2015, then Governor Deal signed into law HB1 (the Haleigh's Hope Act) which allows for possession of medical cannabis oil with a THC level of 5% or less if you have one of 8 qualifying conditions (over the next few years, we increased that to 17 conditions). While far from being perfect, the Haleigh's Hope Act at least permits Georgians with a qualifying condition to possess and use certain medical cannabis oils and it allowed my family to come home in September of 2015.

We still have issues at times to access Jagger's cannabis oils in Georgia but the Haleigh's Hope Act has been life changing for so many children and older patients.

Now 4 years later, I can assure you that many of the original fears our opponents tried to use as arguments against the bill have not come true. For example:

1. [Georgia's teenage marijuana use has NOT increased](#) due to the Haleigh's Hope Act;
2. [Law enforcement have NOT been overwhelmed](#) by the "large" amount of cannabis that was supposed to come to Georgia;
3. We do [NOT have dispensaries at every street corner](#) since we don't have access yet and even if there was access, that is not the vision for the medical cannabis program in GA
4. There are [NO THC gummy bears](#) circulating in the schools;
5. Lastly, Georgia is [NOT any closer to legal recreational cannabis](#) as we were before the Haleigh's Hope Act was signed into law in 2015.

I am sure that you will hear many arguments from both side of the issue over the next few weeks, some valid, some unfounded, but at the end of the day, this actually comes down to one very single question. If it was your child, grandchild or loved one who needed medical cannabis oil to survive, how would you vote on HB 2244?

Thank you for your time

Sebastien Cotte

