The University of Chicago Medicine



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A little boy gets his future back

New hope for children and adults with severe, uncontrolled epilepsy



Surviving advanced head and neck cancer without surgery

Personalized care sets kidney transplant program apart

Kid.

A physician devotes her career to treating and curing a deadly childhood cancer



Stopping Nathan's seizures



When nothing else helped, Nathan's parents turned to Michael Kohrman, MD, and the epilepsy experts at the University of Chicago Medicine

Michael Kohrman, MD, and Nathan Kalina

ive-year-old Nathan Kalina, who likes playing with action figures and acting out scenes of valor from his favorite movies, has been free of seizures for a year, after enduring between 60 and 100 a day for months. Before his family gave up on sending him to preschool, he'd been wearing a face mask and a helmet so he wouldn't hurt himself in seizure-related falls.

Now he's looking forward to kindergarten in September, without any protective gear, and his mother, Megan, is cautiously starting to wean him off some of the five antiseizure drugs he takes to control his myoclonic-astatic epilepsy, also known as Doose syndrome.

"He's completely recovered and suffered no long-term damage," Megan Kalina said. "His milestones have caught up, he's growing like a weed, and we can breathe again."

"Ultimately our goal is no seizures and no side effects." MICHAEL H. KOHRMAN, MD, expert on childhood epilepsy

The Kalinas, who live in Naperville, Ill., previously had tried two other hospitals and many drugs, as well as a special high-fat diet that ended up making Nathan sick. A friend recommended Michael Kohrman, MD, director of the pediatric epilepsy program at the University of Chicago Medicine Comer Children's Hospital.

After trying one more drug, with some success but not enough, Kohrman had Nathan evaluated for surgery. One month after pediatric neurosurgeon Leila Khorasani, MD, implanted a vagus nerve stimulator (VNS), Nathan was seizure free.

The vagus nerve originates in the brain stem and supplies nerve fibers to various organs. The stimulator, powered by a small battery implanted in Nathan's chest, sends a tiny electric shock to the nerve every 5 minutes, causing him a little tickle at the back of his throat but otherwise not bothering him at all.

"No one understands 100 percent why VNS works, but it can reduce seizures in the right kind of patient," says David M. Frim, MD, PhD, chief of neurosurgery. Nathan's apparently complete recovery isn't typical; approximately 30 percent of epilepsy patients treated with VNS experience a major improvement in seizure control, while another 30 percent show some improvement.

The University of Chicago Medicine adult and pediatric epilepsy programs provide seamless care for patients from infancy through adulthood. Both adult and pediatric programs are recognized as Level 4 treatment centers — the highest possible — by the National Association of Epilepsy Centers.

Adult and pediatric epilepsy care is offered on the main University of Chicago Medicine campus in Hyde Park. In addition, pediatric epilepsy experts see patients at offices in Elmhurst, Ill., Hinsdale, Ill., Naperville, Ill., Palos Heights, Ill., and Merrillville, Ind.

The epilepsy program offers surgical procedures that aren't widely available elsewhere, as well as multiple ways to image the brain and study its electrical wave patterns. As a result, the multispecialty team is often able to make the definitive diagnosis that has eluded many seizure patients, leading to more effective treatment.

Patients also benefit from the clinical trials of drugs and other therapies at the University of Chicago Medicine. "We have one of the most active epilepsy research programs in the city, if not in the Midwest," Kohrman said.

On the one-year anniversary of Nathan's surgery, Kohrman received an email from Megan Kalina. "You gave us our son back," she wrote, "and Nathan his future back." uchicagokidshospital.org/specialties/epilepsy uchospitals.edu/specialties/epilepsy



Sharon O'Keefe, left, and Susan Axelrod

The quest for a cure

Susan Axelrod co-founded Citizens United for Research in Epilepsy (CURE) in 1998 out of frustration after not being able to find successful therapy for her daughter Lauren's seizures.

The Axelrods (Susan's husband, David, is an advisor to President Barack Obama) tried countless drugs, special diets and surgery, with no effect. Lauren, now in her 30s, suffered brain damage. But she has been seizure free since 2000, thanks to a single drug that proved effective for her.

Since its inception, CURE has raised more than \$18 million for epilepsy research and awareness.

University of Chicago Medical Center President Sharon O'Keefe was named to the national organization's board in May. "I have seen how epilepsy can disrupt the lives and plans of patients and their families," said O'Keefe, the mother of a child with epilepsy. "I also have seen remarkable progress toward understanding this disease through innovative research. I look forward to this new role in helping speed up the pace of progress in understanding, treating and, we hope, curing this disorder."

For more information, visit cureepilepsy.org.

Epilepsy expert joins team

Pediatric neurologist Charles Marcuccilli, MD, PhD, joined the Pediatric Epilepsy Center on July 5. Marcuccilli, who conducts basic and clinical research in epilepsy and seizure control, will see patients in a new clinic in Hinsdale, III., as well as at the University of Chicago Medicine Comer Children's Hospital.

Mapping the brain

A brain-mapping technique developed at the University of Chicago Medicine puts data from brain scans through a complex mathematical algorithm to produce a 3-D image of the brain that often shows exactly where the seizure activity is occurring. This helps epilepsy specialists decide whether surgery is the best option for controlling the patient's seizures.

David M. Frim, MD, PhD, chief of neurosurgery, says it makes his job much easier and simpler. "We can concentrate on finding the safest and least traumatic way to remove the seizure-causing area," Frim said, "because we're so sure that we are operating on the correct tissue."