HOPE 4 CHILDREN with epilepsy
ABOUT

H4CE is a group of Utah parents whose children have extremely severe forms of epilepsy. Most have multiple types of seizures every day, varying in intensity and length from seconds to hours. The seizures take a toll on the children’s over-all health, ability to function, and quality of life. These children also have a ten-times increased risk for sudden death (SUDEP – Sudden Unexpected Death in Epilepsy). We have tried numerous types of medications, diets and treatments (both mainstream and alternative), but our children are still seizing.

Hope 4 Children with Epilepsy (H4CE) is NOT advocating for a medical marijuana program. Our children need a recently available extract, Alepsia, from a hemp-quality hybrid cannabis plant. It is processed into an oil, tincture or capsule. The oil is TAKEN ORALLY, is NOT smoked and DOES NOT MAKE CHILDREN HIGH.

The cannabis used to make this oil is a new hybrid strain that is very high in medicinal CBD and only contains trace amounts of the psychoactive component, THC. This is termed high-CBD/low-THC cannabis and does not cause a high.

There is much legitimate research showing that CBD has significant neuro-protective properties, while causing fewer side effects than current anti-seizure medications.

Utah has the opportunity to be innovative in its approach to this legislation. With a positive response from the community, as well as the assistance of experts and lawmakers, we can find a way to provide help for our children while removing the potential for abuse.

This isn’t a political issue, and it isn’t an ethical issue; this is a medical and public policy issue.

To learn more and follow the efforts to make Alepsia available, please LIKE the Hope 4 Children with Epilepsy Facebook page and visit our website at www.hope4childrenwithepilepsy.com.

For inquiries regarding the legislation and its progress, please contact our sponsors:

**Representative Gage Froerer (R)**
District: 8
Address: PO Box 379, Huntsville, UT 84317
Email: gfroerer@le.utah.gov
Work Phone: 801-621-0505

**Senator Stephen Urquhart (R)**
District: 29
Address: 634 E 1100 S, St. George, UT 84790
Email: surquhart@le.utah.gov
Work Phone: 435-668-7759
**TALKING POINTS**

**Alepsia**  
*An hope for intractable epilepsy*

Who are we?

- We are parents of children with severe forms of epilepsy. Most have multiple types of seizures every day, varying in intensity and length from seconds to hours. The seizures take a toll on the children’s over-all health, ability to function, and quality of life. These children also have a ten-times increased risk of death.

- Although we have tried numerous medications, diets and treatments (both mainstream and alternative), our children are still seizing.

- The treatments used to control these types of seizures also cause serious side effects, like organ failure, broken bones, sterility, cardiac conditions, blindness and even death. Additionally, some of the drugs prescribed are not approved by the FDA for use in children.

- Our children *desperately* need new treatment options that hold hope for controlling the seizures, stopping the deterioration, and improving their quality of life.

Introducing Alepsia:

- We are *not* advocating for a medical marijuana program. Our children need a recently available extract for epilepsy. Derived from a specific type of hybrid cannabis plant, the extract is given in the form of an oil, tincture or capsule. It is NOT SMOKED and DOES NOT MAKE CHILDREN HIGH. It is called Alepsia.

About cannabis:

- Cannabis plants are made up of over 400 components, but the two main components are CBD & THC. CBD has been shown to provide significant medical benefit, while THC causes the “high”.

- There are many different strains of cannabis, each containing different levels of CBD and THC. The cannabis used to make the extract we need for our children is a hybrid strain that is very high in CBD and extremely low in THC. It does not cause a high, making it unattractive for those selling, buying and using on the street.

- The name of the cannabis plant being used to make this extract is called “Charlotte’s Web”, named after Charlotte, the first child successfully treated with it. Currently, it is only grown in Colorado by the six Stanley Brothers. They then utilize a technologically advanced process to extract it into drops or oils that are sent to an independent lab for testing before being administered.
Is Alepsia safe and effective?

- The amount of THC in this hybrid is low enough to meet the federal definition of industrial hemp, a non-psychoactive form of cannabis. This is the same level of THC that is already found in products on the shelves of our stores here in Utah, including hemp protein, hemp oil, paper, fabric, and other items.

- There is much legitimate research showing that CBD has significant neuroprotective properties, while causing fewer side effects than anti-seizure medications.

- Children being given Alepsia are seeing remarkable results. Currently, 80% are responding positively, with their seizures being reduced by 50% on average. In addition, they are regaining abilities and experiencing an increase in quality of life!

- Alepsia is not a cure, but it is a legitimate treatment. We are very frustrated and sad that we can’t help our children with it because it is technically not legal for us to do so.

Please help us!

- No state in the nation has made a determination allowing only for the use of high-CBD/low-THC cannabis in the form of oral concentrates.

- Utah has the opportunity to be innovative in its approach. With a positive response from the community, as well as the assistance of experts and our legislative sponsors, Representative Gage Froerer and Senator Stephen Urquhart, we must find a way to bring Alepsia to Utah!

- Our children are seizing every day and are desperate for relief. Another year without legislative action means another year of torture and deterioration.
Cannabidiol is rapidly gaining attention as the key to the medicinal value of the cannabis plant. We have compiled links to the most relevant published research articles. This document will continue to be modified as new research is developed.

CBD for Epilepsy


CBD for Schizophrenia


CBD for Cancer


CBD for Nausea

CBD for Alzheimer’s


Cannabidiol and other cannabinoids reduce microglial activation in vitro and in vivo: relevance to Alzheimer’s disease.

**Source**: Neurodegeneration Group, Department of Cellular, Molecular and Developmental Neurobiology, Instituto Cajal, CSIC, Madrid, Spain.

CBD for Parkinson’s


Evaluation of the neuroprotective effect of cannabinoids in a rat model of Parkinson’s disease: importance of antioxidant and cannabinoid receptor-independent properties.

**Source**: Departamento de Bioquímica y Biología Molecular III, Facultad de Medicina, Universidad Complutense, 28040-Madrid, Spain.

![Diagram of cannabinoid actions](Image)
PHYSICIAN STATEMENTS

Dr. Francis Filoux, Chief, Division of Pediatric Neurology, University of Utah Primary Children’s Hospital

“...CBD-based oils (referred to here in Utah as “Alepsia”) should be available as soon as possible to Utah children with severe epilepsy. The substance is not psychoactive or hallucinogenic, it contains less THC than do other materials that can be legally purchased in Utah, and it has absolutely no abuse potential.”

Dr. Catherine Jacobson, Post-Doctoral Scholar in Neurology, Stanford University & UCSF

“CBD appears to be an effective AED in a very difficult-to-control pediatric population of epilepsy. Importantly, it is reported to be extremely well tolerated.”

Dr. Elizabeth Thiele, Director of Pediatric Epilepsy Program, Mass. General Hospital

“My colleagues and I have witnessed the dramatic effect of CBD on many of our pediatric patients. For example, I have a pediatric patient with severe intractable epilepsy who had been experiencing up to 100 seizures every day, despite trials of 18 antiepileptic drugs. After CBD was introduced into his treatment regimen, his seizures decreased dramatically. He now has between 0 and 5 seizures a day. He is also more alert, and turns out to have a wicked good sense of humor.”

Dr. Orrin Devinsky, Director of Comprehensive Epilepsy Center, NYU Langone Medical Center

“For patients who have had little success in treating their seizures with other medications, CBD could be a last resort.”

Cannabidiols: Potential Use in Epilepsy & Other Neurological Disorders
This course will provide an overview of preclinical and clinical data on cannabidiol (CBD), a nonpsychoactive component of cannabis that shows great promise in a variety of neurological disorders.

Dr. Michael Cutler, Professor of Medicine, Division of Cardiology, Case Western University

“There is a extensive body of scientific literature suggesting that high-CBD/low-THC cannabis agents such as “Alepsia” hold great promise for the management of refractory seizure disorder. Perhaps more exciting is that these compounds have a very low side-effect profile. One of the most important questions to ask in this case is does the potential benefit outweigh the potential risks?”

Dr. Alan Shackelford, General Practitioner, Colorado

"There are absolutely clear benefits for a great many people using cannabis. Sometimes it's most effective and sometimes it shouldn't be used at all. And that's up to us as physicians to determine."

Dr. Margaret Gedde, General Practitioner, Colorado

“They can eat. They can put on weight. They can sleep,” she said. “They can actually have a normal childhood.”
November 11, 2013

To whom it may concern

RE: “Alepsia” or Cannibidiol Oil for Utah children with severe epilepsy

Dear Colleague:

I am writing to express my strong support for Utah families seeking to make a specialized cannabis-oil product available to their children here in Utah. I am a pediatric neurologist who has cared for children with epilepsy in Utah for more than 25 years. I am the Division Director of Pediatric Neurology at the University of Utah and a member of the Child Neurology Society. Every day of my professional life I care for numerous children with uncontrolled epilepsy and specifically I care for several children with Dravet syndrome, a type of severe childhood epilepsy that has been in the news in Utah recently relevant to the medical use of cannabidiol. Therefore, I believe I am well qualified to provide an objective medical and neurological opinion on this matter.

Cannabidiol (CBD) is one of the “cannabinoids” or naturally occurring chemical elements found in the natural product Cannabis, or Marijuana. There is extensive “pre-clinical” data (meaning experimental data in animals and laboratory studies) that indicates that CBD as a chemical is effective in reducing epileptic activity, electrophysiologic disturbances analogous to epilepsy or in blocking molecular pathways that are involved in the generation of seizures or epilepsy. Thus, there is extensive and reproducible data demonstrating that, from an experimental point of view, CBD holds great promise as an antiepileptic agent.

In addition to this, there have been recently publicized cases of children with severe epilepsy who have experienced extraordinary seizure control and improvement in their quality of life from natural substances that contain high content of CBD. These substances are purposefully manufactured with high content of CBD (a non-psychoactive component of cannabis) and very low or nearly undetectable levels of tetrahydrocannabinol (THC) which is the “psychoactive” ingredient of cannabis or marijuana. However, due to the manner in which existing regulation regarding availability of cannabis products is interpreted in the United States and Utah, these non-psychoactive products
are not currently available to our Utah patients with severe epilepsy. As a pediatric neurologist who cares for many children with severe epilepsy, I believe any product that is actually legally available in the United States and is legally taken by some of our citizens should be available to United States citizens whether they be residents of Colorado (where the CBD product is legally available) or of Utah (where currently it is not available). In this discussion, the following key points should be considered:

- **CBD oil** is a natural product that is not regulated as a medication by the FDA.
- **CBD oil** ("Alepsia" or "Realm Oil" and similar preparations) is very high in CBD but has THC content that is as low as or lower than other natural substances such as hemp-based creams that currently can be legally purchased in Utah.
- **CBD oil** is not a psychoactive substance; it does not "produce a high" and is not "mind-altering" in its effect.
- **CBD may be extremely effective in some cases**: The anecdotal experience of many patients and families is that CBD oil results in remarkable seizure control with improvement in quality of life. (This is despite the fact that all these children have previously been on numerous antiseizure medications with minimal benefit).
- **CBD appears to be safe**: So far, experience with CBD oil and related products containing CBD indicates that side effects are very limited or non-existent. This alone is a very unusual property for a substance that may produce remarkable seizure control.
- **CBD is not available currently in the US as a pharmaceutical product**: Thus, our patients in Utah currently cannot access this potentially extremely helpful treatment with CBD without physically moving to a state where they can be legally treated with CBD oil or where they can participate in one of two limited medium sized IND trials (which are only available currently at UCSF [California] or NYU [New York]).
- **Pediatric neurologists and physicians routinely recommend substances to their patients that are not FDA-approved medications**: There is no logical reason that CBD oil should not be similarly available.

In summary, I would like to express my strong belief that CBD-based oils (referred to here in Utah as "Alepsia") should be available as soon as possible to Utah children with severe epilepsy. The substance is not psychoactive or hallucinogenic, it contains less THC than do other materials that can be legally purchased in Utah, and it has absolutely no abuse potential. In Utah its use would be supervised by careful and knowledgeable physicians for the benefit of their patients. It is critical that safe and reasonable options for the treatment
of children with severe epilepsy be available in Utah as they are in other states. Otherwise, as a community we would be making the decision to limit access of our children to a potentially life-improving therapy.

Please feel free to contact me if I can provide additional information.

Sincerely yours,

Francis M. Filloux, M.D.
Chief, Division of Pediatric Neurology
The Glenn and Ben Schmidt/Edgar Chair of Pediatric Neurology
Professor of Pediatrics, Neurology
University of Utah School of Medicine
e-mail: francis.filloux@hsc.utah.edu
PROFESSIONAL CONTACT LIST

Dr. Francis Filloux, MD
Chief, Pediatric Neurology
University of Utah Primary Children's Hospital
Professor of Pediatrics and Neurology
University of Utah School of Medicine
francis.filloux@hsc.utah.edu
(801)587-7575

Dr. Catherine Jacobson, PhD
Post-Doctoral Scholar in Neurology
Stanford & UCSF School of Medicine
jacobson.catherine@gmail.com
(415)384-8345

Dr. Elizabeth Thiele, MD, PhD
Director of Pediatric Epilepsy Program
Massachusetts General Hospital
Associate Professor in Neurology
Harvard Medical School
(617)726-6540
(617)726-0241

Dr. Orrin Devinsky, MD
Director of Comprehensive Epilepsy Center
NYU Langone Medical Center
Professor of Neurology, Neurosurgery and Psychiatry
NYU School of Medicine
(646) 558-0803

Dr. Linda Laux, MD
Attending Neurologist – Epilepsy Center
Ann & Robert H. Lurie Children's Hospital of Chicago
Assistant Professor Pediatric Neurology
Northwestern University Feinberg School of Med.
(312)227-3540

Dr. Maria Cilio, MD
Pediatric & Neonatal Epileptologist
Director of Research in Pediatric Epilepsy
UCSF Epilepsy Center
Professor of Clinical Neurology
UCSF School of Medicine
maria.cilio@ucsf.edu
(415)514-8415

Dr. Eric Marsh, MD, PhD
Pediatric Regional Epilepsy Program
Children’s Hospital of Philadelphia (CHOP)
1-800-879-2467

Dr. Alan Shackelford, MD
General Practicioner
Amarimed of Colorado
(720)532-4744

Dr. Margaret Gedde, MD
General Practicioner
Gedde Whole Health, Colorado
(877)237-8571
ABOUT THE HOPE LEADERSHIP TEAM

Jennifer May
Jennifer May and her husband, Cameron, live in Pleasant Grove Utah with their three children Bryson (18), Makayla (15), and Stockton (11). Stockton has Dravet syndrome, a severe form of epilepsy. Cameron works as an investment coach at TD Ameritrade/Investools.

Born and raised in southern Idaho, Jennifer attended Brigham Young University where she majored in Business Education. She left school one semester short of a bachelor’s degree to accept a promotion in the international purchasing and transportation industry.

Through the next several years, Jennifer continued in purchasing and became active in the fitness industry. She and her husband became certified personal trainers and owned a fitness center of their own in Idaho. Later the Mays sold their business and moved back to Utah where Jennifer worked in sales and bookkeeping for Gold’s Gym. She was able to quit working just before the birth of their third child, Stockton.

With the onset of Stockton’s seizures and developmental delay, Jennifer became active in the epilepsy community. She became a HOPE (Helping Other People with Epilepsy) mentor with the Epilepsy Association of Utah and served on their board of directors. Shortly after receiving Stockton’s diagnosis of Dravet syndrome, Jennifer assisted with the development of the original international non-profit organization for Dravet syndrome, IDEA League (International Dravet Syndrome Epilepsy Action League).

Even now, Stockton is suffering daily with the seizures, medication side effects, and the co-morbid conditions that come with Dravet syndrome. Jennifer is one of three moms that have formed Hope 4 Children with Epilepsy to pursue legislation that would allow their children to have access to the promising Alepsia. Jennifer is also currently serving as a parent advocate on the Professional Advisory Board of the Epilepsy Association of Utah.

Annette Maughan
Annette Maughan and her husband, Glenn, live in Cedar Hills Utah with their four children: Glenn (Bug) - 10, Taylor - 8, Ava – 2 and Aiden – 6 months. Bug has refractory epilepsy caused, in part, by a Cerebral Folate Deficiency stemming from a Folate Autoantibody.

Born and raised in Northern Utah, Annette graduated from Roy High and immediately went to work in the retail industry.

After meeting Glenn, Annette learned about computer systems and worked for the Ogden City School District’s Federal Programs as a System Administrator. She followed Glenn to Chicago where Bank of America, located in the Sears Tower, employed her as an AVP of NT Systems. Moving from Chicago to California was a big step, but took them both to the Walt Disney Company where Annette was the System Administrator for their Broadband Division.

After leaving Disney, their first child, Glenn was born. Annette started her own technical consulting business while raising their son. The business, Digital Aces, Inc. did very well and supported the family for 4 years. Bug’s first seizure occurred 6 weeks shy of his third birthday. Once his seizures became a daily encounter, she put the business on hold and began to focus on finding more help for her now regressing son.

They moved their family back to Utah where Glenn took a position with Omniture, now Adobe, as a Director of Product Infrastructure and Annette began volunteering with the Epilepsy Association of Utah. In 2010, she accepted their offer to join their Board of Directors. In 2012, Annette was elected President of the Association and began her service to the epilepsy community of Utah.

In August, 2013, Annette was recruited to the effort to bring Alepsia to Utah after watching her son fail his 8th medication and suffering, on average, 3 seizures a day. Bug now has, at minimum, 2 seizures a day and is cognitively 18 months old.
Emilie Campbell
Emilie Campbell and her husband, Branden, live in Cedar Hills with their two children: Katie (10) and Connor (6). Connor has refractory epilepsy of unknown cause. He’s been seizing daily since birth.

Branden and Emilie both grew up in Las Vegas where they attended high school together. After graduating, they served LDS missions and were married shortly thereafter. Emilie graduated from BYU with a BFA in Photography and has remained busy as a freelance commercial and portrait photographer. Her work has been published worldwide by clients such as American Baby Magazine, Nu Skin Int., Fender Guitars, Gretsch Guitars, 3Form, BYU, Layla Grayce and others. Branden is a professional musician and keeps the family busy traveling with him as he tours the world with his band, Neon Trees.

Branden’s career has allowed Emilie the freedom to spend the majority of her time tending to Connor’s special needs and seeking treatments for him from specialists across the nation. They have yet to find any medicine or treatment that has given Connor any seizure control. Fortunately, their line of work has allowed them to be active in raising awareness and funds for the epilepsy and autism community, specifically through Wasatch Mental Health. Also, Emilie has been instrumental in the formation of Help 4 Children With Epilepsy. She and Branden have lived in Utah County for 20 years and consider it home.

Connor’s seizures have made him unable to transition into deep sleep (REM) without clusters of tonic spasms and drop attacks. A typical night for him means 5-15 episodes of waking and seizing. Sleep has become a daunting enemy, although it’s what his body needs most. Because of his constant state of seizure activity, his developmental delay is severe. He has no words, few fine motor skills, and functions as an 18-month-old. Connor’s last hope is Alepsia.

April Sintz
April and her husband, Kyle, live in South Jordan and have four children. Isaac (7) is their second and was born with Dravet Syndrome, a catastrophic form of epilepsy. Demi (13), Miabella (4), and Jakob (1) are Isaac’s siblings. Kyle is a financial consultant in Portfolio Advisory Services at Fidelity Investments.

April spent her young adult years employed in the emergency department at Alta View Hospital. When their first child was born, she transferred to Admitting before moving on to work as a medical transcriptionist for a dermatologist’s office. Seven years later, after giving birth to Isaac, April created a sub-contracting company, Sintz, Co., where she worked as a financial field consultant for various lending and banking institutions.

When Isaac’s seizures grew to dozens each day, April stopped working to be a full-time caregiver for her, then three, children. She was committed to helping Isaac and, with an infant in tow, spent her days at appointments and therapies. After receiving Isaac’s diagnosis of Dravet syndrome, April scoured the web looking for information and support. She found the IDEA league (International Dravet Syndrome Epilepsy Action League) and reached out to them. They sent Jennifer May to comfort and offer support.

April has become a passionate advocate for Isaac and others with epilepsy. She has been serving on the board of directors for the Epilepsy Association of Utah, working as Director of Support Groups and Purple Day Ambassador. Now, because Alepsia holds new hope for Isaac and other children like him, April is playing an active role in furthering the efforts of Hope 4 Children With Epilepsy.