The Journey from Epilepsy: Jacob's Story

"I remember the day – it was January 24th of '07," recalls Heather Lackie.

She and her two children were alone in her mother's home in Littleton, NH. She glanced at three-week-old Jacob, resting in his car seat, and saw that he was blue, his eyes were "doing funny things," and he was gasping. Frightened, Heather picked Jacob up and was able to settle him down, but when her mother returned home a short while later, the same thing happened again.

They both knew that something was very wrong, so they called the emergency room at Littleton Hospital and told them they were on their way.

"When we got there, he did it again," Heather recalls. "They called CHaD and said they had a little boy with seizures and we don't know why." Jacob was immediately transported to CHaD by ambulance.

So begins the journey together of Jacob Lackie, his courageous family and CHaD's skilled and committed team of pediatric neurologists and neurosurgeons.

"Jacob was very little when I first met him, just three weeks old," recounts pediatric neurologist Richard P. Morse, MD. "He came to the hospital with intractable seizures, multiple seizures per hour at that time." Dr. Morse and his team first used video EEG (encephalograph) monitoring to determine that Jacob was indeed experiencing epileptic seizures.

Jacob's situation was different in many ways. For seizures to begin in the first few weeks of life without an injury often indicates that there's a serious underlying cause. Also, Jacob's seizures were different from most baby seizures, and more frequent. Jacob briefly responded to some medications, but his seizures always came back.

Looking for Causes

"Once we determined that Jacob was really experiencing seizures, the next step was to look for possible causes," according to Dr. Morse. In a case like Jacob's, where the epilepsy is quite severe and "focal," the

underlying cause is very likely to be anatomical – some type of malformation in the brain – so surgical treatment is considered early on.

"At CHaD, we have an unusually fruitful and collaborative relationship between the Neurology and Neurosurgery," says Tina Duhaime, MD, director of CHaD's Pediatric Neurosurgery Program. "Dr. Morse believes that if he's involved in a case where surgery may be the best option, you get the surgeons involved very early. My feeling is the earlier we're involved, the better."

Neurologists help diagnose a problem like epilepsy and consider how likely it is that some type of surgery will help a patient. The role of the neurosurgeon is to determine the potential risks of an operation. Once the medical team has as much information as they can gather, they present it to the family so they can weigh all the known risks and benefits and make a decision.

Dr. Morse's team monitored Jacob's brain activity using electrodes attached to the outside of his head and they identified a "hot spot," where seizure activity appeared to originate. "The discovery of the 'hot spot' was exciting and scary," according to Heather. "We had an answer – at least somewhat of an answer."

The Lackie family decided that they wanted surgery for Jacob. Dr. Duhaime agreed that it looked like surgery might be Jacob's best option, but she asked the family to first try the "ketogenic diet" to see if he would experience any improvement. The ketogenic diet helps two out of three children who try it and it even prevents seizures in some children. The diet is very high in fats and low in carbohydrates, and causes the body to burn fat for energy instead of glucose. For Jacob there was no improvement after about six weeks, so he was scheduled for surgery.

Three Surgeries for Jacob

Jacob's first surgery was to more accurately determine from where in his brain the seizures were arising. Dr. Morse's team used electrodes on the outside of Jacob's head to begin this search and now Dr. Duhaime team used probes to measure and record activity on the surface and inside Jacob's brain. "From that data, we can tell the family if we remove or disconnect a certain part of the brain, what's the likelihood that it will help the seizures and what's the likelihood that can cause harm," explains Dr. Duhaime.

In a second surgery, Dr. Duhaime removed a portion of Jacob's left occipital lobe that the team determined could be removed safely and might reduce Jacob's seizures with minimal other consequences. This reduced the seizure activity only briefly, but Jacob's family was able to report that "we got Jacob back!" During this respite they were able to see Jacob's personality re-emerge from the seemingly endless barrage of seizures, a key encouraging sign for everyone involved.

"Then we needed to have a conversation with the family about disconnecting the entire half of the brain, a procedure we believed had an excellent chance of working to stop the seizures," explained Dr. Duhaime. The risk was that Jacob would almost certainly have some weakness in his hand, but children can often recover to some degree and the medical team believed he'd be able to walk well and use his right arm. Having seen a glimmer of Jacob after the earlier surgery, the Lackie family was not only willing, but anxious to move forward with this surgery. Jacob's spark is back!

"Jacob is seizure-free," says Dr. Morse, "which is a thrill for all of us, most of all for his family. He has managed to gain back most motor skills, he gets around quite beautifully. It's been a fantastic result."

"Jacob's spark came back," adds Dr. Duhaime, "and this is exactly what this family wanted. A great outcome like this isn't possible unless you have teamwork, and the team includes all the people that are behind the tests and evaluations that children like Jacob require. It requires doctors with skills like Dr. Morse and his team, and a surgeon who's willing to take on this kind of risk with the family. But most of all it takes a family that is willing to put aside the fear that families must face in the long-term best interests of the child."

Heather Lackie reports, "Jacob is now mobile, he scoots around on his butt – it's quite cute, and he gets anywhere he wants. He's your typical boy, into everything. And he learns something new every day."

What would she share with other parents facing a similar situation? "Be persistent, be strong, be your child's best advocate. Push on, because your children need you and the doctors need your help too."

Watch Jacob's video story at www.CHaDKids.org ■