EPILEPSY SURGERY:
No longer the last
One evening in October 2008, a very tired John Tilelli got into his car and headed home from his job at a technology company in Northern Virginia. Tilelli, then 50, had suffered tonic-clonic seizures since contracting meningitis at the age of 21. His seizures had been controlled by different antiepileptic drugs over the years. But on that October evening, while driving, he had a massive seizure, striking two other cars and totaling his own.

In the ensuing weeks, Tilelli’s seizures began to spiral out of control, climbing from one every 3 weeks to seven or eight a day. When several new drugs failed to get the seizures under control, his doctor told him the next medication would alter his personality to the point at which he would no longer be able to work. “I thought, well, for me, that’s just not a choice,” Tilelli remembers.

And so it was that, through a referral from his neurologist, Tilelli found himself in the Department of Neurosurgery at Virginia’s Winchester Medical Center, where a team specializes in treating people with epilepsy. After 7 months of testing to determine his eligibility for surgery, Tilelli had a portion of the right temporal lobe of his brain removed on Friday, June 25, 2009. Deeply embedded in the tissue was the source of his seizures—a walnut-sized area irreparably scarred by the meningitis he’d suffered 3 decades earlier. Two days after surgery, Tilelli went home; 2 months later—which even he admits was a bit early—he went back to work. He has been seizure-free ever since.

Over the last several decades, epilepsy surgery has changed the landscape of treatment for people whose seizures can’t be controlled with medication. Yet though it has been in use for more than 50 years, surgery for epilepsy is still often thought of as a last resort: even today, though some 100,000 Americans with epilepsy are candidates for surgery, only a few thousand a year actually have it.

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Surgeons like Dr. Gary Mathern, director of the Pediatric Epilepsy Surgery Program at The University of California, Los Angeles and a member of the Epilepsy Foundation’s Professional Advisory Board, are working to change that, stating that surgery is an option people with epilepsy should consider more often—and much earlier.

“This concept of ‘treatment of last resort’ is something we’ve been trying to dispel for 30 years,” Mathern says. “That approach hurts patients—adults and children—continued on page 7
because of the effects of repeated seizures over time. The risk of not doing something, if you’re a surgical candidate, is higher than the risk of doing something."

Epilepsy surgery has evolved enormously in the last quarter-century, says Dr. Dennis Spencer, chief of neurosurgery at Yale Medical School, who, with his late wife, former Yale neurology chair Dr. Susan Spencer, helped shape the all-important pre-surgical evaluation that determines which people with epilepsy are candidates for surgery. “The major changes started with the computerization of medicine, leading to imaging,” Spencer says. “When the MRI scan became more sophisticated in the 1980s, that really stimulated rapid growth in providing epilepsy surgery for patients, particularly those who have temporal lobe epilepsy.”

Right now, surgery is the only form of epilepsy treatment that can offer some patients a cure. Dr. Gary Mathern, director of the Pediatric Epilepsy Surgery Program at the University of California, Los Angeles

Several studies have shown that African-Americans are less likely than other racial or ethnic groups in the U.S. to receive epilepsy surgery, for a multitude of reasons including problems with access to care and mistrust of the health care system. And many people of all backgrounds, understandably, may simply be afraid of having brain surgery. “When my doctor first suggested this, he said, ‘There’s a chance that they can look at where your seizures are coming from and remove that portion of your brain,’” Tilelli remembers. “That scared the life out of me!”

Together, these factors account for the fact that, as Dr. Spencer puts it, “We’re still getting patients too late.” People who show up for a surgical consult as young adults may have known since adolescence that they couldn’t achieve seizure control with medication. In those cases, Dr. Spencer says, “By the time they’re entering high school and still having seizures, now you begin to see the impact on socialization, interactive relationships, the ability to do sports; come 16, they can’t get a driver’s license; and then it affects their ability to go on educationally, and that affects their life.”

If you go to surgery, you’re talking about a roughly 75 percent chance of freedom from seizures. That’s a huge difference.

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working ability. If they finally are sent to an epilepsy surgery center as adults and epilepsy surgery is performed, and if you can stop their seizures, can they then go back and retrieve some of the socialization? Can they retrieve their ability to find employment? Many of them do not. So the point is to identify patients when they’re younger.”

Despite their fears, he says, parents really should consider surgery even for very young children. “If there’s a chance that they can be more normal and have a better education if we stop the seizures when they’re still a child—and, also, not let them continue to experience the stigma,” he says. “Because there’s still a stigma in epilepsy.”

Dr. Mathern couldn’t agree more, particularly about seizure-induced losses that cannot be recouped. “People with intractable epilepsy are at risk for epileptic encephalopathy, which knocks out IQ points,” he says. “Once you lose that IQ, if you stop the seizures, you don’t get the IQ back. This is why individuals with intractable epilepsy, if they are surgical candidates, should be looking at a surgical option—and it should be a first option, not a third, fourth or fifth option.”

Dr. Mathern feels that among parents of young children with intractable epilepsy, interest in considering surgery actually is on the rise—not because they’re hearing more about surgery from their children’s doctors, but because they’re learning about it online. The Internet and social media sites have become powerful networks for those who have had epilepsy surgery and those considering it; even John Tilelli’s Facebook page features an album of pictures of his brain taken during surgery. “The Net and social networks have done more to educate parents than anything I’ve seen in my lifetime,” Mathern says. “Parents are coming in more prepared and more knowledgeable. Some of them want to look into surgery for their kids even before they’ve failed two to three meds.”

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There are several types of surgery for epilepsy, gauged to different seizure types and focuses, the cause of the seizures and the age of the patient. The most common surgery is temporal lobectomy—removal of a portion of the temporal lobe, the origin of a majority of epileptic activity. Another type of surgery, corpus callosotomy, involves severing the bridge between the right and left hemispheres of the brain to keep seizure activity that originates on one side from traveling to the other.

Hemispherectomy, which is most often performed on children, is the removal of one entire hemisphere of the brain, typically when it has been so badly damaged that it is beginning to compromise the work of the other hemisphere. For young children with intractable seizures, **continued on page 9**

**Surgery is a possibility even for very young children.**

Having brain surgery was a hard decision, but the alternative is a life you don’t want to live anymore. **JOHN TILELLI**

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**PHOTOS COURTESY OF JOHN TILELLI**

**From left, surgeon Dr. Lee Selznick, a seizure-free Tilelli, neurologist Dr. Paul Lyons and psychotherapist Dr. Fred Sabia.**

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often caused by brain abnormalities like cortical dysplasia or degenerative conditions like Rasmussen’s encephalitis, hemispherectomy has become a new universe of treatment. It is particularly visible online, at sites like the Hemispherectomy Foundation (http://hemifoundation.intuitwebsites.com). Also visit www.epilepsyfoundation.org/ecommunities to start or join a discussion about hemispherectomy as a treatment option.

In any form of epilepsy surgery, much of the art of the procedure is in the pre-surgical workup—tests done to determine whether or not someone is a candidate for surgery. Doctors image the brain, trying to locate a seizure focus and map how much and what type of “eloquent” tissue—brain tissue responsible for functions like language, memory, or movement—is located nearby.

A workup usually starts with a standard EEG or invasive monitoring, in which electrodes are surgically implanted in the brain and the patient is then monitored in the hospital for 10 to 14 days to record seizure activity and brain function. Surgeons may do MRI, PET or MEG scans and a Wada test, in which, as Dr. Spencer puts it, “you shut down one side of the brain at a time, in order to talk to the other side briefly” to find out what activity is taking place in each hemisphere. Neuropsychological tests also help determine which functions—like short-term memory or reading comprehension—are intact and which have been damaged.

All of these [neuropsychological] tests make it possible for surgeons to be more precise in removing epileptogenic tissue—the parts of the brain in which seizures are starting—without damaging functional tissue nearby. Epilepsy surgery does involve certain risks beyond the general problems—like infection or anesthesia reactions—that can accompany any type of surgery. Patients who have epilepsy surgery can lose some types of function, and surgeons often know this in advance; agreeing to surgery can sometimes be a question of a patient deciding to take on a permanent deficit—a loss of some peripheral vision, for example—in order to be potentially free from seizures and AEDs. However, the risks of the surgery are most often less than the risks of continued uncontrolled epilepsy, including the risk of sudden death, known as SUDEP.
It’s a deal patients and their families are often more than willing to make. Like many children with intractable seizures, Roxanne Cogil’s daughter Rachel was diagnosed with cortical dysplasia; her seizures, which had started when she was only two, were gradually destroying the right hemisphere of her brain. In March 2009, at the age of 5, Rachel had a hemispherectomy with Dr. Mathern, which stopped the seizures entirely. The surgery’s lasting effects—a limp necessitating a leg brace, loss of some peripheral vision, and weakness in her left arm—don’t stop her from playing T-ball and soccer and taking dance classes. And Roxanne Cogil has no doubt that the surgery saved Rachel’s life. “She’s fabulous. Her language has skyrocketed; she gained 8 months of language in her first four months of recovery,” Cogil says. “The important thing is that the surgery protected her cognitive function from seizures. We really felt like we got our daughter back.”

Even when surgery doesn’t actually cure epilepsy, it often radically improves patients’ lives. Sarah Harris started having seizures and was diagnosed with cortical dysplasia at the age of 12; 4 years later, in 2008, she had epilepsy surgery with Dr. Spencer, who removed 95 percent of the lesion in her right temporal lobe. The prospect of brain surgery hadn’t scared Sarah at all. “She’d really had it; her seizures became increasingly worse, and it got to the point where she said, ‘I can’t keep living like this. If there’s a chance it’ll go away, I’m up for it,’” says Sarah’s mother, Louise. Now, she adds, “Sarah still has a few absence seizures daily, but the big difference is that she doesn’t have to be out of it for hours; she just picks right back up.” “I’m a lot happier than I was before,” Sarah says. Her advice to other teens considering surgery: “Definitely do it.”

And the good surgical outcomes, like John Tilelli’s, are often startlingly good. Dede Lackey, who sustained a devastating traumatic brain injury as a toddler, had lived with both AEDs and persistent seizures for 3 decades when her neurologist recommended that she see the Spencers in 1994. Lackey had surgery with Dr. Spencer, who removed 95 percent of the lesion in her right temporal lobe. The prospect of brain surgery hadn’t scared Sarah at all. “She’d really had it; her seizures became increasingly worse, and it got to the point where she said, ‘I can’t keep living like this. If there’s a chance it’ll go away, I’m up for it,’” says Sarah’s mother, Louise. Now, she adds, “Sarah still has a few absence seizures daily, but the big difference is that she doesn’t have to be out of it for hours; she just picks right back up.” “I’m a lot happier than I was before,” Sarah says. Her advice to other teens considering surgery: “Definitely do it.”

For anyone considering epilepsy surgery, both doctors and patients agree that the first and most important task is to find not just an experienced neurosurgeon, but a team that specializes in surgery to treat epilepsy. John Tilelli was fortunate to find such a team at Winchester Medical Center, his local hospital, where surgeons have had successful outcomes in all of the eight epilepsy surgeries they’ve performed over the last 2 years. “This is my home,” Tilelli says. “I didn’t want to go anywhere else.” But in most cases, particularly for infants or young children needing surgery, finding the best care typically involves traveling to a major teaching hospital in an urban center, where teams have extensive experience with rarer conditions requiring surgery.

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In the year since Tilelli’s surgery, his two sons have gotten to know a very different father than the one they grew up with: a man who now wakes at dawn; walks eight to ten miles three times a week; is 62 pounds down from his pre-surgery weight; works with a support group for people with epilepsy; and seems to have boundless energy—not at all the dad so exhausted by seizures that he often wanted to do nothing after work but sleep. “Having brain surgery was a hard decision, but the alternative is a life you don’t want to live anymore,” Tilelli says. “It’s a chance at a normal life for you and your family—and that was really the only choice I had. It has benefitted me, my family, and, I think, my community, too. I’ve become very passionate about life; I don’t take any day for granted.”