By Erin Graham

catching the lightning

Finding the elusive electrical impulses at the core of epilepsy isn't easy. So neurologists use an arsenal of tools to peer inside the brain and pin down the source of seizures.

The first few times Gwendolyn Guay stared off into space mumbling to herself, her parents assumed she was just lost in thought. "Gwennie has always been strong-willed, so I wondered if she was just ignoring me," says her mom, Nancy. But the episodes became more frequent and stranger: Gwen would become unresponsive for up to a minute, pressing her fingers together while making soft clucking sounds. Soon, Nancy and her husband, Stewart, suspected the staring episodes were actually seizures and took Gwen to a specialist in their home state of Maine, who diagnosed her with epilepsy.

Epilepsy is a disease that remains stubbornly bewildering—to the nearly three million Americans who have it and the doctors who treat it. In some cases, it can be traced to an underlying disease, injury or brain malformation. But in most cases, its origins are a mystery. And while many new epilepsy medications have come on the market, the percentage of people whose seizures can be controlled by drugs remains stubbornly unchanged: two thirds.

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>
> **—Blaise Bourgeois, MD,**
> **Director of Children's Hospital Boston's Epilepsy Program**

Gwen's proved to be one of the intractable cases. For five years, the Guays hoped that a mix of medications would stop her seizures. But some had disturbing side effects, like the shakes and nervous ticks, and every time a drug seemed to work, the seizures would creep back. "I'd almost forget about Gwen's epilepsy and then a seizure would hit," says Nancy. The seizures were hard on Gwen, often leaving her exhausted. Once, a seizure struck during ballet practice, causing Gwen to wet herself in front of her friends. "I felt really embarrassed," she says. "The seizures made me feel different than the other kids."

By Gwen's 9th birthday last September, it was clear that medications weren't working. Her parents took her to see Blaise Bourgeois, MD, director of Children's Hospital Boston's Epilepsy Program, to undergo an evaluation by his team of neurologists, neuropsychologists, radiologists, imaging specialists and neurosurgeons. If the team could pinpoint one place in Gwen's brain that was over-firing and causing the seizures, the surgeons might be able to remove the bad tissue and cure her epilepsy. "It's like trying to defuse a bomb," says Bourgeois. "The hope is that you can go in and remove the trigger." While this kind of surgery is the most effective treatment—and epilepsy's only real cure—only about 5 percent of patients are candidates for it.

Armed with the latest brain imaging devices, the epilepsy team unleashed its artillery of tests, searching for the spot (or spots) where Gwen's seizures were originating—as well as spots that controlled crucial functions like movement, language or memory. "Unless there's a clear lesion, all brain tissue looks the same," says Bourgeois. "It's like looking at a computer chip; you don't know what it does by its appearance, so you need to find out how it works."

So Gwen began a week-long session of 24-hour electroencephalogram (EEG) monitoring to record her brain's electrical activity through 26 electrodes on her head. Results suggested that her seizures stemmed from the left side of her brain, but weren't conclusive, since some signals may have ricocheted from the right side. More clues sprung from sophisticated brain imaging tests. For one, nurses injected radioactive substances into Gwen's bloodstream to track chemical activity and blood flow in her brain; another captured the magnetic fields generated by her brain cells, painting a three-dimensional picture of her brain. Together, the tests narrowed down dozens of possibilities to just a few, and suggested that her seizures were coming from her left temporal lobe, the part of the brain involved in making memories and processing emotions.

Finding what's wrong in an epilepsy patient's brain is an important hurdle, but finding what's right is an even bigger one. Before removing a piece of epileptic brain, Gwen's doctors needed to know how close it was to healthy brain tissue and the possible effects of its removal. They paid special attention to language and memory—two skills traditionally housed in the left temporal lobe, close to the epileptic area. To get a clearer idea of which half of her brain controlled certain functions, doctors

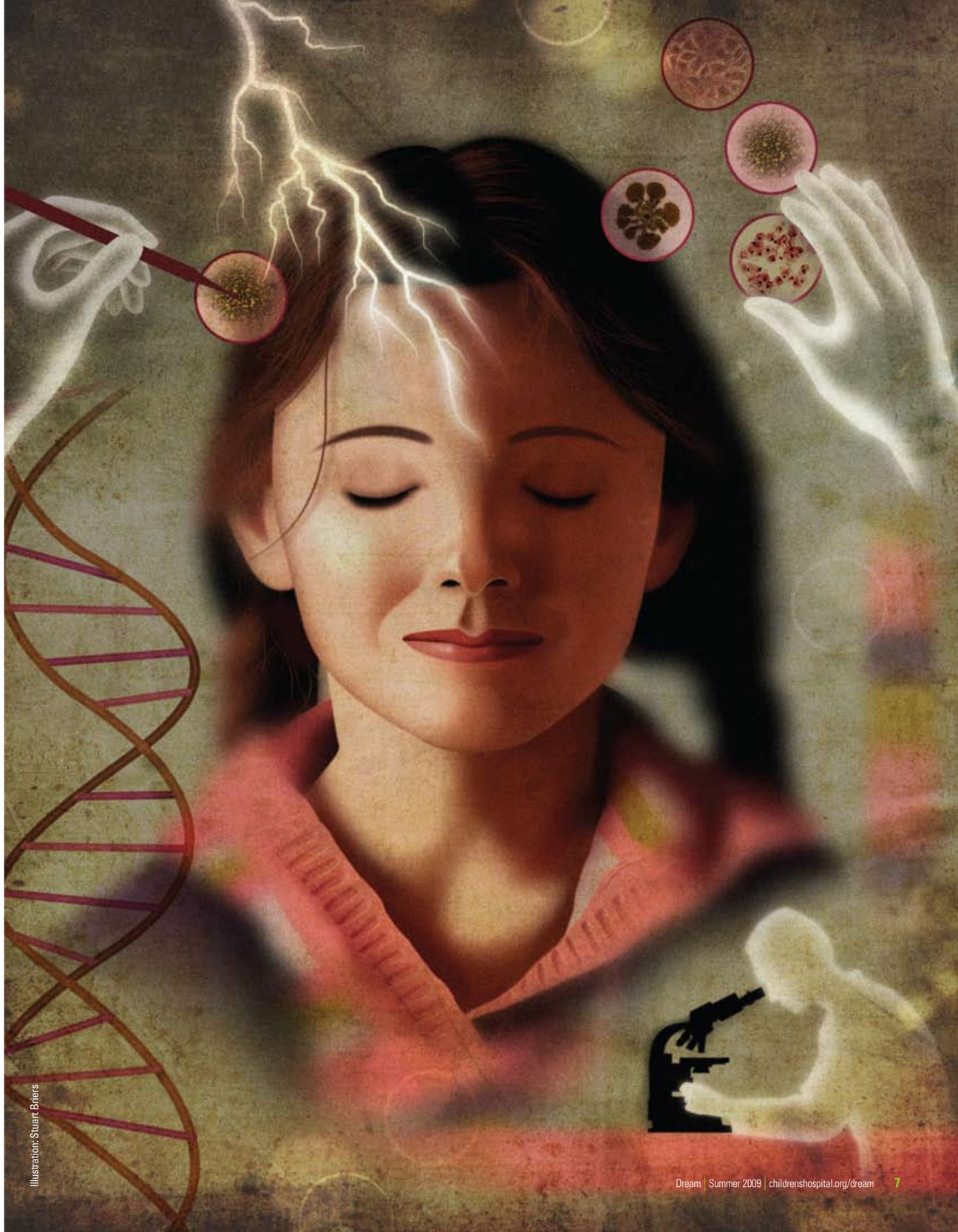

Illustration: Stuart Briers

Photo: Javier Amador-Peña

GWEN and her epileptologist, Blaise Bourgeois, MD, after her life-altering surgery.

performed a dramatic procedure, called a Wada test. Injecting an anesthetic, they put one whole side of Gwen's brain to sleep, causing the opposite half of her body to go briefly limp, as if she'd had a stroke. They then repeated these steps on the other side of her brain. While each side was temporarily shut down, Gwen tried to perform tasks, like moving her arms, counting and remembering images. Sure enough, she couldn't speak or remember when her brain's left side was asleep.

This let Bourgeois know which side of the brain contained the damaged tissue, but surgeons would need would need a detailed map of her brain's functions—millimeter by millimeter—to remove that tissue. So they opened Gwen's skull and placed thin strips of silicon, studded with 108 electrodes, directly on her brain. "It's the most accurate data you can get," says Bourgeois.

After the nearly five-hour operation, Gwen awoke to a headache and scores of fine wires coming out of her head recording her brain activity. A few days later, doctors performed a cortical stimulation test; they asked her questions while applying small shocks to each electrode in turn, temporarily rendering that part of her brain useless. If she failed a task, doctors knew that they'd tapped the part of her brain used for that thought process. Results were good: They zeroed in on the epilepsy, and the areas right around it didn't seem to be used for language. But whether Gwen's memory would be safe was still unclear.

With the "blueprint" of Gwen's brain in hand, the team began an hours-long debate about whether to go ahead with the brain surgery. Neurologists, neurosurgeons, radiologists, nurses and psychologists examined the monitoring and imaging results and tried to gauge the likelihood of success. "We had lots of concerns about Gwen's memory," says Bourgeois. "If we took out functional tissue, she wouldn't be able to recall or retain words." But that possibility had to be balanced against the risks of living with debilitating seizures: injury from falls, accidental death due to drowning and possible long-term effects of medication. Gwen's quality of life was foremost on Bourgeois's mind. "Most of my patients tell me that having even one seizure a week ruins their lives," he says. "Living with her seizures would be a constant worry and self-esteem issue for her as she got older."

Gwen's parents, who needed to make the final decision, also deliberated. They hated the fact that Gwen wouldn't ever be able to drive because of her seizures. "We wanted her to have complete freedom and live wherever she wants to when she's grown up—not just where she wouldn't have to drive," says Nancy. But the fact that Gwen didn't have a crippling disability made the decision difficult. She was a straight-A student who didn't let her seizures interfere with her life—the kind of girl who intimidated bullies two years older than she was if they were picking on her friends. "It's one thing to suffer with your kid when they have a broken leg, it's another to put her through elective brain surgery," says Stewart. "Gwen had a great life as it was. The worst part was worrying about her memory—we wanted to make her better, but keep her the same. We kept thinking: 'Please don't change her.'"

Meanwhile, the team made a significant discovery. Just days before her scheduled surgery, a high-powered MRI brain scan finally revealed a pea-sized malformation in Gwen's left temporal lobe. "It was a big reassurance, and we recommended her for the surgery with a high certainty that it would be a success," says Bourgeois. And the procedure did go smoothly: Surgeons removed the electrodes that had been so useful in mapping her brain, and easily removed the affected area.

"Words can't express the feeling we had when Gwen opened her eyes and immediately started giving me a hard time about having a bad headache and hungry, grumbly belly," says Stewart. Within the week, the Guays left for home.

With a bright new leopard-print bandana and her memory intact, Gwen was looking forward to returning home to her dance lessons and, she hopes, a seizure-free future. "My dad says I'm tough," she says. "He thinks I will most likely be the first woman Navy SEAL."

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