Comments from Amy Smoot, Patient Advocate – DeSoto county

My name is Amy Smoot. First and foremost, I want to thank Chairman Bryan, Senator Blackwell, and the entire committee for inviting me to speak today. I am a stay at home mom with four children. I spent ten years of my life in emergency medicine. When I graduated EMT school, I took an oath to do no harm. I believe part of the reason I am here today is because of that oath. Doing no harm means eliminating things which cause harm. Stopping certain therapies when they have negative effects on patients. Saying the right thing, even when it is hard.Trying everything, even if you disagree with it. Not giving up until you have exhausted all options.

Today, I was asked to speak as a patient advocate. What exactly is a patient advocate, and what do they do? A patient advocate is someone who helps the patient navigate the health care system. Advocacy means getting the prescription medicine your patient can afford. Advocacy means making sure patients have all of the medical equipment and in home care they need. Advocacy means making sure the patient is educated about their health care issues. It also means making sure your patient is in control of their care. In today’s capacity, I will be advocating for three specific children. All three children I will tell you about have horrific seizures. All three have failed multiple pharmaceuticals. All three have been harmed by conventional pharmaceutical treatment of their seizures. I am asking you all to give these children a chance. Today, I am requesting you LEGALIZE THEIR MEDICATION!

I chose these three children, because they are in my area. I will tell their stories. I am demanding you to be compassionate and efficient legislators. I am a volunteer, and tied to no specific organization. I do not own a business, and I am not a farmer. I stand here today as a mother. I am here because I have healthy children. These mothers do not have any other options. They have exhausted them all. When initiative 65 was overturned, the rug was ripped out from underneath them. The hope they had for their children and their futures were extinguished instantly. Medical cannabis can give these families hope. You can change it, and you alone. After all, these children are our future.

The first story and patient I am going to tell you about today is Rylee. Rylee is an incredible nine year old girl. But she is not your normal nine year old, because Rylee is going to change the world.

At just nine months of age, Rylee was admitted for seizures at one of the top children’s hospitals in the nation.  During this hospitalization, a CT scan was done. It was discovered that Rylee had half a brain. The very first hospital stay was traumatizing. Rylee had to be stuck multiple times in every limb. Rylee had to be held down by numerous staff members, as she had not even reached one year of life yet. In fact, Rylee’s grandfathers were kicked out of the hospital because of their vocal opposition to watching their nine month old granddaughter go through pure agony. Unfortunately for Rylee and her family, this was only the beginning to Rylee’s story.

When she was finally discharged from that hospital stay, Rylee came home on so many medications. One of these medications was a gel shot to control her seizures. Her own mother had to administer the shots to Rylee, and she sobbed every single time she gave one to Rylee. This medication regimen went on for six months twice a day. The side effects of this shot were horrible. At nine months old, Rylee was covered in rashes. Rylee also tripled in body size. She even stopped eating all together because of this one medication. Keep in mind, she was still seizing all of the time. These medications were not even working.

For three and a half years, the seizures and hospitalizations continued. Medication after medication were tried, and not a single one worked to stop her seizures. Rylee was put on adult doses of benzodiazepines as rescue medications. She was not even five years old at this point. Rylee was hospitalized so much and so often, that her parents began to lose hope. They were being forced to watch their daughter slip further and further away every single day, and sometimes by the hour. Rylee was so sedated, she became a shell of who she had been before the first seizure. She became catatonic. Dazed. Sleeping a lot. A long way from a normal five year old’s life. When she was five years old in August of 2017, she had her last hospital stay at the local children’s hospital. She spent many days in the intensive care unit, and the adult rescue dosages of benzodiazepines were not even stopping her seizures. After many days and no improvements, her neurologist dismissed her from the hospital and sent her home to make preparations for her death. There was nothing more they could do for her. She had maxed out on the amounts of medication she could have at a time. Any more, and it could cause Rylee to quit breathing, and Rylee was five years old. Her parents did take Rylee home, but they absolutely did not prepare for their daughter to die.

Instead, they packed up every single thing they owned, left their families behind, and moved to Colorado. At this point, they had no idea if medical cannabis would help their daughter, but they at least had to try. On their first visit to the children’s hospital, they knew they made the right decision. Rylee and her family were now American medical refugees.

Rylee had her very first dose of THC oil on October 5, 2017. Rylee had her last seizure on October 18, 2017. Thirteen days after her first dose of THC oil was her last seizure. Thirteen days.

For three years and eight months, her parents have watched as new life was brought to Rylee. New life when they were told her life was over and she would never get better. It took Rylee months to wean off of all of the benzodiazepines. Rylee had her last dose of “FDA approved” medication for her seizures on February 15, 2018.

Rylee takes THC oil three times a day. For the first time in her life she is off all prescribed seizure medications. The THC oil alone is enough to control her seizures.

Why did I choose to tell Rylee’s story today? Rylee and her family are from my congressional district. Rylee’s grandparents still live there today. But Rylee can not come to her home state to visit her grandparents, because her medication is illegal here. Rylee’s story highlights the possibilities which become reality when we legalize medical cannabis. Rylee was not going to get better. But now, she is riding horses, participating in therapy, interacting with her siblings and parents. Rylee is happy, radiant and building her strengths every day. Rylee is getting a new walker very soon, which will give her much more independence than she has ever had before. She will be able to move freely as she wishes. Rylee is teaching each and every one of us that a child who was counted out of life before age five can and absolutely will change the world.

Rylee’s diagnoses:

Lennox-Gastaut syndrome

Schizencephaly

Optic nerve hypoplasia

Optic Nerve dysplasia

The second patient I’m going to tell you about today is Bryan. Bryan is a handsome sixteen year old, baseball loving boy. Bryan had his first seizure at thirteen months old. He was diagnosed with mitochondrial disease at age three and a half. There is no known cure or treatment for mitochondrial disease. Mainly, his family just tries to manage and alleviate some of his symptoms. But, Bryan does not need medical cannabis for his mitochondrial disease. He needs cannabis to help stop his intractable seizures. Bryan has failed over a dozen pharmaceutical drugs. Not a single one stopped Bryan’s seizures.

The majority of the anti-seizure pharmaceuticals have caused damage in ways you cannot comprehend. Bryan became so lethargic to the point he could not even sit up. Some caused excessive drooling. A few even caused Bryan to have new types of seizures - types he never had before. Some have caused severe violent aggressive behaviors. Bryan would be awake for multiple days in a row. We are not talking a little bit of sleep. He would not sleep **at all**, during the day and night. All those side effects and still seizing.

In addition to the seizures and medication side effects, Bryan is still fighting mitochondrial disease. Some of the issues from mitochondrial disease are behavioral issues. Bryan is a very hyperactive child, and he has a very short attention span. On top of all of that, Bryan has numerous food allergies. Cannabis certainly would not cure all of Bryan’s ailments, but it can and would absolutely ease some of his suffering. Reducing harm and providing a better quality of life for Bryan is the least we can do.

Bryan’s Diagnoses:

Mitochondrial Disease

Intractable seizures

Food Allergies

The third and final patient I am telling you about is two year old Myles. At first glance, Myles may seem like your average two year old; fun loving, adventurous, and full of laughter. At almost two months old he had his first seizure. He was taken to the same children’s hospital as Rylee. His parents were told Myles had reflux. One week later, when his mom put him in the pool he turned blue, was stiff, shaking, and lifeless. The type of seizures Myles has cause him to seize for hours at a time. Myles was just a fragile two months old when he seized for an excruciating two hours straight.

Myles and family spent the next twelve months in and out of the hospital. Myles was still seizing all the time. Myles was airlifted close to twenty times over the next several months. Myles was intubated, and each time he was admitted, they’d require loading doses of the “FDA approved” prescriptions. The problem was, these prescriptions were making the seizures worse. Each seizure, their answer was to up Myles’ dosage. They were sent to craniologists and epileptologist. All of them had another medication to add. They were not able to give Myles family any real help or answers. To this day, Myles is still mostly unchanged.

They tried many things: high doses, low does, leveled doses, and so far no changes for the positive. Myles has just gotten worse. Myles has failed six pharmaceutical medications- he is two years old. The rescue medication they gave Myles to stop his seizures, never stopped them - not even once. They had to prove to the insurance company that Myles’ body was not absorbing the rescue medication before they would approve another medication for Myles.

Myles has been on narcotic intramuscular shots, which were showing some help at first. However, his body became resistant to the narcotic. Then the pandemic started. Myles was not able to go to the clinic to be seen as frequently. At thirteen months old, Myles quit talking. Myles wasn’t walking. He was very delayed. If you barely touched him, he got a bruise. When they were finally able to be seen, they had labs drawn. Myles already had liver damage. Now Myles parents were left with an impossible task - leave Myles on the narcotic, which already was not working -  or take Myles off all medication. Myles stopped all medication.

Remarkably, he started trying to walk again. He regained his personality. But he began seizing again - all the time. Now that initiative 65 has been tossed, Mississippi will lose this precious family too. Myles can not wait any longer. His parents are out of options. The physicians do not have anything else they can do for Myles, unless his parents are willing to use more pharmaceuticals. Please help Myles. I am terrified of what will happen to this precious two year old extraordinary little boy. Senators, you are Myles last chance. Please, do not let him down.

Myles diagnoses:

Dravet’s Syndrome

Status Epilepticus

Amy Smoot

amymsmoot@gmail.com