

Medical Marijuana and Epilepsy....

The Wait Continues for Medically Needy Children and Other Qualified Patients

By: Seth A. Hyman

I've learned from being the parent of nine year old medically complex Rebecca "Becca", that for one reason or another, it always seems that children and individuals with disabilities are too often the ones who are neglected and end up with the short end of the stick. My story sheds light on our family's personal plight with our involvement in achieving Florida's first passed Medical Marijuana legislation (Senate Bill 1030) and patients like my little Becca who continues to wait not understanding that every day that goes by could be her last. Through all of Becca's limitations of not being able to walk, talk and being tube fed, it's her intractable epilepsy that is taking years off her life.

According to the CDC, Epilepsy affects about 2.3 million adults and 467,711 children 0-17 years of age in the United States. About 1 in 26 people will be diagnosed with epilepsy at some point in their lives. About 150,000 new cases of epilepsy will be diagnosed in the United States each year. Unfortunately, one third of all epileptic patients are diagnosed with intractable epilepsy. This means their seizures are not controlled by conventional seizure medication and seizures are frequent and severe enough to seriously interfere with quality of life. Epilepsy results in an estimated annual cost of \$15.5 billion in medical costs and lost or reduced earnings and production.

It has been a long road since the beginning of our quest which began in January 2014, when I took my entire family to Tallahassee to be an additional voice for the one thing that could potentially help control Becca's seizures and possibly save her life. There were many families with us there in Tallahassee during the months of session last year. Wheelchairs, oxygen tanks, nurses and all of the necessary items needed to safely experience a daily outing with our special children. It all started with House Bill 843 by the Judiciary Committee and Criminal Justice Subcommittee and co-sponsored by Rep. Matt Gaetz and South Florida's Katie Edwards. The purpose of the bill was to legalize particular strains of cannabis that contained low THC (the ingredient that's euphoric) and high in CBD (Cannabidiol) which has shown some promise to

control seizures in pediatric patients. The flip side of cannabis as a medicine pertains to the CBD and THC levels. Even though CBD has shown to be effective with some seizure disorders, it's the THC that works synergistically with the CBD to have even greater seizure control. Unfortunately, HB 843 and its Senate companion bill mentioned later on both fall short on what is truly needed when it comes to cannabis as a medicine.

The days were long, but we felt good and believed we really had a chance for this bill to pass. This may be the one thing that might help our Becca and others, since we saw children in other states showing some seizure control. HB 843 was not about legalizing marijuana in the traditional sense, but legalizing oil extracted from the cannabis plant called Cannabidiol (CBD). CBD is one of 400 plus compound in the cannabis plant that has shown promising medicinal value. CBD and THC have demonstrated it can help to either control or in some cases totally eliminating seizures in pediatric patients. After the legislators on the House side passed HB 843, a companion bill on the Senate side was needed. Senate Bill 1030 was co-introduced by Senators' Bradley, Bean and Brandes. The Senate had a big task... Just like the House, they too knew this bill had to pass through the legislature for the sake of the children. Many legislators said it had a good shot after seeing the children's faces and hearing first-hand the stories of the desperate parents like my wife and I. One very conservative legislator said to me he did not want to meet Becca since he knew once he looked into Becca's eyes, he would not have a choice but to vote in favor of the bill. We had no one else to turn to and prayed for the bill passage. SB 1030 passed the Senate and was signed by Governor Rick Scott in June 2014.

We thought once the governor signed the bill we were on our way. We learned quickly that just because a bill passes and becomes effective, it does not mean that the actual implementation of the specifics would move quickly. SB 1030 included language that required the Florida Department of Health to determine how the application process would be conceived, how the five nurseries will be chosen and how they will grow and produce a safe oil product for patients.

Unfortunately, even though there were deadlines set within the bills' language when certain tasks and timelines needed to be executed, reality started to kick in and we soon realized the Department of Health (DOH) had a huge task on their hands. Since the bill set specifics dates, we believed by January 2015, five nursery applicants would've been chosen and plants would

be in the ground. But this is Florida... for some reason in Florida things take a little longer, actually a lot longer than other states for good things to happen, even when it comes to suffering children who may die on any given day. SB 1030 has been challenged by nurseries, lobbyists, individuals and businesses that have a financial interest in being awarded one of the five licenses. The first challenge was heard by a Florida judge who ruled the department of health needed to go back to the drawing board and start all over again with their rules and regulations. The second time around, the DOH decided to assemble a rule making committee of nursery owners, patient representatives and others who may or may not have a financial interest in the very same applications they would be applying for. The committee would have to devise the rules, how the applications are chosen and anything else that could potentially arise for a company to produce safe medicine for children.

In February 2015, after the final round of rules were made public, there was a 20 day window for a challenge to be filed with the state. Sure enough on March 12, 2015, the new final DOH rules were challenged again. This time not by a company, not by someone who may have a financial interest like a grower or another business, but by a parent who has a child with brain cancer which CBD has not been proven to be an effective treatment for.

So here we are 15 months after it all started and there is no light at the end of the tunnel on when low THC/high CBD oil will be available for Florida patients. Best case 9-12 months from now provided the legal challenge is thrown out by a judge or our legislature takes action in the coming weeks. The Florida Legislature has before them many medical marijuana bills. The question is will they be heard this session? If not, Floridians may have to opt for another constitutional amendment which could potentially be on the 2016 ballot. I just hope patients can have a chance to try cannabis as a medicine sooner than later. I have seen the patients and heard their story's, it is truly amazing and sad at the same time.