

EDEN'S HEALING GARDEN MINISTRIES

The Deep Story Behind Charlotte's Web

A Little Girl, a Colorado Plant,
and a Movement Larger Than Either

Charlotte Figi's life, Dravet syndrome, CBD-rich cannabis, scientific proof,
legal change, and the difference between living better and living longer.

PUBLICATION 005

AUGUST 2026

CHILD • FAMILY • PLANT • SCIENCE

This publication honors Charlotte without claiming that cannabis cured Dravet syndrome or was proven to extend her life. Educational only; not medical advice.

PUBLISHER'S ANSWER

What Charlotte's Web Was Made to Do

The goal was seizure control and a better life - not a scientifically proven extension of life.

Charlotte Figi was a Colorado child with Dravet syndrome, a rare, severe, treatment-resistant epilepsy that begins in infancy. Her family reported that a high-cannabidiol, low-THC cannabis extract dramatically reduced her convulsive seizures after many standard treatments had failed. A CBD-rich cannabis variety supplied by the Stanley brothers was renamed Charlotte's Web in her honor.

Her story is often retold as "marijuana made for her to live longer." That captures a family's hope but overstates what evidence can establish. Fewer seizures can reasonably improve safety, participation, sleep, and family life. Better seizure control may reduce certain risks in epilepsy. But Charlotte's case did not prove that the extract extended her lifespan, and the product was not a cure for the genetic condition.

The accurate heart of the story

- A child was suffering from relentless seizures.
- Her parents searched beyond exhausted options.
- A CBD-rich preparation was associated with a remarkable improvement reported by her family.
- Her public story moved families, physicians, researchers, lawmakers, and regulators.
- Later randomized trials proved that a standardized purified CBD drug could reduce convulsive seizures in Dravet syndrome.

Charlotte was not merely the name of a product. She was a child whose suffering forced the country to look again.

The Illness Behind the Name

Dravet syndrome is more than seizures. It is a lifelong developmental and epileptic encephalopathy with serious medical risk.

Dravet syndrome typically begins in the first year of life with prolonged seizures, often triggered by fever or temperature change. Many cases are associated with a disease-causing variant in SCN1A, a gene important to sodium channels and brain signaling. Seizures can remain difficult to control and may include convulsive, absence, myoclonic, and other types.

Children may also experience developmental slowing, language impairment, motor and gait difficulties, sleep problems, behavior challenges, feeding issues, autonomic disturbances, and dependence on lifelong caregiving. Some antiseizure medicines can worsen certain seizure types, making specialist diagnosis important.

Why families fear for life

Dravet syndrome carries elevated premature mortality risk from sudden unexpected death in epilepsy (SUDEP), prolonged seizures or status epilepticus, accidents such as drowning, and infections. The Dravet Syndrome Foundation summarizes estimates of premature mortality around 15-20%, while also noting that most affected individuals reach adulthood.

Treatment goals

- Reduce convulsive and prolonged seizures.
- Prevent status epilepticus and injury.
- Use rescue plans promptly and safely.
- Protect development, sleep, nutrition, mobility, and family quality of life.
- Discuss SUDEP honestly while supporting practical risk reduction.

For a family living seizure to seizure, one quiet week can feel like time returned from the edge.

A Childhood Interrupted by Seizures

Charlotte's first seizure came in infancy. By early childhood, her family described a life dominated by medical emergencies.

WHEN	WHAT PUBLIC ACCOUNTS SUPPORT
2006	Charlotte Figi was born in Colorado. She experienced her first seizure at about three months of age.
Early childhood	She was diagnosed with Dravet syndrome. Her family described prolonged convulsive seizures, repeated hospital care, developmental loss, and numerous medication and diet trials.
Around age five	Public accounts reported as many as 300 grand mal or convulsive seizures a week. She used a wheelchair and required extensive care.
2012	After researching CBD and obtaining medical authorization in Colorado, her family tried high-CBD, low-THC cannabis preparations. The first product was not yet Charlotte's Web.
Later in 2012	Seeking a dependable supply, the family connected with the Stanley brothers and used an extract from their CBD-rich plant. Her parents reported seizures falling to only a few per month.
2013	CNN's documentary Weed, hosted by Dr. Sanjay Gupta, introduced Charlotte's story to a vast audience.
2020	Charlotte died on April 7 at age 13 following a serious respiratory illness and seizure-related medical crisis. The precise role of suspected COVID-19 was uncertain; she had tested negative.

A timeline can record events. It cannot measure the courage required to live inside them.

From “Hippie’s Disappointment” to Charlotte’s Web

The plant was unusual because it was rich in CBD and low in THC - not because it was designed to produce intoxication.

The Stanley brothers in Colorado had cultivated a cannabis variety containing high cannabidiol and comparatively little tetrahydrocannabinol. Because it did not produce the “high” sought in the recreational market, it was reportedly nicknamed Hippie’s Disappointment. For a family seeking seizure control without substantial intoxication, that same characteristic made the plant valuable.

Charlotte’s family first tried another CBD-rich source, often identified in accounts as R4. When supply became a problem, they approached the Stanleys. An oil extract from the brothers’ CBD-rich plant was given in measured amounts under the tongue or with food. The plant was renamed Charlotte’s Web after the dramatic improvement her family reported.

CBD and THC are not interchangeable

COMPOUND	KEY DISTINCTION
CBD	Cannabidiol is not intoxicating in the same way as THC. It has antiseizure effects demonstrated for specific prescription use, but can cause adverse effects and drug interactions.
THC	Delta-9-THC is intoxicating and can affect memory, coordination, mood, perception, and heart rate. It is not the compound that made Charlotte’s story medically distinctive.
Plant extract	Contains multiple compounds and can vary by harvest, processing, storage, and testing. A named extract is not automatically equivalent to purified prescription CBD.

The plant’s low intoxicating value became the reason it could carry a different kind of value.

A Report That Changed the Question

Charlotte's improvement began as a family observation, not a randomized clinical trial. That did not make it meaningless; it made it a signal demanding study.

Public reports described Charlotte's convulsive seizures dropping from hundreds per week to only a few per month after beginning the CBD-rich extract. Her family also described renewed alertness, speech, play, eating, and participation. Images of a child returning to her family were more powerful than any policy memo.

Why one case cannot prove everything

- Seizure frequency can fluctuate naturally.
- Families and clinicians know what treatment is being given, which can influence reporting.
- Other medicines, diets, illness, sleep, and development may change at the same time.
- The product may vary chemically between batches.
- A dramatic responder may not represent the average patient.
- One case cannot establish long-term safety, optimal dose, or survival benefit.

Why one case can still matter

A credible, dramatic observation can expose a neglected possibility. It can motivate case series, laboratory work, controlled trials, product standardization, and legal reform. Charlotte's story did exactly that. The ethical response was neither blind belief nor dismissal; it was urgent research.

Anecdote is not the end of evidence. Sometimes it is the knock at the laboratory door.

Why Place and Law Mattered

Colorado did not create CBD, but its medical-cannabis framework created a place where a family could legally try what many states prohibited.

At the time Charlotte's family pursued CBD-rich cannabis, federal law and most state laws made access, transport, research, and medical discussion extraordinarily difficult. Colorado's laws allowed medical cannabis within the state, enabling growers and families to work in a legal space unavailable elsewhere.

After the 2013 documentary, families with children suffering uncontrolled seizures moved to Colorado. They were sometimes called "medical refugees" because crossing a state line could transform a parent from caregiver to potential lawbreaker. Waiting lists grew, and Charlotte's face became inseparable from the debate over access.

The policy effect

- States enacted limited low-THC/high-CBD laws, some bearing Charlotte's Web language.
- Lawmakers heard from families who had exhausted conventional options.
- Researchers and epilepsy specialists faced greater pressure to investigate cannabidiol.
- Public discussion began separating non-intoxicating CBD from high-THC cannabis.
- Commercial markets expanded, creating new access but also new quality and marketing problems.

Colorado was the greenhouse. Charlotte's story was the seed carried across state lines by families, television, and grief.

From a Child's Story to a Randomized Trial

The later evidence did not prove every Charlotte's Web product. It proved that standardized cannabidiol could reduce seizures in Dravet syndrome.

In 2017, a randomized, double-blind, placebo-controlled trial studied pharmaceutical-grade cannabidiol added to existing therapy in children and young adults with Dravet syndrome. The median monthly frequency of convulsive seizures fell from 12.4 to 5.9 in the cannabidiol group, compared with 14.9 to 14.1 in the placebo group. More patients receiving cannabidiol achieved substantial seizure reduction, though adverse effects were also more common.

In 2018, the FDA approved Epidiolex, a purified cannabidiol oral solution, for seizures associated with Dravet syndrome and Lennox-Gastaut syndrome. The indication later expanded to tuberous sclerosis complex and patients age one year and older.

What this did - and did not - establish

ESTABLISHED	NOT ESTABLISHED
A standardized purified CBD drug can reduce seizure frequency in some patients with Dravet syndrome.	That every retail CBD oil or Charlotte's Web product has the same dose, purity, effectiveness, or approval.
Benefits can be measured in controlled trials.	That CBD cures the SCN1A-related disorder or eliminates all seizures.
CBD has clinically important pharmacology.	That natural origin makes it free of adverse effects or interactions.

Charlotte's experience raised the question. Controlled trials gave part of the answer.

Did Charlotte's Web Extend Her Life?

We cannot honestly say that it did. We can say that her family reported fewer seizures and a fuller life for important years.

Dravet syndrome carries life-threatening risks. Reducing convulsive and prolonged seizures is a central treatment goal and may reasonably reduce exposure to injury, status epilepticus, and some seizure-related danger. But proving a survival benefit requires long-term comparative evidence designed to measure mortality. Charlotte's individual history cannot establish what would have happened without the extract.

Her life also reminds us that seizure improvement is not cure. Dravet syndrome affects development, movement, sleep, behavior, autonomic function, and overall medical vulnerability. Charlotte died at age 13 in 2020 after a serious respiratory illness and a seizure-related crisis. Her family suspected COVID-19 during the early pandemic, although she reportedly tested negative, leaving uncertainty around that component.

A better sentence

Instead of "the marijuana was made for her to live longer," say: "A CBD-rich cannabis extract was provided to help control Charlotte Figi's catastrophic seizures. Her family reported a dramatic reduction in seizures and a better quality of life. Her case did not prove longer survival, but it helped lead to research and an FDA-approved CBD medicine for Dravet syndrome."

Length of life is one measure. Life returned to a child - play, voice, presence, fewer emergencies - is another. We can honor the second without falsely claiming the first.

CBD Is Medicine, Not Magic Water

The molecule that helped change epilepsy treatment also requires dosing, monitoring, and clinical judgment.

Prescription cannabidiol can cause sleepiness, decreased appetite, diarrhea, fatigue, vomiting, infections, and elevated liver enzymes. Risk of liver injury is higher with certain medicines, especially valproate, and sedation can increase with clobazam or other central nervous system depressants. Clinicians monitor liver tests and adjust interacting medicines.

For children with epilepsy

- Do not start retail CBD or cannabis without the child's neurologist and care team.
- Do not stop antiseizure medication suddenly; withdrawal can increase seizures and status epilepticus.
- Use a written seizure action plan and prescribed rescue medicine.
- Verify product identity, concentration, dosing units, testing, and legal status.
- Report sleepiness, appetite change, diarrhea, vomiting, jaundice, unusual fatigue, or increased seizures.
- Discuss SUDEP, nighttime monitoring, water safety, fever plans, and emergency thresholds with specialists.

Commercial CBD is not automatically equivalent to Epidiolex

FDA approval applies to a specific purified prescription product with controlled manufacturing, labeling, dosing, trials, and safety monitoring. A similar ingredient name does not make products interchangeable.

Compassion opened the door. Clinical discipline keeps children safe after they walk through it.

What Charlotte Changed

Charlotte's legacy is not simply a product brand or a policy slogan. Her story changed which questions society considered respectable. Families who had been dismissed became witnesses. Researchers gained urgency. Lawmakers confronted the human cost of prohibition. The public learned that cannabis chemistry was more complex than intoxication.

Her legacy includes

- A human face for rare epilepsy: Dravet syndrome entered public awareness.
- A distinction between CBD and THC: the country learned that one cannabis compound could be non-intoxicating yet medically active.
- Family-led research pressure: parents helped move an observation toward trials.
- Legal reform: states reconsidered restrictions on low-THC, CBD-rich products.
- Scientific validation: controlled trials and FDA approval established a defined role for purified CBD.
- A warning about commercialization: a child's story can inspire access while also being used to sell products beyond the evidence.

For Eden's Healing Garden Ministries

Tell Charlotte's story with tenderness and precision. Do not turn her into proof that cannabis cures epilepsy or extends life. Let her story illustrate something more durable: when suffering is heard, compassion can challenge law, observation can become research, and research can become medicine.

"Her name became a web connecting one family's desperate hope to a nation's unfinished science."

CONCLUSION

A Story of Life Returned, Not a Promise of Immortality

Charlotte Figi's family did not seek a symbol. They sought relief for their daughter. A CBD-rich Colorado cannabis extract was associated with a dramatic seizure reduction in their account, and the plant was named Charlotte's Web. Her televised story moved families across the country and helped change law and medical research.

Years later, randomized trials showed that purified CBD could reduce convulsive seizures in Dravet syndrome, and the FDA approved a prescription product. That scientific arc is extraordinary: testimony did not replace evidence; testimony made the absence of evidence impossible to ignore.

Charlotte's Web was not proven to make Charlotte live longer. It was used in hope of controlling seizures and giving her more life inside the days she had. That truth is powerful enough.

"We honor Charlotte best when we remember the child before the product, the evidence after the testimony, and the life inside every number."

Publication: No. 005, August 2026

Publisher: Eden's Healing Garden Ministries

Website: edenshealinggarden.org

SOURCES

Selected References and Further Reading

1. Maa E, Figi P. (2014). "The case for medical marijuana in epilepsy." *Epilepsia* 55(6):783-786.
<https://pubmed.ncbi.nlm.nih.gov/24854149/>
2. Devinsky O, et al. (2017). "Trial of Cannabidiol for Drug-Resistant Seizures in the Dravet Syndrome." *New England Journal of Medicine* 376:2011-2020.
<https://www.nejm.org/doi/full/10.1056/NEJMoa1611618>
3. U.S. Food and Drug Administration. Epidiolex orphan-drug designation and approved indications. Accessed August 2026.
<https://www.accessdata.fda.gov/scripts/opdlisting/ood/detailedIndex.cfm?cfgridkey=421213>
4. U.S. Food and Drug Administration. "FDA Regulation of Cannabis and Cannabis-Derived Products, Including Cannabidiol."
<https://www.fda.gov/news-events/public-health-focus/fda-regulation-cannabis-and-cannabis-derived-products-including-cannabidiol-cbd>
5. U.S. Food and Drug Administration (2018). Original Epidiolex prescribing information and safety monitoring.
https://www.accessdata.fda.gov/drugsatfda_docs/nda/2018/210365Orig1s000lbl.pdf
6. Dravet Syndrome Foundation. "What Is Dravet Syndrome?" Accessed August 2026.
<https://dravetfoundation.org/what-is-dravet-syndrome/>
7. Cooper MS, et al. (2016). "Mortality in Dravet syndrome." *Epilepsy Research* 128:43-47.
<https://pubmed.ncbi.nlm.nih.gov/27810515/>
8. American Botanical Council (2020). "Charlotte Figi 2006-2020."
<https://www.herbalgram.org/resources/herbalgram/issues/127/table-of-contents/hg127-obit-figi/>
9. National Academies of Sciences, Engineering, and Medicine (2017). *The Health Effects of Cannabis and Cannabinoids*.
<https://doi.org/10.17226/24625>

Historical note. Details of Charlotte's treatment and seizure counts originated in family and media reports and were later discussed in medical literature. They should be described as reported outcomes, not as results of a controlled trial of the Charlotte's Web product.

Disclaimer. Educational and religious commentary only. Not medical advice. Dravet syndrome requires specialist care. Do not start CBD, change doses, or stop antiseizure medication without the prescribing clinician. Call emergency services for prolonged seizures, breathing difficulty, serious injury, or other emergencies.