

**Background:**

A newspaper article from Tyler is enclosed that lays out the multiple perspectives about medical marijuana issues for the 2015 legislative session. The link to the article is available at <http://www.tylerpaper.com/TP-News+Local/212089/families-fight-for-legalization-of-medical-marijuana#.VL0aamTF8lQ>

**Public Policy Committee****Agenda Item 9.****Expected Action:**

The Committee will receive an update regarding medical marijuana policies. The Committee may provide guidance to staff or recommendations for Council consideration.

**Council****Agenda Item 11.****Expected Action:**

The Council will receive a report of Committee discussions on this item and may consider recommendations offered from the Committee.

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## Families fight for legalization of medical marijuana

Published on Saturday, 17 January 2015 21:39 - Written by [Adam Russell, arussell@tylerpaper.com](mailto:arussell@tylerpaper.com)



Photo by Sarah A. Miller/Tyler Morning Telegraph. Dean Bortell holds several small, round, white pill containers. His daughter, Alexis Bortell, 9, has intractable epilepsy. The Bortell family is asking state legislators to file a bill to legalize cannabidiol oil, a form of medical marijuana that may help 9-year-old Alexis Bortell who suffers from intractable epilepsy which doesn't respond to pharmaceutical medicines.

Dean Bortell feels as if he's failed his 9-year-old daughter Alexis.

It's his natural, fatherly duty to care for his child when she suffers, he said.

Bortell has been there for her childhood scrapes and bruises. He was by her side in the hospital when at a year old, she battled pneumonia. Doctors prescribed medicine, and she got through it, he said.

But a year and a half ago, Alexis was diagnosed with something he and traditional medicine can't fix.

Alexis suffers from intractable epilepsy, which can trigger seizures at any time, but mostly while she sleeps. She rarely has friends visit, because a compromised immune system can contribute to the frequency and severity of seizures. She also has never slept over at a friend's house because her seizures tend to happen at night.

Her mother, Analiza, sleeps by her side each night, waiting for movements that might represent a triggering seizure.

"My long-term fear is that she won't have a normal life, that she won't be able to be a kid, that she won't be able to live as high a quality life as she could and that her seizures might cause irreversible, debilitating damage if they escalate as she ages," Bortell said. "My short-term fear is SUDEP, sudden unexpected death by epilepsy."

The Bortells tried more than a dozen medications and medicine combinations trying to minimize the frequency and severity of Alexis' seizures. But the medications only made the events worse, "like throwing gasoline on a fire," Bortell said.

Alexis became violent on some medications. She became "zombie-like," on others, Bortell said, and physically injured herself on others.

The Bortells have crisscrossed the country searching for answers and treatment alternatives, but the only successful option they say they've found isn't legal in Texas.

Alexis' epileptologist and a team of neurologists believe cannabis extracts — including cannabidiol (CBD) and tetrahydrocannabinol (THC) — could succeed where traditional medicines failed.

Bortell said he's angry because he feels the state of Texas has failed him and thousands of other families by not yet recognizing the benefits of medicinal marijuana.

Alexis is a registered medical marijuana patient in Colorado but can't take her prescribed medicine because her parents would face felony charges if Child Protective Services finds the drug in her system.

Bortell said he is at the end of the rope and is prepared to move to Colorado if legislation to allow Alexis access to medical marijuana does not become law this legislative session.

But in a ruby-red Republican state like Texas, proposals to legalize marijuana have garnered little traction. However, a wave of medical evidence showing cannabis's medicinal benefits and public outcries for change from desperate families may be shifting the tide.

Public opinion is changing so much so that a group of Republicans are leading the way this legislative session to legalize medical cannabis in limited instances and in limited forms.

State Sen. Kevin Eltife, R-Tyler, has drafted a bill that would legalize cannabidiol-heavy oils used to treat epileptic seizures. The bill would address cases of intractable epileptic seizures and is supported by the Epilepsy Foundation of Texas.

Eltife said these severe epileptic conditions and CBD treatments were brought to his attention by Arp nurse Marcy Bingham, whose son, Jacob, 8, suffers from one of the rarest and most debilitating forms of intractable seizures — Dravet syndrome.

Jacob uses a wheelchair, can't speak and requires around-the-clock medical supervision. His condition continues to deteriorate.

"This bill puts the focus on the patients, most of them children, who deal with horrible seizures on a daily basis," he said. "I try to put myself in the parents' situation, and it has to be tough to know something is there that can help their child but the state says, 'No, you can't.'"

## THE FACE OF MEDICAL MARIJUANA

Eltife said he believes Texas legislators will proceed cautiously when it comes to medical marijuana. But he believes his bill will gain broad support and give thousands of patients and parents treatment options they and their doctors should have.

The CBD oil, which is applied to food or rubbed into the patient's gums, would be highly controlled and does not contain enough THC to give users the euphoric "high" associated with marijuana, Eltife said.

"This is to help their condition, not get them high," Eltife said.

Rep. Stephanie Klick, R-Fort Worth, will file a similar bill in the House.

Eltife said he will be open minded when it comes to other bills that might expand medical cannabis for other illnesses, including cancer, Parkinson's disease and ALS, but that he's focused on helping children, such as Jacob and Alexis.

Alexis said she's ready to be a face for the legalization of medical cannabis in Texas. Bortell said he would have been shocked if he'd been told two years ago that he would be lobbying to legalize medical marijuana. He said he's a Republican, Christian conservative and a disabled veteran who assisted in interdiction efforts in the war on drugs in and around the Caribbean.

But his daughter's health prompted action, he said.

Moving is an option for Bortell, who is a software engineer for the Denver-based Catholic Health Initiatives, that would mean uprooting Alexis and her 5-year-old sister, Avery, from the only home they've ever known. But it would mean leaving behind grandparents, friends and their church, he said.

"We want to stay and fight for Alexis and thousands of other families who might feel they don't have a voice," Bortell said. "If we lose this time, we'll move, but we will continue to speak out."

Alexis has been speaking out and said she does so for children, such as Jacob, who can't speak for himself.

She's spoken in front of more than 2,500 people at a Dallas/Fort Worth National Organization for the Reform of Marijuana Laws rally and will make the rounds, meeting House and Senate members on Tuesday during Patient Alliance For Cannabis Therapeutics' patient lobby day.

The Bortells live in Texas House District 33, represented by Rep. Scott Turner, of Frisco, and Senate District 2, represented by Sen. Bob Hall, R-Canton, who both have conservative, Tea Party-type ideals.

Hall said it would be inaccurate to say he supported medical marijuana but that he supports "treatments and drugs legitimately prescribed by legitimate doctors."

The freshman senator met with the Bortells recently, and while he sympathizes with them and other sick Texans, he said the details, such as setting limitations of access and determination of need within any bill regarding the medical use of marijuana, would decide whether it gets his vote.

"People need to have access to treatments and drugs their doctors prescribe, and that runs the spectrum from pharmaceuticals that aren't available in the U.S. to marijuana," he said. "But I will not support weak legislation."

Hall "has questions and concerns, and I understand that," Bortell said. "But he was nothing short of a statesman, because he was willing to listen and actively engaged in the conversation. That's all we want is for them to listen, because if they hear the stories and what a growing number of doctors are saying, it should be a no-brainer."

But, Bortell is worried other legislators may take a stance similar to Turner, who told the family he would not support any cannabis bill.

In an October statement to the Bortells, Turner said, "I understand that a parent would do almost anything to reduce the suffering of their child, and my thoughts and prayers are with the families facing these difficult situations. At this time, however, I do not support legalizing marijuana for medical purposes. In addition to significant moral and ethical concerns, there is widespread disagreement in the medical profession regarding the safety, effectiveness and long-term side effects of this proposed treatment.

"As a legislator, I will continue to engage in a thoughtful process, speaking to medical professionals, fellow clergy, families, ethicists and other medical professionals, so I can continue to make an informed, principled decision in this matter," Turner wrote.

Turner didn't respond when asked by the Tyler Morning Telegraph at a recent Austin event about his stance on medical marijuana to help people with debilitating diseases.

When asked if he was aware Rep. Klick would file CBD legislation in the House, Turner said he was aware of the bill and would listen. "I'm a good listener," he said.

The Texas Sheriffs Association has gone on record that it would vigorously oppose legislation with cannabis components, including medical marijuana, broad legalization or decriminalization. Bortell also expects pharmaceutical companies that have invested billions of dollars in FDA-approved drugs to lobby to stop medical cannabis bills.

Dr. Bob Deuell, a 30-year family physician who served as District 2 state senator from 2003-2015, said his main concern would be controlling the drug. He said the abuse of prescribed medications is a real problem, and that he suggests only

specialists, such as general neurologists, should prescribe the drug as a medicine of last resort.

Deuell noted a recent Journal of Neuroscience study that showed the detrimental effects of marijuana on young brains.

“It’s addictive, and it causes damage,” he said. “I don’t think it should be the first line of defense, but if a specialist refers it, I don’t think its use should be restricted (by that patient).”

But he said some prescription drugs, such as hydrocodone and oxycodone, are “more dangerous than medical marijuana.”

Deuell said he had a file of bills that would have addressed laws restricting the use of medical marijuana similar to Eltife’s. He said he’s glad Eltife is carrying it.

The Bortells said they have received nothing but support, albeit, reluctant and probing at times, from other legislators.

#### MEDICINE vs. “POT”

The District of Columbia and 23 other states, including Colorado, Illinois, New Mexico, Arizona and California allow the medical use of cannabis. Colorado’s medical marijuana laws allow eight qualifying conditions, including cancer, glaucoma, HIV/AIDS, muscle spasms, seizures and severe pain. Other states’ conditions lists vary but include drugs for Alzheimer’s, multiple sclerosis, PTSD and migraines.

Mrs. Bingham sees Eltife’s bill as the only chance for Jacob, who has multiple seizures each day because of advancing Dravet Syndrome.

Like the Bortells, the Bingham have traveled the country to meet with geneticists, neurologists and other specialists looking for options. But after trying 16 medications with no relief, they are considering moving to Colorado for access to a kind of CBD oil that has helped hundreds of Dravet Syndrome sufferers.

“We’re desperate,” Ms. Bingham said. “There are no more drugs to give him. The ones they have given him have caused horrific side effects, and we’re asking to use extracts from a plant but the state of Texas has said, ‘No, no, no.’”

The high-CBD concentrated strain, Charlotte’s Web, is named after Charlotte Figi, a Dravet patient, who suffered hundreds of seizures each week before she began taking daily doses of the oil. Since she began treatment, she has reported dramatic physical and cognitive improvement.

The Epilepsy Foundation Texas believes CBD oils should be an available treatment option if patients, their family and their physician-led medical teams feel it might reduce the number of seizures and limit the possibility of severe consequences including death and major disability.

The Epilepsy Foundation will support the limited use of non-euphoric cannabidiol (CBD) rich oil in Texas for the treatment of severe epilepsy as directed and guided by board certified physicians.

“We support Sen. Eltife’s bill, so Texans and their families do not have to move from our state to have access to this promising treatment option.

“CBD oil is an important ray of hope for those who have not found success with current treatments,” said a foundation spokesman in an emailed statement.

But Bortell said Charlotte’s Web would not help his daughter, because the ratio of CBD is too high and does not help a large number of intractable seizure sufferers.

Bortell said ratio numbers in the pre-filed version of the bill released by Eltife’s office appear to be at the threshold of what would help Alexis. “That’s where the doctors told us to start,” he said. “It’s an arbitrary number until doctors experiment with the ratios to find what works for her.”

Neurologist William Gilmer, chairman of the Texas Medical Association's Science and Public Health committee, said Bortell's concern is exactly why government should allow scientific studies of the hundreds of natural compounds in cannabis and determine their uses and effectiveness in various forms on various illnesses.

The medical association likely will support broader legislation regarding medical marijuana, but his personal opinion is that government should not dictate his treatment options if his opinion is backed by science.

The Bortell's situation is "the perfect example of why we should open this substance up to research. What constitutes the right ratio? Science answers those questions," he said. "In my mind the Legislature should not tell me what I can and can't prescribe if there is scientific evidence supporting it."

Dallas/Fort Worth National Organization for the Reform of Marijuana Laws Director of Operations Max Davidson called any bill suggesting Colorado-style legalization of recreational marijuana "dead on arrival."

Davidson said the group is focused on medicinal use and helping patients with debilitating illnesses, including epilepsy, various forms of cancer and even PTSD. But the group does not support "CBD-only" legislation that could narrowly limit its value to millions of suffering Texans, he said.

The group also wants to see marijuana possession decriminalized for people carrying less than one ounce of pot. Legalization remains the group's long-term goal, he said.

"Right now we are focused on helping people who are suffering and dying needlessly. It's a pro-life stance, a quality of life stance," he said. "But the organization is broadly focused on repealing marijuana prohibition in Texas and around the country, because it's an antiquated, ignorant law."

Eltife said he would not support broad legalization of marijuana, and he doesn't expect legislators will view his bill as a foot in the door for recreational marijuana.

"No. We're talking medicine. We're talking about something that will be highly regulated and prescribed by board certified doctors. I truly believe that if (legislators) look at the facts and the medical benefits patients are experiencing in other states, they'll view it as medicine and that is what I'm presenting and supporting," Eltife said.

The Bortells said Colorado has one of the most stringent processes in the country when it comes to prescribing medical marijuana. Two board-certified specialists verified Alexis' condition warranted access to medical marijuana in Colorado.

The family doesn't care how heavily regulated the drug might be as long as they have access.

Bortell acknowledged arguments, including Turner's regarding the lack of research and unknown side effects on patients and negative effects on brain development in young users. But quickly added that each could be refuted by various merits.

He'd rather risk points off his daughter's IQ rather than infertility, liver and kidney damage and even death, which are side effects of legal prescription drugs prescribed to her.

Alexis could not finish her school aptitude tests while medicated, he said. She scored in the top 4 percent nationally on her last test. He said legislators could expect to hear compelling testimony from patients and doctors regarding the benefits of medicinal marijuana.

At their doctor's recommendation, Alexis is not using any prescription drugs now. Her parents monitor her around the clock, looking for warning signs, such as mood changes or blinking eyes — telltale signs a seizure could be looming.

Bortell is hopeful legislators listen. He is hopeful they listen to patients and families and doctors who see the benefits of cannabis and approve a bill that will allow his family to stay home.

“All we’re asking for is a chance,” he said. “When the gavel falls in May, we’ll know if we have to leave Texas.”

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