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ANNALS OF MEDICINE

THE DEEPEST CUT

How can someone live with only half a brain?

BY CHRISTINE KENNEALLY

JULY 3, 2006

At nine o'clock on July 28th last year, Wendy Nissley carried her two-year-old daughter, Lacy, into O.R. 12 at Johns Hopkins Hospital to have half of her brain removed. Lacy suffers from a rare malformation of the brain, known as hemimegalencephaly, in which one hemisphere grows larger than the other. The condition causes seizures, and Lacy was having so many—up to forty in a day—that, at an age when other toddlers were trying out sentences, she could produce only a few language-like sounds. As long as Lacy's malformed right hemisphere was attached to the rest of her brain, it would prevent her left hemisphere from functioning normally. So Lacy's parents had brought her to Johns Hopkins for a hemispherectomy, which is probably the most radical procedure in neurosurgery.



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Wendy laid her daughter on the operating table. Because Lacy was so small, it took the anesthesiologist almost ninety minutes to insert her intravenous lines. George Jallo, the attending neurosurgeon, spent a long time arranging her head on gel padding and then drew “Cut here” markings on her shaved scalp. The rest of Lacy’s head, including her face, was covered with a sterile drape. Jallo made one long cut across the top of her head from the front to the back, and another at right angles to the first, which started midway along it and stopped just in front of her right ear. He folded back the scalp and made small holes in her skull with a power drill, outlining a rough semicircle. Then he used the drill to connect the dots and removed a portion of the skull. He cut another T in the dura, a thin, leathery membrane covering the brain. Gently, he peeled back two large flaps.

By half past one, Jallo and a resident had already removed the right frontal lobe. David Lieberman, the pediatric neurologist who had examined Lacy when she first came to Johns Hopkins, looked on, shaking his head in wonderment. “It’s so open,” he said, turning to me. “Normally, with brain surgery, you make a hole about this big”—he curled his thumb and index finger into a circle.

After removing the frontal lobe, Jallo embarked on the parietal lobe. In case complications put a sudden stop to the surgery, it was important to take out the seizure hot spots first, gradually working through the hemisphere in descending order of priority: after the parietal lobe would come a small section of the occipital lobe, then the temporal lobe, then the rest of the occipital. Finally, Jallo would cut the corpus callosum, the bundle of fibres that connect the two hemispheres of the brain. The surgeons slowly worked around each side of the parietal lobe, making tiny pinches in the brain with electric cauterizing forceps. There was a slight smell of burning in the bright, noisy operating room. As the cut became deeper and wider, the tissue on either side browned and blackened, and the lobe started to move back and forth. At the bottom of the parietal wedge, the clean white of nerve fibres was visible; as the lobe was severed, they came apart like string cheese. A surgical technician bent toward Jallo with a small plastic bowl in his hands. Jallo picked the lobe out of the skull—it was the size of an infant’s fist—and dropped it into the container.

As she led me out of the O.R., Eileen Vining, the attending neurologist, said, “Did you see how rigid it was? Normal brain sags in your hands.” Vining talked quickly, moving from one complicated idea to the next, punctuating each with “O.K.?” and an expectant nod. She had been in and out of the operating room all morning, and now she was off to find the Nissleys and tell them how Lacy was doing.

Four hours later, Vining took me back into the O.R. Lacy’s right hemisphere was gone, and her cranium looked like a wide, uneven bowl. I could see the deep cavity where the frontal and parietal lobes had been, and



“I can’t talk now—he’s right here.”

the white-pink color inside the base of the skull. In the middle of the remaining brain was a shallow mound where Jallo had left a layer of nerve fibres to protect the ventricle, a fluid-filled pocket that cushions the brain and the spinal cord. The white matter there was now gray-black. Jallo and his resident lightly touched their forceps to it, and the cauterizers fizzed, sealing the brain to prevent microhemorrhages. Hemorrhaging is a constant concern in brain surgery, and at one point in the operation Jallo decided to leave in a small piece of the right occipital lobe which threatened to bleed dangerously. Jallo glanced at Vining and Lieberman, and the doctors stretched forward to look at the severed corpus callosum. Over and over, the surgical technician poured in saline, and Jallo and his resident drew it out again with a loud suction pump.

When he had finished removing brain tissue, Jallo tipped in small packets of Surgicel, a feathery white substance that helps blood to clot. It melted onto the surface of the brain. "That was good. There was not a lot of bleeding," Vining said. "You never know what you are going to get until you open it up. Sometimes you just go in there and you hold your breath and pray."

In the final hour, Jallo sutured Lacy's dura, which had shrunk slightly from dehydration, and filled the right side of her head with saline. The technician then brought the missing section of the skull back to Jallo, carrying it in a wide right angle over surgical carts rather than risk moving it over the floor. Jallo reattached it, using four tiny dissolvable plates made of a sugarlike substance. He then closed the scalp incision with a staple gun, leaving seventy-eight aluminum staples in Lacy's skin. The hemispherectomy had taken nine hours. The resident bandaged Lacy's head, gently turned her onto her right side, and stuck a piece of tape on her head that said "This side up."

I first met the Nissleys three months before Lacy's surgery, at their home in Palmyra, Pennsylvania. As I drove up, I could see Lacy's father, Mike, dangling a leg over the edge of the front porch. He looked like a surfer, with a goatee beard and gold-lens Oakleys pushed back on his head. Wendy sat on a chair near the front door, and Lacy's four-year-old sister, Lily, flitted around the adults. Lacy, blond like her mother, lay across Wendy's lap. "She had a seizure just before you got here, so she's sleeping now," Wendy said. They invited me inside.

Lacy had her first seizure on October 13, 2003, when she was four and a half months old. Wendy had been doing laundry, and when she turned around she saw that Lacy's lips were blue and that she was shaking. She called 911, but by the time the ambulance arrived the seizures had ended. In the following month, the family went to the hospital many times, but, on each occasion, by the time they got there the spell had ended and there didn't seem to be anything wrong. The doctors took an MRI but saw nothing unexpected, and they suggested that Lacy might have acid reflux or sleep apnea, or could even be doing it on purpose, out of anger. "But she wasn't angry," Mike said. "She was sitting there happy, and all of a sudden it hit her like a train." One doctor put her on phenobarbital, increasing the dose each time there was another seizure. "It made her lethargic, like she was drunk," Wendy said. That November, Lacy had a terrible attack. "Her arm went up in the air," Mike said, throwing his left arm straight up, stiff. "Her lips went blue. She was having them in a row." By the time the ambulance

came, the seizures had subsided, but the attendants advised the Nissleys to get in their car and take Lacy to Johns Hopkins anyway. The drive took two hours, and, just as Mike and Wendy walked over to the triage nurse, Lacy began another cluster of seizures. The nurse said, “We’ve got to get you a room.”

At Johns Hopkins, David Lieberman ordered another MRI. The scan seemed normal, and after a week of further testing Lacy was sent home without a clear diagnosis. Lieberman, in consultation with Eileen Vining and the Johns Hopkins epilepsy group, tried to control the convulsions with medication. Lacy was weaned off the phenobarbital and put on Dilantin and Ativan. They tried Diastat, Topamax, and, later, Tegretol and Keppra. But the seizures continued. When they hit, Mike and Wendy would lay Lacy on the floor and talk to her. “Every couple of minutes, she would moan and groan like she’s in pain,” Wendy told me. Mike nodded. “They said that seizures don’t hurt,” he said. “I don’t know that I believe that.” As we spoke, Lacy sat up a few times and turned to look at me. When I waved and said, “Hi,” she said, “Ba.” Twice, she smiled; once she looked completely terrified. Each time, she turned her shaky head toward her mother and nestled down.

In April, 2004, Lacy returned to Johns Hopkins for four days of continuous EEG monitoring, and again in November for another MRI. The scan showed that she had an enlarged right hemisphere. The bulge on the right made the midline between the two lobes bow slightly toward the smaller side, and there was a strange foginess on the right side of the scan, whereas the left was clear. Lieberman told the Nissleys about hemimegalencephaly. “We had a diagnosis, finally, and we were happy with that,” Mike said. “It’s not sleep apnea. It’s not acid reflux. It is something. We didn’t know if she was going to die.” Diana Pillas, who coordinates counselling at the Johns Hopkins epilepsy center, told Mike and Wendy about various possible treatments. They could try a ketogenic diet—which is ninety per cent fat and has been shown to stop convulsions in some children—but Lacy would be restricted to a special liquid formula for two years. She also told them about hemispherectomies. “I couldn’t believe it. I didn’t know people could do that and be alive,” Mike said. “The first question I had was ‘Well, what do they put in there?’ ”

After the initial shock, Mike and Wendy decided that the surgery was the best option. Lacy’s seizures had hindered her development to the point where she couldn’t walk unless she was holding someone’s hand, and she hadn’t learned how to chew. The seizures were also becoming more frequent, and they knew that children with her condition tended to live much shorter lives than their peers. The Nissleys were concerned about the costs, though. Mike worked as a butcher at a local supermarket, and Wendy, a doctor’s receptionist, had had to quit working in order to look after Lacy; no day-care program would take her. Johns Hopkins put them in touch with another family whose child had had the procedure, and who told the Nissleys about the financial aid that was available. They finally made a date.

I bumped into Mike and Wendy as I came out of the O.R. with Vining. They were smiling but tense. “We were really stressed,” Mike said later. “We were all wondering if it was the right thing to

do. No one said it, but we all knew what we were thinking.”

Neurosurgery began with trepanation, the prehistoric practice of scraping, sawing, or boring a hole in the skull. Trepanned skulls, some as old as ten thousand years, have been unearthed in Europe, Africa, Asia, and the Pacific Islands. Knowledge about the brain’s anatomy has accumulated from the time of Galen, in the second century, but neurosurgery was not recognized as a distinct specialty until the early twentieth century. Since then, neurosurgeons have saved many brains by selectively destroying some of their tissue. They’ve injected brains with pure alcohol, electrocuted them, and inserted wire loops and metal probes and wiggled them about. They have frozen brain tissue, and they have burned it. But no brain surgery is as dramatic as a hemispherectomy. “A hemispherectomy is the opposite of everything you are taught in neurosurgery,” Jallo told me. “You are told throughout your residency training to preserve the brain, get what you have to get, do your work, and leave, but with this you have to take out everything along the way.”

The first recorded hemispherectomy was performed, in 1888, on a dog by Friedrich Goltz, a prominent German physiologist. (Apparently, the post-op animal exhibited the same personality and a minimal reduction in intelligence.) In humans, the operation was pioneered by Walter Dandy, a Johns Hopkins neurosurgeon, who, in 1923, performed his first hemispherectomy on a patient with an aggressive brain tumor in the right hemisphere. The patient lived for three and a half years, until the cancer invaded the remaining hemisphere. Dandy performed another four hemispherectomies, all for patients who had brain cancer in their right hemispheres. In 1938, the Canadian neurosurgeon Kenneth McKenzie performed a hemispherectomy on a child suffering from seizures that could not be controlled with drugs. The operation was a success, and hemispherectomies came to be more popular as a treatment for chronic seizures than for cancer. But eventually the operation fell out of favor. Doctors found that, around ten years after the surgery, some patients became paralyzed or comatose, and sometimes died. This was caused by a buildup of cerebrospinal fluid, a saline-like substance that cushions the brain. The fluid is produced at the rate of about one teaspoon per minute, and in normal brains it is reabsorbed—the total supply of fluid renews itself every five hours. But in some cases the trauma of the operation seemed to prevent this, and the resultant pressure could distort the skull and push the remaining brain to one side, a condition known as hydrocephalus.

The hemispherectomy’s resurgence in popularity is largely the work of John Freeman, a pediatric neurologist who has been at Johns Hopkins nearly his entire career. Tall and charmingly gruff, Freeman is seventy-three and semi-retired, though when I visited him before Lacy’s operation he was still putting in forty hours a week in his cluttered office. “Semi-retired for a workaholic,” he said. Freeman saw a few hemispherectomies while on a training fellowship at Columbia, and started ordering them for patients at Johns Hopkins in the early nineteen-seventies. By then, hydrocephalus could be detected early, with scans, and the excess fluid drained to other parts of the body, where it was reabsorbed naturally. In the early nineteen-eighties, he proposed the treatment, for the first time, for a patient with a diseased left hemisphere—a thirteen-year-old girl who suffered such

uncontrollable seizures that she had spent several months in the intensive-care unit. The prospect of removing a left hemisphere—rather than a right one, as had been the case in previous operations—was daunting. It is generally thought that language is situated in the left half of the brain, and no one could say for certain what the effect of removing that hemisphere would be. “We worried about that,” Freeman said. “What would your life be like if you couldn’t talk, and you couldn’t understand, and you were just there and aware?” While a number of the hospital’s faculty approved the operation, an outraged senior physician vetoed it. But the only alternative, Freeman observed, was for the girl to remain in intensive care for the rest of her life, so the following week, when the doctor in question was away, Freeman went ahead and arranged the operation. “Can you imagine doing a hemispherectomy without the assurance that the patient would talk?” he asked. The operation was a success, and the girl recovered the ability to speak. “Now,” he said, “I can tell the families: they all talk.”

If Freeman revived the practice of hemispherectomies, their leading practitioner has been Ben Carson, who joined Johns Hopkins in 1984 and, at thirty-two, became the youngest head of pediatric neurosurgery in the nation. A star in his field, Carson has written a book about his transformation from angry teen-ager in Detroit to renowned neurosurgeon. He did his first hemispherectomy a year after coming to Johns Hopkins. The *Washington Post* wrote a story about it, and soon the hospital was getting calls from doctors all over the country saying that they had patients with intractable seizures whom they wanted to send. Carson has now performed more than a hundred hemispherectomies. One of his oldest patients had the surgery in his thirties.

Carson’s office, like Freeman’s, is strewn with files, books, and X-rays, and there is an abundance of photographs, cards, honorary Ph.D.s, and gifts—a hanging plate painted with poetry, a framed sampler embroidered with “Dr. Carson,” and, on the windowsill, a statuette of a handsome black man in a white doctor’s coat who looks exactly like Carson. In person, Carson is mild, tired, and friendly. He told me that when he started doing hemispherectomies he would reach in and slice out an entire hemisphere at once. But he modified this practice after one patient went into a coma for a month. Carson believes that the patient’s brain stem was moved about excessively during the procedure. “It’s too much like what I’m doing right now,” he said, grappling with a plastic model of the brain in an effort to pop out a recalcitrant lobe, which eventually shot off into the mess on the floor. I asked him Mike’s question, about all that space left by the missing lobes. In the past, he said, doctors worried about this and tried to anchor the remaining brain by stitching it to the dura. They would put all kinds of things in the cranial cavity—one surgeon used sterile Ping-Pong balls. But, as Carson did more hemispherectomies, he realized that the brain’s own drip of cerebrospinal fluid could adequately fill the cavity. Sometimes the remaining brain moves during the weeks following the surgery, but usually by less than an inch. “It doesn’t seem to be a problem,” he said. Much of Carson’s method is intuitive. “You develop a feel for the brain,” he said. “Normal brain feels like a very soft boiled egg. A bad brain feels like a mushy apple.”

Freeman and Carson haven't merely pioneered the surgery; with their colleagues at Johns Hopkins, they have undertaken research into the effects of hemispherectomy on behavior, language, and psychology. "We as a group here in pediatric epilepsy have changed the way children are handled," Freeman told me. "It's not just the surgery; it's the network and the contact. It's the best thing I've ever done, and I don't even do them." Freeman and Carson are in the process of handing the practice over to Eileen Vining and George Jallo. Each doctor somehow resembles his successor. Freeman and Vining are obsessive clinical researchers and vigorous wranglers of surgeons, doctors, and patients. Jallo, like Carson, has a quiet intensity and the gentlest of handshakes. When I asked the surgeons how it's possible for people with half a brain to live, let alone have a life, each of them spoke about plasticity, flexibility, redundancy, and potential, and then they smiled and said the same thing: "We don't really know."

“A fter I got this car, I noticed so many CR-Vs,” Christina Santhouse said. “I guess you notice them after you get one.” Christina was driving a nice, steady five miles per hour above the speed limit on the way to the Bristol Pike Lanes bowling alley, in Croydon, Pennsylvania. She recently turned eighteen and got her license on the second try. Her family outfitted her Honda CR-V with an extra-long rearview mirror, additional side mirrors, a knob on the wheel for steering, and a rod that brings control of the indicator over to the right side. As an eight-year-old, Christina played soccer, swam, and did karate. Then she contracted Rasmussen's encephalitis, a little-understood condition that causes chronic inflammation of the brain. One day at the Jersey Shore, her foot started twitching, and within a few months, as the right side of her brain deteriorated, she was having hundreds of seizures a day. Christina became Johns Hopkins hemispherectomy case No. 30—her surgery took fourteen hours, one of the longest operations Carson has performed. The alterations to Christina's car are necessary, because she has impaired motor function on her left side. (Each hemisphere of the brain primarily controls the opposite side of the body.) She also lost sight on the left side of each eye, and now wears prism glasses that bring the left field of vision over to the center of the eye. When I met her, she had taken her S.A.T.s and just finished high school, coming in seventy-sixth in a class of two hundred and twenty-five. Last fall, Christina was a freshman at College Misericordia, in Dallas, Pennsylvania, where she's studying speech pathology.

When we pulled into the parking lot of the bowling alley, she parked in the same spot that she always used. She wore jeans, a college hoodie, pink nail polish, and Skechers sneakers. A small brace beneath her jeans kept her left leg straight, though she still had a slight limp, and her left arm was partly paralyzed. "I can do this"—she shrugged her left shoulder, moving it and the arm around. "I can't do this"—she twinkled the fingers of her right hand at me. Christina booked us a lane and we sat down to put on our bowling shoes. She was on her high-school varsity bowling team for four years, and in her final year she was captain. She pulled a leather glove onto her right hand with her teeth and then insisted that I go first.

I knocked down eight pins, and Christina knocked down six. "I get really nervous and my arm gets

stiff,” she said. “Also, I haven’t practiced for a month. And the finger holes in my ball are cold.” In the next round, I knocked down seven pins, and Christina bowled a strike. As the game continued, my score lagged, while Christina bowled spare after strike after spare. Her ball weighed fourteen pounds. I’m at least seven inches taller, so I started out with a sixteen-pound ball. After almost losing it on the first backswing, I changed to a fourteen-pound ball. As my elbow began to ache, I moved to a twelve, then a ten. Christina doesn’t have the balance necessary to run and throw the ball, so she positions herself at the bottom of the lane, crouching slightly and swinging it like an underhand discus. I tried bowling like Christina. She coached me on where to stand and what to aim for, but my first ball, deprived of the momentum that comes from a running walk to the edge of the lane, dropped straight into the gutter. The second time, I swung harder and my ball rolled just a little farther before it hit the gutter. On the third try, I knocked down one pin. Christina explained that you have to work out which side you’re stronger on, and step to that side as you swing. Her final score was a hundred and seventy.

Christina is a spectacular example of how well children can do after a hemispherectomy, but she is no outlier. Many children who have had hemispherectomies at Johns Hopkins are in high school, and one, a college student, is on the dean’s list. The families of these children can barely believe the transformation, and not so long ago neurologists and neurosurgeons found it hard to believe as well. I asked Jallo if he remembered his first hemispherectomy. “Yes and no,” he said. “I don’t remember the patient. It was more of a ‘Wow.’ I was a resident in training and I assisted in one of the operations. I didn’t realize you could take out that much brain tissue and have someone be so functional and useful in society. What amazes me is that, if someone all of a sudden strokes out half of the brain, more likely than not they are not going to survive. Yet a lot of these people develop their seizures when they’re very young, or in utero, and when you take out half of their brain in one sitting it’s as if they weren’t touched.”

There are wide variations in recovery, and any brain surgery carries grave risks. Many factors affect how well a patient does—age at the time of a condition’s onset, age at the time of the operation, the nature of the condition itself, and the determination of parents and caregivers to maintain an intense schedule of therapy before and afterward. Possibly the greatest danger is posed by the brain’s veins and arteries, which are so numerous and so wildly, individually arranged that they are impossible to map and very hard to control. Excessive bleeding can send patients into shock and then into comas from which they never return, or it can wipe out most brain function. The other conflicting challenge of the surgery is the necessity of making sure that enough tissue is removed. Freeman once saw a small boy who made good progress for six months following a hemispherectomy, after which he began to deteriorate. His doctors discovered that they had left a small piece of the excised hemisphere in the child’s head. It was, said Freeman, no larger than the top joint of his thumb. But the electricity from that piece of neural tissue was enough to compromise the remaining hemisphere. The boy had another operation, a “redo,” as the doctors at Johns Hopkins informally call it, in which the bad piece of brain was removed. After that, he had no more seizures.

The brain's remarkable capacity for recovery has long fascinated scientists. Bradley Schlaggar, a pediatric neurologist and a professor at Washington University in St. Louis, told me about an experiment that he conducted for his Ph.D. He transplanted the visual cortex from an embryonic rat's brain into the brain of a newborn rat, placing it in the spot occupied by the somatosensory cortex, which is responsible for such bodily sensations as pressure and temperature. Once the second rat had grown up, Schlaggar took a look at its brain and discovered that the transplanted chunk of visual cortex was functioning as a somatosensory cortex. Such a basic architectural feature of the brain was thought to be entirely hardwired, but Schlaggar showed that brain tissue could reprogram itself to serve different purposes. In another experiment, Leah Krubitzer, a professor of psychology at the University of California, removed large pieces of the brains of newborn marsupials. Once the marsupials became adult, she examined the brains again and found that they had organized themselves in such a way that the visual, auditory, and other somatosensory areas were all in the same relative positions that they would occupy in a normal brain, but they were smaller, commensurate with the total space available.

Schlaggar said that, in the mid-eighties, researchers invoked plasticity to explain the brain's ability to compensate for sudden damage—as when a stroke victim relearns to walk or talk. Now, Schlaggar said, the concept is used to describe a far more basic operation of the brain, including how it develops from childhood to adulthood, and even how an adult brain changes when a new skill is learned: “The idea is that when you talk about plasticity you are talking about every bit of learning that we do.” For a long time, the assumptions that neuroscientists made about what was going on in a child's brain were based on how the adult brain worked. But now it seems that the brain's internal configuration depends on the age of the brain. If an eighteen-year-old's brain sustained some kind of damage, Schlaggar explained, it would occur in neural terrain that is organized differently from, say, that of a two-year-old, even if the injury was in the same spot. Children with damage to a particular area of the brain often suffer losses that are different from those sustained by an adult who experiences the same trauma.

When Schlaggar lectures on plasticity, he shows slides of the construction of the St. Louis Arch. “As the structure goes up, the relationship between the scaffolding and the leading edge of the two sides of the arch change as they rise up to meet in the middle,” he said. “The interaction between the scaffold and the emerging mature structure is dynamic.” The ever changing scaffolding of the developing brain, Schlaggar said, means that the functional organization of the brains of children performing a task can look quite different from that of adults engaged in the same task. If you show seven-year-olds and thirty-year-olds a word and ask them to generate a verb for that word, the two groups can do so with equal accuracy and in the same amount of time, but they use slightly different regions of the brain to arrive at their answers. Children, Schlaggar explained, use extra regions of the brain during their development which, like scaffolding that falls away, are no longer needed when the brain's architecture is mature.

Although the plasticity of Christina's brain in the years following surgery has enabled her to live a

remarkably normal life, other aspects of her experience have been hard. When we were alone in the car, Christina told me about years of social difficulties. “I didn’t tell many people at high school, but it kind of got out,” she said. She didn’t make friends until junior high. A few years after the operation, one of her mother’s relatives phoned to say that there was a photograph of Christina in *The National Enquirer*. Before going to Misericordia, Christina hoped for a fresh start, but when she spent an introductory night there her roommate showed her a photocopied article about her hemispherectomy. A psychology professor had handed them out to her class.

After bowling, Christina drove me to her home and I spoke to her mother, Lynne, and her grandmother Mary Lou. We looked at photographs taken the day of the hemispherectomy, and we watched a video of Christina at Johns Hopkins before the surgery. She is sitting on a bed, and her foot begins to twitch. Within seconds, the twitches multiply and cascade through her body, and she falls back onto the bed completely helpless. In another video, Carson strides from the O.R. after Christina’s hemispherectomy. He looks utterly invigorated. Lynne, waiting outside, clasps his hands and then crumples before him in tears.

The day after Lacy’s surgery, Jallo came by early to visit her. She was moving her right arm and leg weakly, and her color was good. The next day, she started to run a fever, and then she had the worst seizures she’s ever had—three in a row, each ten minutes long. This was not unusual—most practitioners think it’s caused by the trauma of the operation—but it wasn’t good. The doctors adjusted her medication, and over the next few days she improved. When I phoned Mike, he said that, four days after the surgery, she had been out of bed a few times to be held in her mother’s lap. “She’s not doing much of anything on the left side,” he said. The left side of Lacy’s body had always been weak, because it was controlled by the damaged right hemisphere. With that hemisphere gone, Lacy would need a year’s intensive therapy to remind her brain of the existence of her left arm and leg. Three weeks after the surgery, Lacy’s staples were removed and she was released from the hospital.

On a wet October day more than two months after the operation, I drove back to Palmyra. As I pulled up to the house, I could see two small heads at the front window. Lily and Lacy were standing side by side on the couch, peering out. The doctors had told Mike and Wendy that it could take Lacy six to twelve months to get back to where she had been before the operation, but since July she had made extraordinary progress. “We thought she’d be a blob for a few months,” Mike said. “But once she started eating and got her strength back she was straight at it.”

We sat again in the living room. Lacy was pale and skinny, and her white-blond hair was an inch long. The scar underneath was barely visible. She was in constant motion, crawling and walking about on her knees. Sometimes, when she crawled, she dragged the knuckles of her left hand on the floor. She babbled and squealed, and she said “Yeah” when I asked her how she was. She helped herself to a bottle of milk and drank from it while she idled on her knees. She surfed around the furniture and stood at an activity table in front of me. When I held out my right hand to her, she wobbled for a second and then grabbed it with her left hand. She swung her right hand around, placed it on top,

paused, and was off again. Then she sat with her back to me. She kept looking over her right shoulder to see if I was still there, then looking away. “She’s really silly all the time,” Mike said.

A month after the operation, Lacy began seeing a physical therapist, an occupational therapist, and a speech therapist on a regular schedule. The speech therapist would talk with her face right up against Lacy’s, and after a few sessions Lacy began moving her mouth to mimic the therapist. She learned some sign language, and used the sign for “more” a lot at the dinner table, where she could now eat the same food as her family. She still had to take the anti-convulsants Tegretol and Keppra twice a day, and the doctors thought that it would be a year before she could stop. But there had been no more seizures, and, the week before I visited the Nissleys, Lacy had taken three steps by herself for the first time.

By early December, Lacy was walking everywhere, and in January the family returned to Johns Hopkins for a scheduled checkup. In Jallo’s report, he wrote that Lacy had done beautifully. She had had no seizures, and she was babbling and walking independently. She was “a happy child.” Lacy still showed a clear preference for her right side, but he wrote that he hoped for an improvement in tone and a loosening up on the left side.

For two months after that, Lacy walked and played, but in March she had a setback. Wendy put her down for an afternoon nap, and about fifteen minutes later she had a seizure. Wendy said, “She just woke up, instantly, with her eyes bulging out.” The seizure lasted a few seconds, and afterward Lacy rolled over and went to sleep. She woke up happy. Everything was fine for a few days, but then she had another seizure, again about fifteen minutes after she had fallen asleep. “We were shocked,” Wendy said. “Lacy went about seven months without any seizures. It is disappointing.” The seizures increased steadily—after about a month, there were a few every day, each lasting five or six seconds. According to Wendy, Lacy didn’t appear particularly distressed by them, though occasionally they made her more tired. “We are not sure what the next step will be,” Wendy said, but she and Mike remained optimistic. For Lacy’s third birthday, they had a big cookout in a rented pavilion at a local park beside a lake.

When Wendy drove Lacy back to Johns Hopkins, Vining was thrilled with her general progress. Developmentally, she said, Lacy was fulfilling expectations, and even the recurrence of the seizures wasn’t unduly alarming. “They are very mild,” she said. There were no signs of them on the EEG and they lasted, in total, less than a minute per day. Vining speculated that Lacy might have outgrown the dosage of one of her anti-seizure medications, and she increased it. After a few weeks, however, there was no improvement; the seizures were lasting longer, and had begun to show up on the EEG. Vining switched Lacy to a different anti-convulsant, Trileptal. Another possible cause of the problem was the tiny nub of occipital lobe that Jallo had left in Lacy’s brain during the operation. I asked Vining whether Lacy would ever need a “redo” to remove that final piece of the right hemisphere. She explained that only time would tell. Vining was hopeful that the new drug would solve the problem. If it didn’t, she said, they would have to think seriously about going in again. ♦

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