

Epilepsy Foundation: CBD for Epilepsy

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About the Epilepsy Foundation

- The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the approximately 3.4 million Americans with epilepsy and seizures
 - We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services
- There is no “one size fits all” treatment option for epilepsy, and about a third of people living with epilepsy – approximately 1 million – suffer from uncontrolled or intractable seizures, with many more living with significant side-effects despite available treatments
 - Individuals with uncontrolled seizures live with the continual risk of serious injuries and loss of life
- For these reasons, the epilepsy community is in a unique position – we know CBD can help control, and sometimes completely control, seizures in individuals who have often tried and failed on all other options

Lainie's Story

Lainie was diagnosed with Juvenile Myoclonic Epilepsy as an adolescent in 2015

- She had already failed 8 other seizure medications, and had been told there was a 1% chance of ever getting seizure control
- She started CBD in Sept 2017 for generalized convulsive seizures
- She has not had a convulsion since 4 days after starting CBD
- Lainie is not alone – she uses a currently unregulated product and has found success
- It is vital that individuals not lose access to CBD because we know it works for them
- Epidiolex cost per year: \$32,500 (\$2,708/month)
- Haleighs Hope cost per year: \$4,800 (\$400/month)

Considerations

- CBD has now been proven to be an effective treatment for the most severe forms of pediatric epilepsy, in some cases eliminating seizures entirely
- There are few (if any) other drugs that are FDA approved as life-saving medications while remaining on the market as a dietary supplement
- In the best case scenario, all people with epilepsy who have appropriate need for this medication would receive it as “pharmaceutical grade”
- This is not feasible for everyone-Many people with epilepsy (including children) are currently being medicated with CBD oil from various sources (including state licensed distributors)

- Abrupt removal of CBD from these individuals (as for many anti-seizure medications) could lead to seizure worsening, injury, or even death
- Unfortunately many people are taking CBD but are unaware of:
 - The variability of drug consistency
 - The side effects, including risk of liver injury
 - The potential for serious drug interactions

Our Recommendation

- Preserve access to CBD for those who need it as a live-saving medication
- Ensure that there is consistency in available product
- Create some manufacturing standards
- Increase availability of important information such as potential side effects and drug interactions