

# 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