



For Immediate Release

**Epilepsy Association of Utah & Hope 4 Children With Epilepsy
Announce Opening of Utah's Hemp Extract Registration Program &
Approval of University of Utah's Epidiolex IND Study**

SALT LAKE CITY – *Tuesday, July 1, 2014*

The Epilepsy Association of Utah (EAU) and Hope 4 Children With Epilepsy (H4CE) are pleased to announce that, effective July 1, 2014, Utahns suffering with intractable epilepsy have been granted legal access to high-CBD/low-THC cannabis oil through two new programs: the Hemp Extract Registration Program and an FDA-approved Investigational New Drug (IND) study. The registration program becomes effective July 8th, and the IND study selection process will begin within the next two weeks.

The passage of HB105 Plant Extract Amendments ("Charlee's Law"), allows patients with intractable epilepsy to possess and utilize high-CBD/low-THC (non-psychotropic) cannabis extract as a form of treatment. These patients are required to obtain a "written certification" and "evaluation record" from their neurologist and to file an application, along with a \$400 fee payment, with the Utah Department of Health. Patients and caregivers will be issued a registration card providing a targeted exemption from the state's Controlled Substance Act. Legal extracts must contain no more than .3% THC and no less than 15% CBD. The oil must have a "certificate of analysis" provided by an independent lab and must be properly labeled.

The cost of the Hemp Extract Registration Program is paid by the \$400 fee; there is no cost to the state of Utah. The Epilepsy Association of Utah and Hope 4 Children With Epilepsy are raising money for their Medical Assistance Program with a fund dedicated to offset the cost of the card and/or extract for families who qualify financially.

HB105 allows for the cultivation of hemp for research purposes under the Utah Department of Agriculture, but general cultivation, extraction, testing and sale of cannabis-based products remains illegal within the state. Transportation across state lines, as well as possession within any state, continue to be illegal under federal law. HB105 only protects patients with intractable epilepsy from Utah state prosecution for possession.

Through a separate and different program, the University of Utah's Department of Pediatric Neurology has been granted an IND study of GW Pharmaceutical's new cannabis-based CBD extract called Epidiolex. In contrast to the oil available under the Hemp Extract Registration Program, Epidiolex is nearly pure CBD. The study will allow for 25 of the most severe cases of pediatric epilepsy in patients between the ages of 2 and 17 years old. Medication will be provided at no charge to the enrolled patients.

Jennifer May with Hope 4 Children With Epilepsy had this to say about the new options for Utah's epilepsy sufferers, "This is something new and different, so we're excited to give it a shot. It's not going to be a miracle for everyone, but it's going to be for some."

The following resources are available for patients and caregivers who are interested in pursuing high-CBD/low-THC cannabis extract as a treatment for intractable epilepsy:

- For general information and FAQ, visit www.hope4childrenwiththeepilepsy.com
- For information about applying for a Hemp Extract Registration Card, visit www.health.utah.gov
- To place a patient name on a waiting list for high-CBD cannabis extract, visit www.theroc.us

- To receive information about the Epidiolex IND study, call the University of Utah Primary Children's Hospital CBD hotline at 1-801-662-5939.

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ABOUT THE EPILEPSY ASSOCIATION OF UTAH

Founded in 1973, the Epilepsy Association of Utah is a 501(c)(3) charity dedicated to enhancing the quality of life for all individuals living with epilepsy and seizure disorders. One in 26 people will develop epilepsy at some time in their lives, totaling over 100,000 people in Utah alone. Epilepsy is the fourth most common neurological disorder in the US, after migraine, stroke and Alzheimer's. The Epilepsy Association of Utah offers a public education program, statewide support groups, personal and professional advocacy, college scholarships, art exhibits, educational conferences, summer camp and more. Visit <http://epilepsyut.org> for additional information.

ABOUT HOPE 4 CHILDREN WITH EPILEPSY

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 overall health, ability to function, and quality of life. These children also have 10-times increased risk for sudden death. We *desperately* need new treatment options that hold hope for controlling the seizures, stopping the deterioration, and improving quality of life for our kids. We have been lobbying to make high-CBD/low-THC cannabis extract available in Utah to those who suffer with intractable epilepsy. The extract is NOT smoked and it CANNOT get anyone 'high', but it CAN save the lives of our children. Visit www.hope4childrenwithepilepsy.com for additional information.

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