

Dream

Understanding encephalitis

At age 5, Collin Goodchild faced a mysterious foe—and an uncertain future

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For parents, families and friends of Children's Hospital Boston

Winter 2011 | childrenshospital.org/dream



CHOOSING the challenge

As part of her treatment for a rare leg cancer, Caitlynne McGaff chose an unorthodox treatment—and a more active life. **PAGE 6**



Children's Hospital Boston

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Visit Children's blog, *Thrive*, for these online exclusives:

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Remembering Aidan

One patient's story: My toddler's head injury

What do kids learn from nonverbal TV shows?

Does the medical community do enough to reach out to the LGBT youth?

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WINTER 2011

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Encephalitis had Collin Goodchild's parents terrified and his doctors and nurses searching for answers. Neurologist Mark Gorman, MD, looked at an old problem in a new way to try and get Collin his future back.



 **Thrive**, Children's Hospital Boston's pediatric health blog, is updated every day with inspiring stories and the latest news in pediatric health. Visit childrenshospitalblog.org to check it out.

SNIPPETS

IN HER OWN WORDS

The strain of childhood illness

By Shannon Kaiser

Shannon Kaiser, a mother of two chronically ill children, shares how her family handles the stress created by her kids' medical conditions.

If you drove by my house this morning, it would've looked like a scene from an old TV show. Lunches were handed out, good-bye hugs given, and in a blur, three of my kids were out the door, laughing and running toward the big yellow school bus at the end of the street. Seems picture-perfect, doesn't it?

What you won't see is a mother who cries after the door is closed. A mom who's tired and scared but doesn't have time to dwell on it because she's needed elsewhere—to clean feeding tubes, prepare heparin flushes or start making arrangements for her son's brain surgery.

You also won't see a dad who's worked three double shifts in a row to stay ahead of the medical bills. You won't see him on his day off, too tired to be the father or husband he wants to be.

This is reality for our family, and we're not alone. My husband and I are like thousands of other parents with chronically ill children, struggling to take care of our kids and ourselves.

In 2003, our son Sean was born with Chiari malformation, meaning the bottom part of his cerebellum sticks through his skull and down into his spinal canal. It can be extremely painful. He's already undergone one surgery, and at age 7, he's getting ready for a second. It's scary, but we know his neurosurgeon at Children's Hospital Boston, Dr. Benjamin Warf, will do everything he can to help Sean.

On top of Sean's needs, our 4-year-old daughter, Brigitte, was born with Noonan syndrome, a genetic disorder that affects various parts of the body. Brigitte's case is more severe than most and treatment is hard on her. We see roughly 14 specialists at Children's, but her favorite is Dr. Daniel Kamin, of Children's Gastroenterology department. We're at the hospital a lot so it's not unusual for the halls to echo with the sound of Brigitte calling, "Kamin, come here!" She beams when she sees him, and his devotion to her is a great source of comfort to our family.

While we're thankful for the amazing care our kids receive, it's still a lot to deal with. People often ask, "How do you do it?" Honestly, I don't know how to answer. There are days when I just want to crawl under the covers and hide, but I know shutting down isn't an option. I have to find ways to cope.

One thing that has helped me is writing. When I started blogging, I noticed that most blogs about parenting sick kids focused on how well everyone is doing. I admire the authors' strength, but sometimes wonder if they're really as together as they seem. When I write, I strive to be honest. I don't want pity from my readers, but understanding. The parents of children with chronic illnesses aren't begging for sympathy, but that doesn't mean they're superheroes all the time. Sometimes we need to vent, cry or both. It gives us a moment to recharge our batteries. For families like ours, if you're not overwhelmed every now and again, you're not grasping the reality of the situation.

I think it's important for moms and dads of sick kids to embrace some of that fear and uncertainty. It's empowering. It drives us to do things most people can't imagine doing. It helps us help our kids.


That's not to say it makes things easy. The fear and strain caused by our kids' medical conditions has made life a struggle, but anything worth having is worth fighting for. So we continue to fight; for our kids' health, for our marriage and for a semblance of a "normal" life.

And we find coping strategies. I'll keep writing, my husband will continue to work overtime and our children will learn that life isn't fair, but it's worth fighting for. It will make them more compassionate people and we'll all be stronger for it. And thanks to great doctors like Dr. Warf and Dr. Kamin, we get to strengthen as a family. That makes all the fighting seem worthwhile.



GIVING CONSTANT MEDICAL CARE to Brigitte and Sean, two chronically ill siblings, can be hard on their parents.

MORE AT CHILDRENSHOSPITAL.ORG/DREAM/WINTER11

 Read about a mother who discovered she had to care for herself before she could care for her sick child.

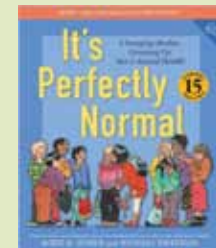
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Shark Girl



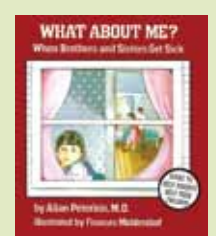
It was another day at the beach for Jane Arrowood, until a shark attack took her arm. *Shark Girl* gives readers a glimpse into a girl's personal struggle with physical loss. Read "Choosing the challenge" on page 7.

It's Perfectly Normal



With unbiased answers to many "birds and bees" type questions, *It's Perfectly Normal* offers young people important information about growing up. Read "Precocious puberty" on page 10.

What About Me?: When Brothers and Sisters Get Sick



Laura is scared and jealous of the attention her younger brother receives when he becomes sick. It includes suggestions for parents to help their well children cope with a chronically ill sibling. Read "Things are looking up" on page 12.

Parenting Children with Health Issues



This book offers plenty of advice for parents who are raising kids with chronic illness, medical conditions and other special health care needs. Read "The strain of childhood illness" on page 3.

All books are recommended by Alison Clapp, Children's Hospital Boston's librarian

What's on the (You)Tube

YouTube is the world's most popular video sharing web site, and with over 12,000 visits a month to Children's YouTube page, we're right in the middle of it all. Subscribe to youtube.com/ChildrensHospital to see great videos about the research, patients and staff that make Children's a leader in science-driven care.



Dream magazine is now interactive!



Visit Children's Hospital Boston's Youtube page



This interactive issue of Dream uses Quick Response (QR) code technology, allowing you to find out more about featured articles via your smart phone. Simply download a QR reader application in your smartphone's app store (we recommend i-nigma) and use it to scan the barcode next to selected articles. It's a free service, but standard data rates may apply based on your telephone provider.



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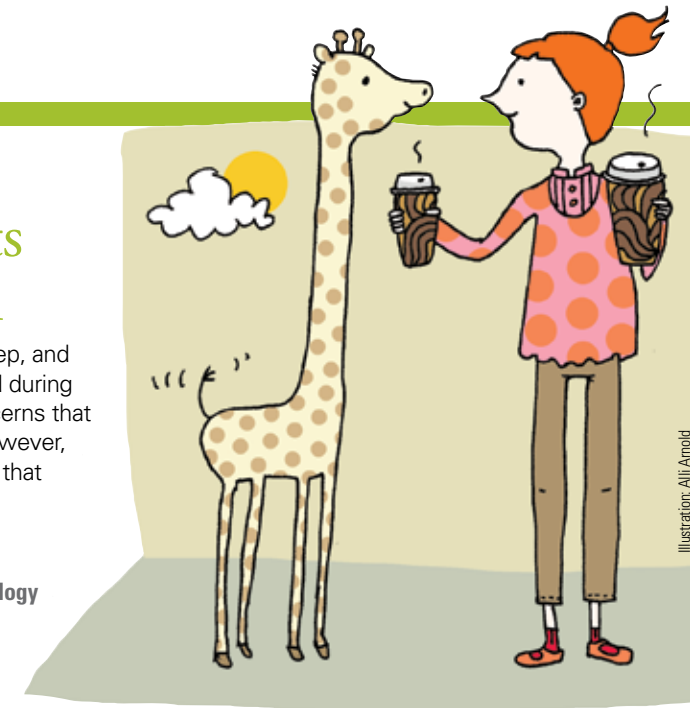


FACT OR FICTION?

Coffee stunts your growth

Since coffee may impair sleep, and growth hormone is secreted during sleep, there have been concerns that coffee will stunt growth. However, there are no data to support that assertion.

—Laurie Cohen, MD, Director of NeuroEndocrinology



Illustrator: Alli Arnold

Q & A

School refusal

School refusal, which affects around 4 percent of school-aged children, can lead to long-term school absence and have serious consequences if left untreated. We spoke with Jayne Singer, PhD, clinical psychologist in Children's Hospital Boston's Developmental Medicine Center, to learn more

Q: What should a parent do if her child refuses to go to school?

A: Treatment depends on the root cause, so moving quickly is crucial. A child who's afraid to leave her mother requires very different management than a child who has a phobia of a fire alarm. The longer the child is allowed to stay home, the harder it is for the her to get back into the routine of feeling comfortable in school. So the sooner the root is identified and treated, the better.

Read the rest of the Q&A about school refusal

WHITE COAT QUOTE

"If the standard for what [body type] is considered desirable is that much harder to obtain, it may lead to more young people developing eating disorders in order to achieve it."

—Alison Field, ScD, from Children's Hospital Boston's Division of Adolescent Medicine, on whether the culture's focus on childhood obesity could be leading to more eating disorders.

CONCUSSIONS ARE A HOT TOPIC RIGHT NOW. HERE, BY THE NUMBERS, IS THEIR IMPACT ON KIDS ACROSS THE COUNTRY.

473,947

Number of emergency room visits each year by children ages 0 to 14 years for traumatic brain injuries (TBIs).



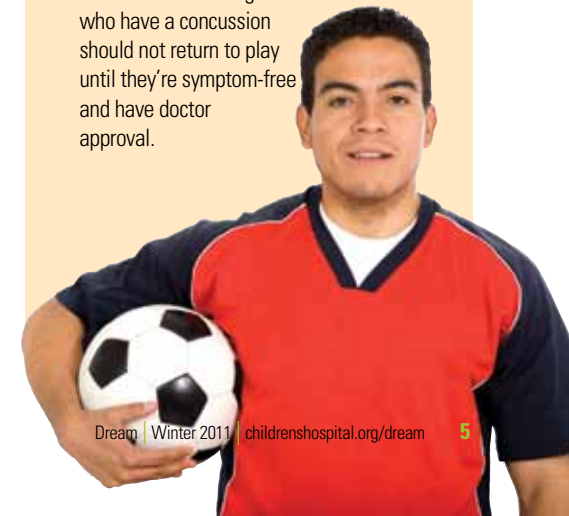
75 percent of TBIs are concussions.

2x

Children that go to an ER for head injury treatment are nearly twice as likely to experience another head injury as a child who hasn't sustained one.

0

The number of concussion symptoms a child athlete can display before being allowed back in the game. Athletes who have a concussion should not return to play until they're symptom-free and have doctor approval.





CAITLYNNE MCGAFF ties her ice skates onto her prosthetic foot at Boston's Frog Pond. The rotationplasty procedure has helped Caitlynnne stay as active as she was before her cancer diagnosis

Photos: Wehbi Chappell

CHOOSING the challenge

As part of her treatment for a rare leg cancer, Caitlynnne McGaff chose an unorthodox treatment—and a more active life.

By Joshua Feblowitz

It all began with a troublesome pain near Caitlynnne McGaff's right knee. At the time, it didn't seem like there was anything to worry about: An occasional bruise or bump was typical for the energetic 7-year-old, who was involved in a wide range of athletic activities, including gymnastics, ice-skating, basketball and soccer. The pain in her leg, her parents thought, was no doubt the result of this active lifestyle, a minor injury that would go away on its own. Yet week after week, Caitlynnne's leg continued to bother her.

It was only by chance during a routine check-up that the issue came to the attention of the family's doctor. What followed was a battery of medical tests to find the source of her persistent pain. Day after day, Caitlynnne's right leg was poked, prodded and scanned by an array of medical specialists. "I was definitely scared," recalls Caitlynnne. "I was going from test to hospital to nurse to doctor, being asked questions." After a whirlwind of medical detective work, her doctors shared the unthinkable diagnosis: cancer.

Caitlynnne had a bone tumor known as an osteosarcoma growing just above her knee, the most common location for this aggressive tumor. The eighth most common cancer in children, osteosarcoma is still a rarity, affecting only about 600 children per year in the United States. To have a chance at a cure,

Caitlynnne would need intensive treatment, including both chemotherapy and surgery.

There was hardly any time to process this news. Chemotherapy started right away, a jarring new reality that put a stop to her many activities. The treatment made her hair fall out and left her listless and constantly nauseous. Yet through it all Caitlynnne stayed strong with the help of her family who did whatever they could to make the long hospital stay more bearable. "My dad started doing what he called a 'brave bank,'" she says with a smile. "Every time someone said, 'you're so brave' he had to give me a quarter. It was little things like that helped relieve my fear and stress."

Weeks into Caitlynnne's chemotherapy regimen discussions began about the second phase of treatment. The chemotherapy could only do so much; the tumor, as well as the bone and tissue around it, would have to be removed to give Caitlynnne the best shot at a cure. Children's Hospital Boston orthopedic surgeon Mark Gebhardt, MD, explained the options to the family: Caitlynnne could have an allograft (a donated bone), an implant made of metal and plastic, or a type of partial amputation known as a rotationplasty.

A rotationplasty is a surgical procedure that is both elegantly simple and medically unusual. "You're basically amputating the part with the tumor except for the nerves," explains Gebhardt. "Then you take the upper

SARA SWAIM, RN, BSN, and **MARK GEBHARDT, MD** helped Caitlynn decide which option was best—and how to live life to the fullest once the surgery was over.



end of the shinbone and you attach it to the thigh bone. In the process of doing that, you rotate it 180 degrees so the ankle becomes adjacent to the opposite knee." The result is a new "knee" formed by the rotated ankle and foot.

Though dramatic, the surgery offers better mobility than a traditional amputation, allowing children to still have a functional "knee" made up of what used to be their ankle. And unlike a typical amputation, patients don't experience any phantom pain, the aches and other sensations that amputees sometimes feel from the limb that's no longer there. It also offers advantages over an allograft or implant, Gebhardt explains, which would not only limit Caitlynn's activities, but also require more surgery as her bones grew. "If you use a metal prosthesis or an allograft," he says, "you can't do as many things athletically because they can loosen or break."

However, a rotationplasty also comes with one major disadvantage: the unusual appearance of the child's new leg, a backwards foot where the knee used to be. The way the leg ultimately looks, says Sara Swaim, RN, BSN, an experienced orthopedic nurse at Children's, "is the factor that's difficult for people to move beyond."

This abnormal-looking result, says Gebhardt, is what makes the surgery controversial. "You're doing an operation where you're removing the tumor, but you're also ending up with a deformity. Most of the time in medicine we don't create deformities. And so some surgeons absolutely won't do it." Yet, for the right patient, says Gebhardt, the rotationplasty has powerful advantages, allowing them to maintain an active, athletic lifestyle without any limitations.

For the McGaff family, it came down to a single, wrenching choice between Caitlynn's active lifestyle and a normal-looking leg. What made this choice a little bit easier, says her mother, Doreen, was the chance to meet with children who had both types of surgery. As the McGaffs weighed the options, they met with a young girl about Caitlynn's age, Olivia, who had gone through the very same surgery. "It's such a different procedure, it's hard to wrap your mind around it," remembers Doreen. "You can see pictures, but you just don't get it until you can see somebody and you can see how well they're functioning."

Even after the meeting, Caitlynn's parents were still torn, but the time for a decision was drawing near: Caitlynn was scheduled for surgery only a week later. So they presented the options to her. "We felt like she should have a say, even though she was only 7," says Doreen. "It's her body."

Caitlynn knew she wanted to have an active life. She wanted to jump and run and play outside. She wanted to join her parents and younger brothers in any adventures the future might hold. Together, Caitlynn and her parents made the decision to have the rotationplasty, says Doreen, "and there's been no looking back."

At first, Caitlynn says, it was difficult to adjust to the new sensations and her leg's appearance after surgery. "I was learning how to move my 'ankle,' which is used as my knee," she says.

"It was weird. It also didn't help that I got questions and stares everywhere."

Physical therapy was also extremely challenging, recalls Caitlynn. "It was so hard, so frustrating to not be able to just walk or run normally." She first had to adjust to moving her foot in a completely new way and then to using a prosthetic lower leg that fit over her new "knee".

But Caitlynn stuck with it. Within a few months she was back to walking, and by the end of the year, she could run, jump and even do gymnastics again. "I could still do everything that I could do before," she says. It was almost like there was no change at all except that it looked different."

Since the surgery, Caitlynn's parents have gone to great lengths to help her be active and independent, hiring special instructors to help her get her athletic talents back. "We never want to even present the idea that she might not be able to do something or might not do it as well," says Doreen. "We just didn't want to put that in her head."

All of Caitlynn's hard work and her parents' love and support have paid off. Today, she is cancer-free and walks without a hint of a handicap. The only sign of her year-long ordeal is the faint metallic gleam of her prosthesis beneath her leggings. She's a sophomore at Boston Latin High School, where she's involved in softball, show choir, singing and acting. In her free time, she rock-climbs, water-skis, ice-skates and plays softball. Although she lost her leg, the rotationplasty allows her keep pace with her friends and family members.

"I've been told that I can live a normal life," says Caitlynn, "so that's just what I've been doing."

[MORE AT CHILDRENSHOSPITAL.ORG/DREAM/WINTER11](http://CHILDRENSHOSPITAL.ORG/DREAM/WINTER11)

Watch a one-time patient describe how her care at Children's inspired her to want to become a nurse.

Read about the latest cancer research done Children's.

Watch a video of Caitlynn water skiing, playing softball and swimming.

Find out what this is on page 4



RESEARCH BRIEFS

THE LATEST DISCOVERIES FROM CHILDREN'S RESEARCHERS

Children's launches Vector, a science and innovation blog

Vector is Children's Hospital Boston's new blog covering hot and timely topics in science and innovation, with a special focus on scientific, business and policy issues. The blog is written by and for scientists, clinicians, inventors, innovators and followers of the latest discoveries, topics and trends in science and medicine.

Replacing Children's print magazine of the same name, Vector blog is a timely, quick read designed to bring readers up to date on the latest news from Children's and beyond.



Watch a video of Dr. Rossi's breakthrough research.



Find out what this is on page 4



Children's researcher honored by TIME magazine

Children's researcher Derrick Rossi, PhD, was named one of the "People Who Mattered" in 2010 by *TIME* magazine. Rossi is an investigator at the Immune Disease Institute/Program in Cellular and Molecular Medicine at Children's. His research led to the invention of a safer method for creating pluripotent stem cells, a scientific breakthrough that received widespread coverage in the medical community and mainstream media.

New national study examines concussion management in high school sports

A new study co-conducted by researchers at the Sports Concussion Clinic at Children's examined concussions in high school students, using state-of-the-art computerized neuropsychological testing. Injured student athletes who received the tests were less likely to return to play within one week of being diagnosed with a concussion, lessening their chances of sustaining a second, more dangerous, head injury. This is the first national study to describe the mechanism, symptoms and management of sport-related concussions in U.S. high school athletes and could prove important in preventing young athletes from getting multiple concussions.

Children's is key player in largest genomic study of deadly brain tumors

Medulloblastomas are the most common—and among the most deadly—malignant brain tumors of childhood, and the nature of each tumor varies greatly from patient to patient, making standardized treatment difficult. In the largest genomic study of human medulloblastomas to date, researchers from Children's, together with collaborators, have identified six tumor subtypes with distinct molecular "fingerprints" that will improve doctors' ability to direct and individualize treatment. Recognition of tumor subtypes will allow patients who need the most aggressive interventions to get them, and let patients with better prognoses avoid treatments that may carry potentially long-term neurological and cognitive side effects.

[MORE AT CHILDRENSHOSPITAL.ORG/DREAM/WINTER11](http://CHILDRENSHOSPITAL.ORG/DREAM/WINTER11)

Watch a video chronicling the many talents of Leonard Zon, MD, director of the Stem Cell Program at Children's.

Learn more about the current state of spinal cord repair.

Will a child's early exposure to germs affect his immune system when he's older?





Jon R. 10

Illustration: Jon Reinert

PRECOCIOUS puberty

By Tripp Underwood

For most parents, few developmental milestones are more dreaded than their daughters starting puberty. The idea of their sweet, innocent little girl turning into a moody, hormonal young woman is enough to keep most moms and dads up at night. The only saving grace for some of these parents is the belief that puberty is still years away.

But what if, even with a daughter still in kindergarten, the physical and emotional rollercoaster ride of puberty is lurking just around the corner? According to a recent study by the American Academy of Pediatrics, this is reality for more and more American families. The study followed girls of various ethnicities, locations and backgrounds, and found that by 7 years old, more than 10 percent of Caucasian girls and 23 percent of African-American girls showed signs of breast development, indicating that puberty has begun.

There are plenty of theories about what's causing the shift, but most lack scientific backing. Environmental factors like an increase in the amount of hormones found in food or continued exposure to household toxins like bisphenol A (BPA) are often blamed, but based on current data, many in the medical community feel their role in earlier-occurring puberty is overstated.

"There are studies suggesting that BPA and other endocrine disruptors can cause changes in pubertal development in animals, but data on how this relates to humans is limited," says Diane Stafford, MD, assistant clinical director of the Division of Endocrinology at Children's Hospital Boston. "Given the complexity of pubertal timing, and the number of things we still don't know about it, it's difficult to make a clear cause and effect association between any particular environmental exposure and changes in the timing of puberty."

An increase in the average weight of American children is also believed to be a factor. Girls who are overweight may grow faster and go through puberty earlier, and being overweight makes it more difficult to distinguish between fatty breast tissue and true breast development. However, when data from older studies of the timing of puberty are adjusted to account for an average increase in body mass, the numbers still indicate that girls are hitting puberty slightly earlier, regardless of weight.

One of the biggest concerns with precocious puberty is the effect it will have on the child's adult height, since most of a person's adult height is achieved during pubescent growth spurts. But children who enter puberty at a young age often finish growing early as well. By the time they reach adulthood they are often much smaller than their peers who grew steadily until their early teens.

Emotionally, early puberty can lead to a number of difficulties, from self-esteem issues to an increased likelihood of taking unnecessary risks. How a young girl reacts to the changes in her body—and how others react to her as a result—can make the preteen years very difficult for girls who start developing before they're mentally prepared.

"There are plenty of children who are not psychosocially capable of handling the emotional and physical changes of an early puberty," says Stafford. "The most common concerns for these kids are that they're more likely to feel different than their peers and become an easier target for bullies."

There is also concern that they're more likely to have sexual contact before they're cognitively ready."

In cases where an early puberty may pose serious physical or emotional problems, there are medical treatments that can delay the process until the child is old enough to handle the change. In addition to counseling, a drug is introduced into the patient's system that quiets signals from the brain to the ovaries, reducing the rate of estrogen production and slowing the body's transition to adulthood. Then, when enough time has passed and the patient is ready, treatment is stopped and the body naturally picks up where it left off. The procedure is proven to be safe, but as Stafford points out, the decision to use drug therapy for conditions that don't directly threaten a patient's health can't be made lightly.

"The decision to halt puberty with treatment is more subjective than most things we do in medicine," she says. "So everything you do must be looked at on a case-to-case basis to ensure it's the right course of action for the patient."

Not surprisingly, most parents who opt to have their child undergo puberty-suppressing therapy have a harder time ending treatment than they do signing up for it, especially the fathers.

"Picking a time to end therapy can be particularly tough for dads, who have a hard time letting go of their 'little girl,'" she says. "But no matter how hard the decision, I always remind them that puberty isn't a disease, it just feels that way sometimes."

[MORE AT CHILDRENSHOSPITAL.ORG/DREAM/WINTER11](http://CHILDRENSHOSPITAL.ORG/DREAM/WINTER11)

- Learn more about Children's Division of Endocrinology.
- Read about a young transgender patient seen by the team at the Gender Management Service Clinic at Children's.
- Watch Children's "It Gets Better" video.



Find out what this is on page 4

Things are LOOKING UP

By Cara Gillotti

Not all seizures in children are violent. Some could even go unnoticed. Others might cause a child to go instantly dark, like an unplugged lamp—unable to respond and staring into space. That's what happened to Collin Goodchild on July 1, 2008, when he was almost 6.

After a second seizure almost 10 days later, Collin came to Children's, unable to walk in a straight line or follow a moving finger with his eyes, and his arm was jerking uncontrollably. "Our minds were racing," says Collin's father, Mark. "It was a complete nightmare."

Children's doctors diagnosed Collin with encephalitis, an inflammation in the brain that can be caused by a number of things, including viruses, bacteria and the body's immune system turning against itself.

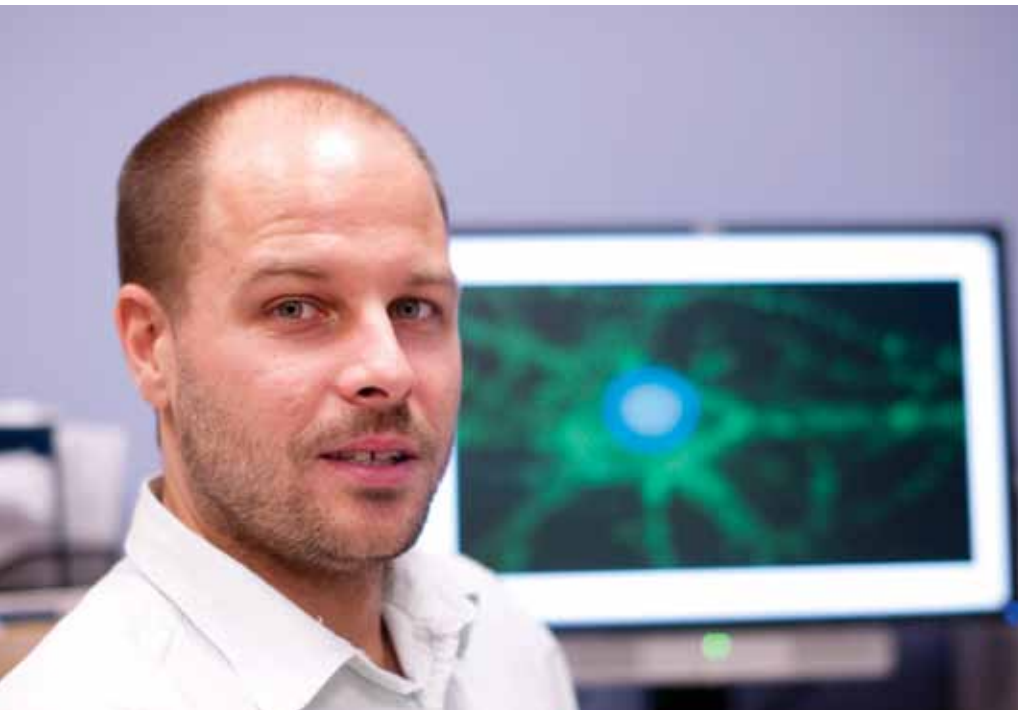
Fortunately for the Goodchilds, encephalitis—which is often confused with the more dangerous bacterial meningitis—is rarely fatal in the United States. But identifying its cause can be a real challenge. There are a few tests that can recognize certain causes, but often doctors and families never know for sure what's behind a child's encephalitis. "The doctors tested Collin for everything they could, but everything was coming back normal," says Mark. "I was glad he didn't have the bad things he was being tested for, but it wasn't giving us any answers, so it was kind of bittersweet."

Encephalitis is known to cause symptoms like fever, confusion and difficulty walking and talking, but these often subside over time. Unfortunately, there's no way to know how long this might take, or what, if any, long-lasting effects the encephalitis might lead to down the road. "The doctors can tell you, 'We hope he'll talk again. We hope he'll walk again. We hope he'll eat on his own,'" says Mark. "But they don't know—that's what's so scary."

The weeks following Collin's diagnosis were a nightmare for Mark and Suzette. Collin's arm-jerking developed into a full-blown movement disorder, with episodes of uncontrollable thrashing and screaming. The doctors finally brought the disturbing episodes under control, but only by medicating Collin very heavily.

Photos: Tracy Powell

COLLIN GOODCHILD lost the ability to walk and speak after getting encephalitis.



MARK GORMAN, MD, neurologist, connected the dots between Collin's encephalitis and that of a group of women with ovarian tumors.

“The doctors would come in and ask him to raise his hand, wave, blink, whatever. He wouldn't do it. It was almost like he was somewhere else”

—Suzette Goodchild

Soon, his speech began to dry up. “He could still use a few words, like ‘yes’ or ‘no’, but other than that he could barely talk,” says Suzette. “And I don’t know if he was following instructions either. You’d ask questions, and he wouldn’t do things. It was like he didn’t understand. The doctors would come in and ask him to raise his hand, wave, or blink, but he wouldn’t do it. It was almost like he was somewhere else.”

A few days later, Collin lost the ability to walk. Shortly after that, he couldn’t even swallow on his own and began receiving all his nutrition through a feeding tube inserted into his stomach.

Mercifully, after three or four weeks, Collin’s symptoms started to subside as his brain began its long, slow healing process. He began to swallow again, so he could get some of his nutrients by drinking small amounts of liquid. It was encouraging, but he was far from out of the woods. He still couldn’t walk or communicate, so began extensive physical, occupational, speech and feeding therapy.

Fortunately for children like Collin, young brains are not yet fully developed, so they’re strong and adaptable. But it’s nearly impossible to say how much of the brain will heal—once the medical emergency passes, you can see a light at the end of the tunnel, but no one can say what you’ll find when you get there.

So the Goodchilds kept doing everything they could to get Collin well. “We went anywhere and everywhere we needed to go,” says Suzette, including kindergarten, a prospect his parents would have never deemed possible a month earlier. Collin spent about an hour each day in school, working with an aide and soaking up his surroundings. He still couldn’t communicate, and received a majority of his nutrients through a feeding tube, but he was walking again and slowly rebuilding his strength and dexterity.

Flash of insight

On the day in December that would change Collin’s life, his neurologist, Mark Gorman, MD, woke up suddenly in the middle of the night with an idea. He remembered a study he’d heard about at a conference that described a subset of encephalitis patients with movement disorder, just like Collin. It wasn’t an obvious associa-



COLLIN, left, his brother Colby and their parents, Suzette and Mark, are getting back to normal after a very trying battle with encephalitis.

tion to make, because these patients were women with ovarian tumors, but Gorman focused on the similarities. He quickly located and contacted the doctor who had first identified this subset, and described Collin. The doctor agreed that it sounded like the same set of symptoms, and identified them as indicators of a certain type of encephalitis known as anti-NMDA receptor encephalitis.

Things moved quickly after that. Gorman sent a sample of Collin’s blood and spinal fluid for testing, and sure enough the results came back positive for anti-NMDA receptor encephalitis. Finally, after months of uncertainty, Collin’s phantom malady had a name, and it was something Gorman could treat. Collin was placed on an intensive three-day round of steroids, and monthly sessions of a four-hour-long infusion of a blood product called IVIg.

Turbocharged recovery

“Even after the first treatment, we felt things were getting better,” says Suzette. “And then in February, he had his second IVIg and his gross motor skills started to click, just like that. We had him on a handbike, and his arms and legs were just going.”

One day in March, she was in the kitchen and Collin was in the living room with his younger brother Colby. “They were just sitting there, and as usual Colby was doing all the talking since Collin couldn’t,” says Suzette. “But then I heard a voice and I said, ‘Oh my God, that’s not Colby, That’s Collin!’” Suzette called Mark and told him to come home.

“The kids were sitting at the table, and Colby was all excited,” says Mark. “He’d say ‘Dad, watch this... Collin, say circle.’ And you hear this little voice: ‘cir-cle?’ And

Colby would say, ‘Collin, say star,’ and he’d say ‘star.’ He said square, he said triangle. It was unreal.”

Two days later, Collin was picking cashews out of a bag of trail mix, repeating the word cashew. “We were all laughing,” remembers Suzette. “We just thought ‘This is a miracle. We’ve been waiting months for this.’” Later that week Collin went in for his third IVIg and came out speaking full sentences. The room exploded in joy.

From then on, Collin’s turbocharged recovery took off. He started responding to what people were saying to him, and asking questions of his own. “It was by far the most amazing thing I’ve seen,” says Gorman. “I just asked him normal stuff I’d ask any 5 or 6 year old.” Most thrillingly, his knowledge was intact, and words flooded back into his vocabulary. Kitty Petty, the Children’s education consultant who helps Mark and Suzette with Collin’s academic program, says the fact that Collin retained so much from before the encephalitis is very significant. “He’s not just parroting words, he’s recognizing things and identifying them,” she says. “These are important cognitive activities.”

At school, Collin began to be tested on writing, numbers, shapes and colors. More people than he will ever know watched in delight as he sailed through the goals that were set for him.

Now, when they’re not snowboarding in Maine, Collin and Colby are classmates in first grade. “People take so much for granted,” Suzette says. “When something like this happens, it sets you back, and makes you realize that if you have faith, and a strong family, and the community that we do, that you can get through it. And we did. We really did.”

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