COMPASSIONATE ACCESS FOR EPILEPSY ANNOUNCES SUPPORT FOR TEXAS COMPASSIONATE USE ACT
Legislation would allow Texans living with intractable epilepsy access to critical treatment option

DALLAS, March 3, 2015 – Compassionate Access for Epilepsy (C.A.F.E.) Texas announced its official support today for the Texas Compassionate Use Act, which would help Texas residents who qualify under the Act to access cannabidiol (CBD) that may help decrease the incidence of uncontrolled, or intractable, seizures. The Texas Compassionate Use Act (Senate Bill 339 and House Bill 892), recently filed by primary authors Senator Kevin Eltife (R-Tyler) and Representative Stephanie Klick (R-Fort Worth), and joint authors Representative John Zerwas (R - Richmond), Representative Bill Zedler (R-Arlington) and Representative Garnet Coleman (D-Houston) and co-author Representative James White (R-Woodville), would create a tightly regulated process for cultivation of cannabis, for production and dispensing of cannabidiol (CBD) treatments to patients with uncontrolled seizures. Many patients with intractable epilepsy have seen dramatic reductions in seizures through the use of CBD without exhibiting adverse reactions. The legal barriers to access have led parents to take drastic measures, including leaving Texas, to seek treatment for their children.

Epilepsy and Its Effects
More than 2.8 million Americans live with epilepsy, a neurological condition that produces recurring seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. Despite advances in epilepsy therapy over the past several decades, about a third of people living with epilepsy cannot achieve seizure control with current Food and Drug Administration (FDA) approved treatments, and many more experience significant physical, cognitive and behavioral side-effects associated with epilepsy medications. Nearly 150,000 Texans are living with intractable epilepsy and uncontrolled seizures, putting them at continual risk of serious injuries, including loss of life. This is why many individuals who have run out of options turn to CBD.

Cannabidiol Oil
The stigma surrounding cannabis has led to misunderstandings about CBD as a treatment option for children and adults living with intractable epilepsy. CBD oil is derived from cannabidiol, a component of the Cannabis Sativa plant. CBD oil for the treatment of epilepsy is rich in cannabidiol but low on THC, the psychoactive component of the cannabis plant. Children living with severe and catastrophic forms of epilepsy have experienced a dramatic reduction in the number of seizures when treated with CBD oil, which is not smoked and has no addictive qualities. Many families of children living with uncontrolled seizures who have run out of options are considering CBD, but legal barriers prevent them from gaining access to this treatment option. A well-known example of CBD oil for the treatment of uncontrolled seizures is the Charlotte’s Web™ hybrid strain developed and cultivated for a young epilepsy patient, who also has Dravet Syndrome, named Charlotte Figi in Colorado.

“There are risks and side-effects associated with every treatment, including those approved by the FDA, but every day without seizure control is a risk to life,” said Donna Stahlhut, founder and chief executive officer, Epilepsy Foundation Texas - Houston/Dallas-Ft. Worth/West Texas. “That is the one certainty every child with intractable epilepsy and their parents face every single day. The Epilepsy Foundation is committed to supporting families as they explore all epilepsy treatment options - including CBD - by advocating for legal access to this treatment option when recommended by a physician, and by removing barriers to research into the connection between cannabis and seizure control so families can make informed decisions.”

The American Academy of Pediatrics believes more research should be done on CBD and its potential benefits, and recognizes the need for compassionate access for children living with uncontrolled seizures. In a January 2015 policy statement, the organization reaffirmed their position against the legalization of marijuana but also said that, “Notwithstanding this opposition to use, the AAP recognizes that marijuana may currently be an option for cannabinoid administration for children with life-limiting or severely debilitating conditions and for whom current therapies are inadequate.”

Kenzie’s Story Began with a Virus
Kenzie of Fort Worth was nine when she developed post encephalitic seizures disorder, which is believed to have been caused by a simple virus. Since her intractable epilepsy diagnosis, she takes daily medications and endures life-threatening seizures that affect her mentally and physically. But perhaps the most damage has been done to her “heart.” Kenzie, now 21, feels the brunt of her disability from a social perspective. She sees other young adults living their lives and doing things she simply cannot, and it affects her deeply.
“Kenzie’s life is at risk every day, and she’s experienced thousands of seizures,” said Melinda Clark, Kenzie’s mother. “Our daughter is simply looking for hope - hope for a better quality of life - and that’s what the Texas Compassionate Use Act offers.”

Karley’s Fight for Life
The first two years of Karley’s life have been wrought with ER visits, EMU and ICU stays, lack of essential sleep, and constant prodding by doctors, all leading up to a the diagnosis of Dravet Syndrome, a rare form of intractable epilepsy that begins in infancy. Karley currently takes FDA-approved antiepileptic drugs for seizure control yet she battles seizure attacks on a daily basis; she periodically has tonic-clonic episodes lasting between 30 to 90 minutes that require multiple rescue medications and emergency room care to stop the convulsions. The Fort Worth native struggles with balance and motor skills and is nonverbal and constantly agitated throughout the day. Her expressive and receptive language skills have actually regressed to a three-month-old level and she hasn't made any progress cognitively since she was nine months old.

“Texans who suffer with intractable epilepsy have limited treatment options that often result in poor quality of life with marginal seizure control,” said Jeff Davis, Karley’s father. “For some patients, seizure control is a matter of life and death. Providing intractable epilepsy patients with legal, physician-directed access to CBD as a treatment option offers the opportunity for a better quality of life. As parents of a child with intractable epilepsy whose future is uncertain and whose condition can change drastically from one day to the next, my wife and I should be allowed to make treatment decisions for Karley with her epileptologist without having to leave her support system. The Texas Compassionate Use Act will allow us to do that.”

Leaving Home: Abbu’s Story
Originally from San Antonio, Ibrahim “Abbu” was diagnosed with Batten Disease, a form of intractable epilepsy, at age five. His family learned of CBD’s potential to improve the lives of patients with intractable epilepsy, and, because it’s legal to obtain the oil in Colorado, moved thousands of miles from home for the chance at treatment. Before starting treatment, he was taking seven medications daily and struggling with seizures. It has been a year since he began using CBD oil as a treatment, and his parents have noticed a drastic improvement, with a reduction in the frequency of his seizures. Abbu is also taking lower doses of just three other medications. Abbu has two younger siblings, who love their big brother but would also love to rejoin their friends in Texas.

“The Compassionate Use Act would allow us to return to Texas - our home - and continue to treat our son's life-long condition,” said Fahad Afeef, Abbu’s father. “It was well worth uprooting our family to see our boy not suffer with uncontrollable seizures, but it would have been so much better if we had the option in Texas. Not all families living with intractable epilepsy have the ability to drop everything and move out of state, like we did.”

The Future
Despite the need for more research, CBD is a viable treatment option for individuals living with intractable epilepsy who have run out of options and live with the continual risk of serious injuries and loss of life. “Research into medications derived from CBD is underway, but gaining approval for cannabis research studies is complicated and expensive. FDA approved cannabis treatments are years away and individuals experiencing dozens of uncontrollable seizures every day cannot afford to wait that long,” said Sindi J. Rosales, chief executive officer, Epilepsy Foundation Central & South Texas. “This is why we call on the state to create a limited and tightly regulated medical cannabis program that ensures safe and legal access to CBD.

The Epilepsy Foundation’s national office actively advocates for increased access and research. “Nothing should stand in the way of patients gaining access to potentially lifesaving treatment,” said Philip M. Gattone, president and CEO, Epilepsy Foundation. “If a patient and their healthcare professionals feel that the potential benefits of medical cannabis for uncontrolled seizures outweigh the risks, then families need to have that legal option now -- not in five years or ten years. For people living with severe, uncontrolled epilepsy, time is not on their side.”

To learn more about CBD treatment and outcomes, visit www.epilepsy.com and www.cafetx.org.

###

About C.A.F.E. Texas
Compassionate Access for Epilepsy Texas (C.A.F.E. Texas) supports 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. C.A.F.E. Texas provides a voice for many Texans who suffer from severe epilepsy and traditional treatment options as prescribed by their physician have not worked. C.A.F.E Texas is a project of the Epilepsy Foundation Texas affiliates, with support from the Epilepsy Foundation national office. This initiative was launched to support policy changes that will benefit patients and families, especially families with small children who have catastrophic forms of epilepsy. C.A.F.E. Texas brings together Texans and nonprofit organizations that support compassionate access to and physician-directed therapeutic use of cannabidiol (CBD), a component of the cannabis plant, to treat epilepsy.