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## GENERAL SESSION

March 12, 2014

### ***Program Topic: What You Need to Know about Legislation (HB105), Marijuana, and Medicine***

**Presented by: WSLC Pres. Kari Malkovich**

#### **Speakers:**

**Annette Maughan** – Board of Directors, Epilepsy Assoc. of Utah

**Jennifer May** – Citizen/Parent Advocate for Medical Alesia

**JoAnn Petrie** – BYU Psychology Dept; Substance Use Disorder Counselor

**Brad Daw** – Chair, Policy Task Force, SMART Utah County Coalition

**Julianna Ogden** – Public Health Professional; Nationally Certified Health Specialist (CHES)

**Laura Warburton** – Independent Volunteer Lobbyist

**Annette Maughan**, spoke in favor of **HB105 Plant Extract Amendments**. The bill recently passed the house, and a heavily amended substitute has just unanimously passed the senate. Ms. Maughan introduced *Hope4Children* as a political arm of the Epilepsy Association of Utah.

*Hope4Children* originated from a discussion between Karen Glenn and Jennifer May in 2012 about the use of cannabis as a treatment for epileptic seizures. They expressed frustration with the available treatment drugs and the serious side effects produced. They brought the discussion to Ms. Maughan. She began to seriously investigate the cannabis option.

After gathering information, including potential risks and benefits, she presented the information to the Epilepsy Association of Utah board. The board supports this research and issued a statement to that effect on August 26, 2013: "*The Epilepsy Association of Utah (EAU) recognizes the potent nature and reputation cannabis has gained in recent news. While the EAU does not condone the abuse of marijuana or recreational*

*use of marijuana, we note the medical value and potential the extraction of Cannabidiol (CBD) from the plant has for the epilepsy community.*" Ms. Maughan finds it noteworthy that the Epilepsy Association of Utah is thus far the only one in the country to release such a supportive statement.

Rep. Froerer's bill, **HB105**, also acknowledges the promising research by facilitating a Utah-based program through which children suffering from epileptic disorders in our state may obtain access to cannabidoid oil, a.k.a. Alesia or "Charlotte's Web" (named after Charlotte Figi, a child who experienced a remarkable reduction in seizures while using it).

**HB105** has been substituted nine times, which indicates considerable scrutiny. Ms. Maughan emphasized, "There is no slippery slope here, because the pilot program focuses only on research. The research studies will soon reveal desired results or they will not." Language in the bill has been honed to keep the research narrowly focused on just this formula and only on epilepsy treatment, although some cancer

patients are anxious for their own forthcoming study.

Responding to questions, Ms. Maughan again affirmed the cannabis oil is very high in CBD (28% optimal) and very low in THC (less than .3%.) Again, THC is the harmful, psychoactive opioid component. CBD is the desired component that may effectively suppress seizures. The oil is extracted from hybrid cannabis plants developed to yield the desired amounts of each component (High CBD/Low THC). It can be mixed into soft foods and eaten. It is not smoked and cannot produce a “high.”

### **Reported by Stuart Gygi**

**Jennifer May**, also speaking in favor of **HB105**, showed a video clip of her son in the throes of one of the epileptic seizures he suffers up to 40 times each day. His illness, Dravet syndrome, is a rare form of epilepsy that began in infancy. He is currently on three Federal Drug Administration (FDA) approved drugs. They are all dangerous drugs that inflict long-lasting side effects, including organ failure, blindness, broken bones and cardiac arrest.

FDA approval for such drugs can take many years. Ms. May said she has also tried a wide range of alternative remedies promising relief to her son, but to no avail. The cost of her son’s medication averages \$6,500 monthly.

A relatively new treatment offers hope. It is a derivative of the cannabis plant, called Alepsia. Mr. May emphasized the fact that although the cannabis plant is used to produce marijuana, it also produces hemp. Hemp products include industrial fiber fabrics, as well as organic oils, seeds, and flour sold over the counter in health food stores. The Alepsia oil is also a hemp product. It is not marijuana.

The two main components of the cannabis plant are Cannabidiol (CBD) and Tetrahydrocannabinol (THC). Alepsia oil is very *high* in CBD. Emerging research indicates CBD can provide a medical benefit for seizures. Alepsia oil, like hemp, is also extremely *low* in THC, the opioid that produces the euphoria for marijuana users.

Responding to questions Ms. May said the Alepsia, or “Charlotte’s Web” oil treatment for epilepsy has shown promising results in a Colorado study tracking 180 children for the past two years. Approximately 80% of the children treated have shown marked improvement, with an average 50% reduction in weekly seizures.

Currently, there is no Utah experimental study available. **HB105** is necessary to bring Alepsia into the state and begin a study involving Utah children. The Utah Health Department will establish the program and track results. The University of Utah has applied to be involved with trials of Alepsia and Charlotte’s Web. Other cannabinoid research also indicates possible advantages for cancer treatment.

### **Reported by Pam Grange**

**JoAnn Petrie**, offering reservations about **HB105**, said her perspective as a brain researcher and the mother of a son who suffered brain damage from heroin use, impels her to add a cautionary voice to the discussion surrounding any type of cannabis use for young children. Her son died of a heroin overdose after first developing a dependence on prescription drugs following a sports injury.

One of her concerns is the fact that the human brain becomes susceptible to various chemical disorders over the course of its development from infancy to adulthood. She believes cannabis oil studies are not nearly extensive enough yet to determine its safety for long-term use in the developing brain neurotransmission processes that manifest themselves in infants, re-adjusts in young children, and continue to change as adolescents mature to adulthood

Neurotransmitters in the human brain respond to cannabinoids in varying ways as the brain develops. There is not enough solid research to indicate how even low THC-level cannabis will effect brain development and the laying down of long-term memory. Cognition may also be downgraded. A woman’s brain chemistry, Ms. Petrie said, is particularly susceptible to the introduction of THC in the early stages of brain development.

Responding to questions, Ms. Petrie said she had serious reservations about **HB105** in its original form and was opposed to it. A number of the bill's problems were resolved as it moved through the legislature and underwent modifications. She still confesses to mixed feelings upon its passage, but is hopeful now that it may result in a safer, more scrupulous Utah trial study.

One of Ms. Petrie's lingering concerns is that general practitioner doctors already incorrectly prescribe or over-prescribe anti-depressants, particularly to women. Epilepsy falls along the same spectrum of brain disorders as does depression and bi-polar disease. LSD was originally developed in a lab as a remedy for heroin addiction. The public tends to seize upon modern remedies like Alepsia as "wonder drugs." Pharmacists, she contended, are already lining up to carry it. She feels it best to proceed with cautious optimism.

#### **Reported by Stuart Gygi**

**Brad Daw** began his remarks by affirming **HB105** to be "one of those bills that can have a huge impact for good." He, like Ms. Petrie, was opposed to the bill in its original form. A former legislator himself, he lobbied for the wording to be tightened and some loopholes closed. He believes the bill was flawed in its original state and was very likely to produce serious unintended consequences. He also stressed that he is not an "across-the-board adversary" of cannabinoid oil use.

Mr. Daw said he and other opponents of the original bill asked for, and got, some important changes to it. The overall scope of the bill was narrowed. Needed requirements were inserted regarding the growth and sale of the cannabis plant, as well as stricter oversight of the production, labeling, and distribution process for the Alepsia product itself.

Responding to questions, Mr. Daw said a reliable database for tracking case studies and a "Sunset Clause" (stipulating the bill will cease to have effect after a certain date unless action is taken to extend it) will further strengthen the ninth substitution of **HB105**. The legislature will revisit the bill again in 2016.

The issue of limited cannabinoid use can now safely move forward, Mr. Daw said. "The legislative 'sausage making' process is an exciting one," he continued. "It looks good enough to fry up and eat now."

#### **Reported by Pam Grange**

**Julianna Ogden** voiced her concern over the eventual loosening of laws surrounding marijuana. Calling them "careless allowances by society," she said they may well lead to a growing number of her generation (young single adults) eventually being devastated by drug use. Her concern arises from having seen so many of her friends systematically fall prey to drug addiction. Without exception, she said, marijuana was their gateway drug of choice.

Speaking of the three types of people who have a vested interest in the consequences of **HB105**, she said, "I ask that the reckless are quieted, the concerned with good intentions are heard, and those inherently lawful (people) are protected." Expressing empathy for the afflicted children who may benefit from cannabis oil treatment, she still urged caution with legislation that may embolden a reckless few outside the medical system to take advantage. "We need to keep in mind," she said, "that one person's relief shouldn't lead to another's demise."

Ms. Ogden believes allowing cannabis to be grown and harvested in our own state (as may eventually happen at the University of Utah) has the potential to "open the flood gates to great danger physically, emotionally and mentally to masses of people." She believes the growth, cultivation, and harvesting of cannabis plants should, at the very least, always remain outside the state.

The particular constraints Ms. Ogden would favor are these: First, the product should be brought into the state by prescription only. Second, it should go directly to neurological specialists. Each specialist should then either administer it to the patient or dispense it to the legal caregiver. Third, the caregiver must be registered with the Department of Health.

Ideally, caregiver registration should meet the following requirements: (1) Extensive relevant

testing (2) Documentation from multiple medically qualified physicians and (3) The imposition of large annual fee to attain a waiver specific to this product only. Finally, she said, it would be in the state's best interest that the prescribing neurological specialists be required to take a course specific to the cannabis extract and its distribution.

**Reported by Pam Grange**

**Laura Warburton** is an independent, volunteer lobbyist who first took this issue to Rep. Froerer, the chief sponsor of **HB105** in the House of Representatives. The bill passed the house with 62 votes. It passed unanimously in the senate. She is proud of the way the bill was lobbied by the families of epileptic children. "They brought a handshake to the discussion," she said, "not a hammer."

Ms. Warburton said the bill in its final form (**HB105S09**) is a bill that will serve Utah's epileptic children and their families very well until 2016. Then it will be re-evaluated in light of the tracking and study results. She is also interested to see how the legislation can be strengthened even more, going forward.

Responding to questions, Ms. Warburton said she is a former addict herself who has seen, firsthand, the devastation of illicit drug abuse.

She appreciates the public resistance to Utah becoming a "medical marijuana" state. For this reason it is in the public interest to increase our understanding of the important differences between cannabis oil and marijuana.

The federal government's Agricultural Act of 2014 (a.k.a. The Farm Bill) redefined hemp. Tucked into the \$1T bill is an amendment that relaxes a 75-year old restriction on growing industrial hemp. This applies to the seeds, stalks, and flowers of cannabis plants that contain .3% or less of the opioid THC. The Act also allows for a facility such as the University of Utah to grow, cultivate, and harvest cannabis plants.

Mr. Warburton said the birth and passage of **HB105** represents the best in our form of government. Any citizen may approach a legislator with an issue of concern. She urged all to get to know who their legislators are. We should not hesitate to give them input on the issues that are important to us. **HB105**, she said, is proof that we can surmount differences, hear each other, and work together to bring about good legislation. There is no fiscal note attached to the bill, since caregivers will assume individual payment for the required registration cards

**Reported by Pam Grange**

**NOTE:** A Resolution on the governor's Health Utah Medicaid Expansion Plan was put forward by the *Health & Human Services Committee*. **The Resolution was amended and passed.**

**THIS BULLETIN IS A PUBLICATION OF  
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