

## New Anti-Seizure Medication for Adolescents

*Le Bonheur Neuroscience Institute publishes first paper studying use of cenobamate in adolescents*

Cenobamate is effective in treating focal seizures in adolescents and is a viable option for those with a history of rash as a reaction to anti-seizure medications, according to an article published by Le Bonheur neuroscientists in *Pediatric Neurology*. This study marks the first published work on the use of cenobamate in the pediatric population. Results showed that more than 50% of patients had at least a 50% seizure reduction following the addition of cenobamate to their treatment plan.

Research was led by Le Bonheur Neuroscience Institute Summer Plus Fellow Taylor Elliott, a student at Rhodes College in Memphis, Tenn. Co-authors were Le Bonheur Medical Editor Andrew J. Gienapp, Le Bonheur Neuroscience Institute Co-Director James W. Wheless, BScPharm, MD, and Le Bonheur Psychiatric Mental Health Nurse Practitioner Tracee Ridley-Pryor, DNP, who also serves as director of Research



Le Bonheur Neuroscience Institute Co-Director James Wheless, BScPharm, MD, was a co-author on a recent study that found cenobamate to be an effective treatment for focal seizures in adolescents. This is the first published work on the use of cenobamate in the pediatric population.

Strategies and Collaboration for Pediatric Neurology at the University of Tennessee Health Science Center.

"In our real world study we were able to build upon prior controlled studies about the efficacy of cenobamate for treating focal seizures," said Wheless. "Our study extends

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## A Clear Path

*Omaha family finds answers, healing for son's rare brain tumor*

Eleven-month-old Callum Kauzlarich of Omaha, Neb., had a bump on his head. His parents, Kyle and Blair, wanted a clear answer. Was this ridge on their son's skull something to be concerned about?

The answer wasn't so black and white.

A CT scan revealed that the ridge on Callum's skull was indeed harmless. But the scan also uncovered something else — Callum had a tumor in the middle of his brain.

"A whirlwind of emotions come over you," said Blair, who works in 3D medical printing. "I see these things all day, but you never think that it's going to be your kid."

Callum had a choroid plexus papilloma in the third ventricle, a rare and benign brain tumor. However, its location caused hydrocephalus leading to elevated pressure in his brain. Because of this, surgery was required. Soon.

This diagnosis threw the Kauzlarich family into a maze of doctors' appointments.



Le Bonheur Chief of Pediatric Neurosurgery Paul Klimo, MD, MPH, holds Callum Kauzlarich at follow-up after a successful brain tumor resection surgery. Klimo was able to remove Callum's tumor in its entirety. Today, Callum's development is growing by leaps and bounds.

They received diverging opinions from three separate consults with seemingly no clear way forward, they said.

"We were interviewing brain surgeons for a very important job, but how do you choose a path forward when you have no knowledge?" asked Blair, in reference to her

search for the best place for Callum's surgery.

"After every one of these appointments we would sit in the car for an hour just trying to digest everything that had been told to us," added Kyle. "We were pretty frustrated because we were hearing different things from different doctors and none of the options felt quite right."

But after Kyle shared his son's diagnosis with his workout group, a new route emerged that put the Kauzlarichs on their journey to Le Bonheur Children's and Paul Klimo, MD, MPH, chief of Pediatric Neurosurgery and Co-director of the Neuroscience Institute at Le Bonheur. One of the members knew another Omaha family whose son was successfully treated through Le Bonheur's joint Pediatric Brain Tumor Program with St. Jude Children's Research Hospital.

The family put the Kauzlarichs in direct contact with Klimo, and within minutes they were texting him Callum's brain imaging.

One look at the scans and Klimo told them: "I know I can do it." Performing almost 200 brain surgeries each year, Klimo was familiar with removing abnormalities in the

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Referrals: 866-870-5570

[www.lebonheur.org/neuroscience](http://www.lebonheur.org/neuroscience)

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with The University  
of Tennessee Health  
Science Center/College  
of Medicine and  
St. Jude Children's  
Research Hospital





use into the adolescent age group showing its effectiveness in the pediatric population for the first time.”

Researchers performed a retrospective chart review of patients 12 years and older in Le Bonheur’s Comprehensive Epilepsy Program currently treated with cenobamate. Forty-five medication-resistant Le Bonheur epilepsy patients, who had tried an average of 12 anti-seizure medications prior to cenobamate, were treated with the medication. Of those patients, 28 also experienced a prior rash with prescribed medications.

Le Bonheur clinicians found that most adolescent patients treated with cenobamate experienced a reduction in seizure activity and were able to wean off at least one other anti-seizure medication with no patients developing a rash as a side effect.

Results showed that 60% of patients responded to cenobamate, obtaining at least a 50% decrease in the number of focal seizures, with 16% becoming seizure free during the study. In addition, before starting cenobamate, patients were taking an average of three anti-seizure medications, but at follow up anti-seizure medication was decreased by at least one medication in 49% of patients. Of the study patients

who previously experienced rashes with prescribed medications, none experienced a rash due to cenobamate, establishing a new treatment option for this subgroup.

“The slightly greater than 50% responder rate is especially impressive in this population, who have had documented failure to a high number of prior anti-seizure medications,” said Wheless. “Many had also undergone prior epilepsy surgery or device therapy as a treatment option. They represent some of our patients with the most difficult to control epilepsy.”

Cenobamate was used alongside other anti-seizure medications, with lacosamide, cannabidiol, clobazam and felbamate being the most common. The most common side effect when adding cenobamate to a patient’s regimen was somnolence, which could be minimized by decreasing the cenobamate dose. None of the patients discontinued cenobamate because of adverse events.

“This promising finding supports the need for extrapolation studies for children and adolescents,” said Wheless. “Further studies of cenobamate in pediatric population are needed to determine if this is a viable treatment option for younger populations.”

*“The slightly greater than 50% responder rate is especially impressive in this population, who have had documented failure to a high number of prior anti-seizure medications.”*  
*James Wheless, BScPharm, MD*

same anatomic space as Callum’s tumor. “Dr. Klimo offered a different approach, yet again, but he sounded very confident in what he was saying and very matter of fact,” said Kyle. “He told us, ‘We’re going to do it this way, and we should have no problem getting the tumor out completely in one piece.’”



Callum Kauzlarich plays prior to his brain tumor surgery. The Kauzlarichs found Le Bonheur and Klimo through another family in their hometown whose child had also undergone brain tumor surgery with Klimo.

The path forward was finally clear for both Kyle and Blair. They drove their son to Memphis and checked in at FedExFamilyHouse — a free place for Le Bonheur families to stay directly across from the hospital.

They met Klimo and his team on a Monday morning to prepare for surgery the next day.

“Dr. Klimo put us both at ease,” said Blair. “He was finally the one person I could trust with my son’s life. We knew Le Bonheur was the right place.”

Callum had his resection surgery on Feb. 22. Klimo removed the tumor by approaching it between the two halves of the brain and making a small opening in the corpus callosum, the structure that connects the two halves. The tumor was removed in its entirety, and Callum did not require a drain. He came out of

surgery with only a bandage on his head covering the three-inch incision.

After just two nights in the Neuro ICU, Callum was discharged to FedExFamilyHouse and a day later cleared to head back home. The Kauzlarichs returned to Omaha post-surgery just two short weeks after they first discovered the tumor in Callum’s brain. Kyle and Blair saw an immediate change in their child.

“There was a new light in our son — his eyes and expressions were totally different,” said Blair. “He had always been a sleepy kid, and we didn’t realize why. He’s so happy now.”

Callum is growing by leaps and bounds. Since his surgery, he started therapy close to home, turned 1 year old and exploded in his motor skills. One potential side effect of his surgery was loss of short-term memory due to the location of the tumor, but Callum continues to perform well with short-term memory tasks.

He will visit St. Jude every three months for the next few years for follow-up and observation. Klimo and

the Kauzlarichs anticipate no long-term impact from Callum’s brain tumor.

“Callum has gone through a unique experience and, even though he’s not going to remember any of this, I hope that he looks back and recognizes all the love and compassion that so many people gave him and our family,” said Kyle.

But the Kauzlarichs don’t see their brain tumor journey as completely over. They now work to help other families facing a brain tumor diagnosis find the path that Callum took for healing through Le Bonheur’s Brain Tumor Program and Klimo’s expertise. Working with the SammyStrong Foundation,



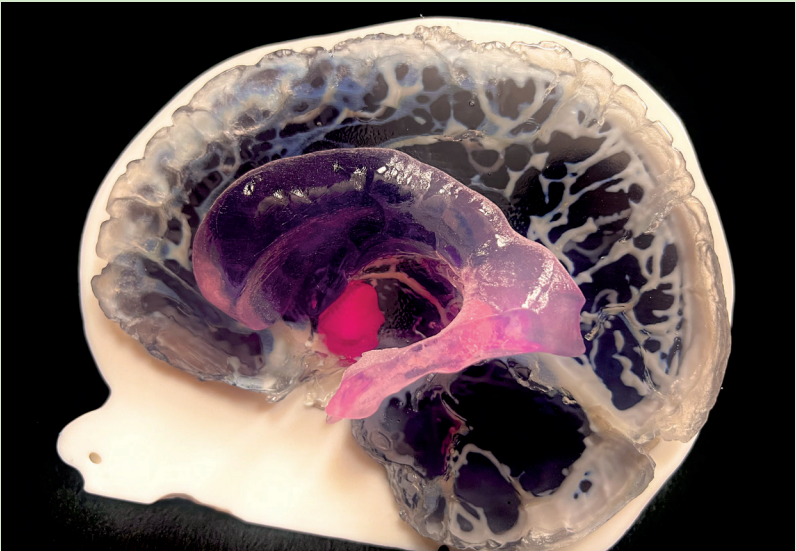
Callum Kauzlarich plays with his dad, Kyle, after his surgery. The brain tumor was removed in its entirety, and Callum returned from surgery with just a bandage and three-inch incision.

started by another Le Bonheur brain tumor patient family in Omaha with the mission to support children, families and organizations fighting pediatric brain cancer, the Kauzlarichs have already helped other families find their way to Klimo and Le Bonheur — from Omaha and beyond.

They have also donated part of Callum’s tumor to St. Jude for research — another way that the Kauzlarichs are doing anything possible to help future families facing a similar journey.

“Through the whole experience, we were overwhelmed with an outpouring of compassion. Everyone at Le Bonheur and FedExFamilyHouse were very supportive and cared a lot about helping us work through this,” said Kyle.

“It was the worst case scenario, but the best outcome possible,” adds Blair. “I don’t know how to put into words how grateful we are for Dr. Klimo and his crew.”



A 3D model designed by Callum’s mother, Blair Kauzlarich, and printed at the 3D Printing Center at Clarkson College shows the tumor in the third ventricle of Callum’s brain. Le Bonheur Chief of Pediatric Neurosurgery Paul Klimo, MD, MPH, was able to remove the tumor in its entirety leaving Callum with only a three-inch incision after surgery.



# Le Bonheur Neuroscience Institute welcomes new providers

**Jenny Schmidt, MD**, joined Le Bonheur as a pediatric neurologist. She completed her Child Neurology residency at the University of Tennessee Health Science Center. Schmidt is a member of the American Academy of Neurology and the Child Neurology Society.



Jenny Schmidt, MD

**Nir Shimony, MD**, joined Le Bonheur as a pediatric neurosurgeon. He completed his residency in Neurosurgery at Tel-Aviv Medical Center and his fellowship in Pediatric Neurosurgery at Johns Hopkins All Children's Hospital. Shimony is a member of the American Association of Neurological Surgeons, Congress of Neurological Surgeons, Society of Neuro-Oncology and American Epilepsy Society. His clinical and research areas of expertise include epilepsy surgery, tumors and lesions of the brain, brainstem and spinal cord, intraoperative neurophysiological monitoring for advanced epilepsy and tumor resection, use of minimally-invasive techniques such as advanced endoscopy and



Nir Shimony, MD

keyhole surgeries for brain lesions and intractable epilepsy.

**Steven Sogge, MD**, recently joined Le Bonheur as a neuroradiologist. Sogge completed a residency in Radiology and a fellowship in Neuroradiology at Pennsylvania State University Hershey Medical Center. Sogge is a member of the American College of Radiology Leadership Institute, American Society of Neuroradiology and the Radiological Society of North America.



Steven Sogge, MD

**Sarah Weatherspoon, MD**, is returning to Le Bonheur's Neuroscience Institute as a pediatric neurologist. Weatherspoon completed her Child Neurology residency and Clinical Neurophysiology fellowship at Cincinnati Children's Hospital Medical Center. She is a member of the American Epilepsy Society, American Academy of Neurology and Child Neurology Society. Her clinical areas of special interest include epilepsy in infants, tuberous sclerosis complex and epilepsy surgery.



Sarah Weatherspoon, MD

## IN BRIEF

### Gipson receives K23 NIH grant for TSC and autism research

Le Bonheur Pediatric Neurologist and Neurodevelopmental Disabilities Specialist **Tanjala Gipson, MD**, recently received a K23 grant from the National Institutes of Health (NIH) for her project "Early Communication in Tuberous Sclerosis Complex (TSC) and Its Prediction of Autism." The objective of this study is to examine potential predictors of language outcome and autism spectrum disorder (ASD) severity in infants with TSC. Currently, despite the high risk of language difficulties and ASD in TSC, very little to no data are available about the origin and trajectory of language in TSC and how this might predict outcome. This project builds on previous research from Gipson that found deficits in early vocal development in most infants with TSC regardless of the diagnosis of ASD.

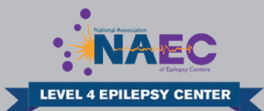


Tanjala Gipson, MD

opportunity to receive leadership development training and network with rising leaders from around the globe.

### Epilepsy program receives NAEC reaccreditation

The Comprehensive Epilepsy Program in Le Bonheur's Neuroscience Institute recently earned reaccreditation as a Level 4 Epilepsy Center from the National Association of Epilepsy Centers (NAEC). This is the highest level awarded to epilepsy centers and one of only a few Level 4 centers in the United States.



### Le Bonheur Neuroscience Institute begins partnership with UCB

Le Bonheur epilepsy experts have partnered with UCB to examine the impact of seizure clusters on patient and caregiver quality of life. The collaboration aims to leverage the power of education and real-world evidence to address the research gap, expand awareness and enact positive change in the health outcomes of individuals with seizure clusters. As a part of the project, Le Bonheur experts will develop resources designed for patients and caregivers that address the importance of the proper use of rescue medications outside the hospital.



### Ridley-Pryor named to ILAE Leadership Development Programme

Le Bonheur Nurse Practitioner and Director of Research Strategies and Collaboration for Pediatric Neurology at the University of Tennessee Health Science Center (UTHSC) **Tracee Ridley-Pryor, DNP, PMHNP-BC**, was recently named to the International League Against Epilepsy (ILAE) Leadership Development Programme 2022, which took place in conjunction with the 14th European Epilepsy Congress. The Leadership Development Programme supports the preparation and advancement of young physician leaders from select ILAE chapters around the world. Through this program, Ridley-Pryor had a unique



Tracee Ridley-Pryor, DNP, PMHNP-BC

### Raja receives Junior Faculty Research Grant

Le Bonheur Pediatric Neurologist **Ashmitha Raja, MD**, recently received a Le Bonheur Junior Faculty Research Grant for her research project titled, "Intracortical Inhibition: A Biomarker for Tic Disorders." The grant was funded by the Children's Foundation Research Institute.



Ashmitha Raja, MD

### Chourasia receives St. Jude Early Career Clinical Scientist Award

Le Bonheur Pediatric Neurologist **Nitish Chourasia, MD**, was awarded the St. Jude Early Career Clinical Scientist Award for his research on genetically-based epilepsy. The title of his project is "Gene Discovery in Epilepsy of Unknown Etiology and Deep Phenotyping of Genetics Associated with Developmental and Epileptic Encephalopathy." The project aims to provide a collaborative clinical and research platform between the Mefford lab at St. Jude Children's Research Hospital and Le Bonheur's Neuroscience Institute to facilitate gene discovery and deep phenotyping of genes associated with developmental and epileptic encephalopathy.



Nitish Chourasia, MD



*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.

*Institute Co-Directors*  
**Paul Klimo, MD, MPH**  
**James W. Wheless, MD**

Gwen Beard, PsyD  
Elena Caron, MD  
Beth Anne Cavanaugh, MD  
Asim F. Choudhri, MD  
Nitish Chourasia, MD  
Jorge A. Lee Diaz, MD  
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Sarah Weatherspoon, MD

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# 15th Annual Pediatric Neurology Symposium at Le Bonheur's Neuroscience Institute

**T**hank you to all who attended the 15th Annual Pediatric Neurology Symposium! It was a weekend filled with eye-opening presentations, collaboration and networking. This year, we presented the Kayden R. Vinson Distinguished Scholar and Lecture Award to Heather C. Mefford, MD, PhD, a physician scientist at St. Jude Children's Research Hospital. This award, made in honor of epilepsy patient Kayden Vinson by her family, brings a leading scholar in pediatric epilepsy to the Mid-South to teach physicians. Mefford presented two lectures on her work related to genetics and epilepsy and neurodevelopmental disorders.



Le Bonheur Neurologist and Director of the Headache Center Ankita Ghosh, MD, presents on headaches in the pediatric population at the symposium.



Heather C. Mefford, MD, PhD, a physician scientist at St. Jude Children's Research Hospital, receives the Kayden R. Vinson Distinguished Scholar and Lecture Award from Le Bonheur Neuroscience Institute Co-Director James Wheless, MD.

Save the date for the  
**16th Annual  
Pediatric Neurology Symposium**  
**March 31 – April 1, 2023**  
**Westin Memphis Beale Street | Memphis, Tenn.**  
Registration will open early 2023.