

Memphis, Tennessee

Brain Waves

Neuroscience Institute

Summer 2019

'The Miracle Drug'

FDA approves pharmaceutical grade cannabidiol oil for epilepsy treatment

fter trying four different epilepsy medications to eradicate their son's seizures without success,

the Eagle family of Stuttgart, Ark., was given two options: undergo surgery for a vagus nerve stimulation (VNS) implant or take part in a trial for a new drug – cannabidiol (CBD) oil.

"Our choice was clear," said Jackson's mom, Ashley. "We could either do surgery or do the trial, and it seemed that the better option was to attempt the trial first."

Jackson is one of many children with epilepsy who are benefiting from the newly Food and Drug Administration (FDA) approved Epidiolex, a drug derived from the CBD compound in the Cannabis plant.

To date, 60 to 65 percent of patients using CBD oil at Le Bonheur Children's have seen a reduction in their seizures.

Le Bonheur began its study of CBD oil for epilepsy

treatment in 2015 with a clinical trial and immediately began to see a reduction in quantity and duration

of seizures in many cases.
Although derived from the
Cannabis plant, CBD oil is not
psychoactive as it does not
contain any tetrahydrocannabinol (THC) – the chemical
responsible for most of
marijuana's psychological
effects

While CBD oil is commonly found at third-party dispensaries, Le Bonheur Chief Neurologist James Wheless, MD, co-director of the Neuroscience Institute, makes clear the differences between this and prescribed Epidiolex. Third-party CBD can vary in quality from month to month,

while Epidiolex has to meet stringent federal standards and is pharmaceutical grade prescribed by a physician like any other medication. Prescription Epidiolex ensures that each dose is consistent and composed of pure CBD oil – no impurities, pesticides or herbicides.

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Le Bonheur was the only Tennessee hospital to participate in a cannabidiol oil trial that brought Epidiolex to market. Now more than 15 Le Bonheur patients benefit from this medication.

Referrals: 866-870-5570 www.lebonheur.org/

neuroscience

A pediatric partner
with The University
of Tennessee Health
Science Center/College
of Medicine and
St. Jude Children's



Jackson Eagle

CBD oil provides relief for 2 year old with TSC

Ashley Eagle of Stuttgart, Ark., thought that her son, Jackson, was just having febrile seizures. But after an unrelated ER visit for salmonella poisoning, doctors noticed that his seizure activity was increasing – and his seizures were not due to a fever.

Multiple tests finally determined that 5-month-old Jackson's seizures were caused by tuberous sclerosis complex (TSC) a diagnosis that the Eagle family had never heard of before.

After a visit to the Le Bonheur TSC clinic, Jackson spent a week in the Epilepsy Monitoring Unit (EMU) and began trying various medications to get on the right path to seizure control.

"He did really well on those medications for a while," said Eagle. "But then he began to have more frequent seizures, and his development was really suffering."

The Eagles returned for another stint in the EMU in



Jackson Eagle, now 3 years old, participated in Le Bonheur's trial for CBD oil and continues to see a remarkable reduction in seizures.

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'The Miracle Drug', continued from page 1

Jackson Eagle, continued from page 1

After five years of trials around the country, the FDA approved the drug for use early 2018. Currently Epidiolex is approved to treat two specific epilepsies – Lennox-Gastaut Syndrome and Dravet Syndrome, both of which are associated with convulsive seizures. However, other epilepsies are now being studied to see if Epidiolex would provide seizure relief, and children with other conditions have already been able to obtain the medication, Wheless said.

Epidiolex has several advantages over other epilepsy medications. Comparatively, the side effects are less severe and easier to tolerate, and patients generally see a drop of seizure frequency and duration within the first few doses. If the patient is going to respond well to CBD oil, it will be clear within a few weeks of beginning the medication, Wheless said

"Discovering the newest therapies and medications is vital to providing the best outcomes possible for children whose ongoing seizures cannot be controlled with medicine, change in diet or surgery," he added. "CBD oil is part of the Neuroscience Institute's commitment to provide patients with the best option for managing seizures – there is no 'one size fits all.""

October 2017 when Le Bonheur Chief Neurologist James Wheless, MD, gave them the options for 2-year-old Jackson – surgery for vagus nerve stimulation (VNS) implant or the cannabidiol (CBD) oil trial. Eagle asked Wheless, "If this was your kid what would you do?" His answer: the trial.

In the months leading up to the trial, Jackson had seizures every single day. He began CBD oil on Jan. 2, 2018. He had nine seizures that month as he adjusted to the medication and then went 154 days without a seizure – the longest ever in his young life.

"For any parents considering CBD oil for their child's seizures, I would say 'Give it a shot,'" Eagle said. "It's been so amazing for Jackson, we call it the miracle drug. I feel that it could be a useful tool to help other kids as well."

Not only has there been a dramatic drop in seizure frequency, Jackson is growing in his cognition and development by leaps and bounds. Whether it's simple everyday tasks like taking shoes and socks off or enjoying sliding down a slide, he continues to do things that he wasn't able to do just one year ago.

"CBD oil has reduced Jackson's seizures but also given him an opportunity to be as normal a child as possible," said Eagle. "Le Bonheur is fabulous – they don't treat you like you're a patient they treat you like you're one of their family members."



LE BONHEUR LAUNCHES PODCAST

Twice a month Le Bonheur experts offer insight into the world of a top children's hospital, the complex cases that reinforce their purpose and innovations on the health care horizon through the newly launched podcast "Peds Pod." On a recent episode, James Wheless, MD, discussed how CBD oil works and addressed frequently asked questions. To listen to this episode and view the full podcast library, visit www.lebonheur.org/podcast.



Case Study: Deonna Horton **Anaplastic astrocytoma (grade III)**

10-year-old Deonna Horton was an average sixth grader until her seizures began suddenly in June 2018.

"She was outside playing ball with her brother Davion," said Deonna's grandmother, Maxine Banks. "She stepped off the curb to kick the ball, and she fell on the ground and started having a seizure." Her brother carried her into the house where she started acting like herself again. It wasn't until Deonna had another seizure a month later that Maxine knew that something serious was happening.

After a trip to Le Bonheur in an ambulance, she was seen by Kelley Ward, NP, who prescribed medications to control her seizures. Deonna's seizures continued, to the point that after the seizure ended she would be paralyzed on her right side.

An MRI revealed that Deonna had a walnut-sized brain tumor in an area of her brain which generally controls the movement of the right side of the body. Deonna was referred to neurologist Amy McGregor, MD, who performed a presurgical evaluation in the Epilepsy Monitoring Unit including transcranial magnetic stimulation (TMS). Because of the location of the tumor, doctors needed to know more about Deonna's motor function cortex before attempting surgery.

"Specialized preoperative neuroimaging at Le Bonheur was very important in Deonna's surgical management," said Deonna's neurosurgeon, Stephanie Einhaus, MD. "Our goal was to get the entire tumor but not hurt her motor function on the right side of her body. There was no room for error."

Deonna underwent TMS in order to identify her motor control areas, especially the areas in the left hemisphere around the tumor. TMS determined that her right leg function was controlled by areas just along the anterior and posterior margins of the tumor.

On Aug. 24, Deonna underwent a successful surgery to remove the tumor. Surgery was close to some brain areas that had been identified by TMS as important to Deonna's right leg function. Because of this, she did experience "foot drop," or weakness, numbness and difficulty using her right foot and leg that can be experienced temporarily after neurosurgery. After undergoing physical therapy, Deonna now walks with barely any limp.

"We were able to do the operation in the intraoperative MRI suite performing two intraoperative MRIs during the case to check on the completeness of the tumor removal," said Einhaus. "She awoke with a paralyzed right leg immediately after surgery which resolved within two weeks as hoped." After a pathology report, Deonna and her family found out that her tumor was malignant — anaplastic astrocytoma (grade III). She would need to continue treatment at St. Jude Children's Research Hospital. Le Bonheur is home to one of the nation's largest pediatric surgical brain tumor programs in partnership with St. Jude.

Deonna has been seizure free since her surgery in August. She continues to undergo physical therapy with Le Bonheur and is completing a six-week session of chemotherapy and radiation at St. Jude.



Deonna Horton, 10

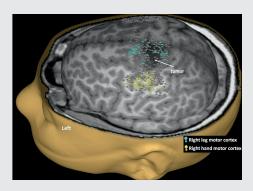
Diagnosis: anaplastic astrocytoma (grade III)

Imaging: TMS

Treatment: surgery, chemotherapy

and radiation

Result: seizure-free since surgery



TMS identified brain areas that control Deonna's right hand and leg function to be close to but not within the tumor. Therefore the tumor was safely removed without affecting leg and hand function. The figure shows the tumor (white arrow). The brain area controlling her right leg (cyan pegs) was found to be in front of the tumor, and the brain area controlling her right hand (yellow pegs) was found to be to the side of the tumor.

13th Annual Pediatric Neurology Symposium

Thank you to everyone who joined us for our 2019 Pediatric Neurology Symposium. We hope you enjoyed your time in Memphis learning about state-of-the-art practices and trends in treating pediatric neurology patients.



Kim Meador, MD, (right) was the recipient of this year's Kayden R. Vinson Distinguished Scholar Award and Lecture. He is clinical director of Stanford Comprehensive Epilepsy Center in Palo Alto, Calif.



Over 100 neurologists and neurology providers from around the country attended this year's symposium.

Le Benheur n's Hospital

Namrata Shah, MD, professor of Pediatrics and Neurology at the University of Tennessee Health Science Center, presents multiple case studies on auto-immune encephalitis in pediatrics.

Save the Date:

14th Annual

Pediatric Neurology Symposium April 17-18, 2020

The Westin Memphis Beale Street, Memphis, Tenn. Registration will be available in early 2020.

IN BRIEF

Michael Wiggins begins as new Le Bonheur president



Michael Wiggins, MB, FACHE

Michael Wiggins, MB,
FACHE, began his tenure as
the new Le Bonheur president
in April. Wiggins comes to
Le Bonheur from Children's
Health in Dallas, Texas, where
he served as senior vice
president of Clinical Operations
and the Northern Market and
administrator of Children's
Medical Center Plano. He
was selected via a national

search process that included candidates from throughout the country. He succeeds Meri Armour, who retired after 12 years at Le Bonheur.



Neuroscience Institute currently recruiting pediatric neurologists

If you are looking for an outstanding opportunity to work in a state-of-the-art pediatric neurology program at a world-class children's hospital, look no further. The University of Tennessee Health Science Center and Le Bonheur are currently recruiting pediatric neurologists. Now is your chance to join one of the top neuroscience teams in the country.

For a complete job description or to apply, please email Dr. James W. Wheless at jwheless@uthsc.edu.





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Le Bonheur

Brain Waves is a quarterly publication of the Neuroscience Institute at Le Bonheur Children's Hospital. The institute is a nationally recognized center for evaluation and treatment of nervous system disorders in children and adolescents, ranging from birth defects and learning and behavioral disorders to brain tumors, epilepsy and traumatic injuries.

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more about our Neuroscience Institute.













First patient undergoes functional scan on new TRIUXTM neo MEG

he Neuroscience Institute has begun using the new TRIUXTM neo MEG to locate seizure foci and functional mapping.

Connor, at right, one of the first patients to undergo this new brain scanning technology, has a history of intractable localization related to epilepsy. With the MEG, neuroscientist Roozbeh Rezaie, PhD, was able to approximate where his seizures originated and map the regions which control sensation and language. Epileptologists used MEG findings in combination with other diagnostic tests to determine the optimal treatment approaches for controlling Connor's seizures.

The new MEG provides several advantages for neurologists and neurosurgeons. In addition to the large number of sensors and advanced aspects that improve accuracy, mitigate operating costs and suppress noise, the TRIUX™ neo MEG can be utilized to scan patients who were previously unable to undergo testing with MEG due to implanted medical devices.

To refer a patient for MEG imaging, contact Teri Willard, 901-287-7130.

