

# The Hazards of Growing Up Painlessly

By JUSTIN HECKERT

Published: November 15, 2012

New York Times Magazine

The girl who feels no pain was in the kitchen, stirring ramen noodles, when the spoon slipped from her hand and dropped into the pot of boiling water. It was a school night; the TV was on in the living room, and her mother was folding clothes on the couch. Without thinking, Ashlyn Blocker reached her right hand in to retrieve the spoon, then took her hand out of the water and stood looking at it under the oven light. She walked a few steps to the sink and ran cold water over all her faded white scars, then called to her mother, “I just put my fingers in!” Her mother, Tara Blocker, dropped the clothes and rushed to her daughter’s side. “Oh, my lord!” she said — after 13 years, that same old fear — and then she got some ice and gently pressed it against her daughter’s hand, relieved that the burn wasn’t worse.

“I showed her how to get another utensil and fish the spoon out,” Tara said with a weary laugh when she recounted the story to me two months later. “Another thing,” she said, “she’s starting to use flat irons for her hair, and those things get superhot.”

Tara was sitting on the couch in a T-shirt printed with the words “Camp Painless But Hopeful.” Ashlyn was curled on the living-room carpet crocheting a purse from one of the skeins of yarn she keeps piled in her room. Her 10-year-old sister, Tristen, was in the leather recliner, asleep on top of their father, John Blocker, who stretched out there after work and was slowly falling asleep, too. The house smelled of the homemade macaroni and cheese they were going to have for dinner. A South Georgia rainstorm drummed the gutters, and lightning illuminated the batting cage and the pool in the backyard.

Without lifting her eyes from the crochet hooks in her hands, Ashlyn spoke up to add one detail to her mother’s story. “I was just thinking, What did I just *do*?” she said.

Over six days with the Blockers, I watched Ashlyn behave like any 13-year-old girl, brushing her hair, dancing around and jumping on her bed. I also saw her run without regard for her body through the house as her parents pleaded with her to stop. And she played an intense game of air hockey with her sister, slamming the puck on the table as hard and fast as she could. When she made an egg sandwich on the skillet, she pressed her hands onto the bread as Tara had taught her, to make sure it was cool before she put it into her mouth. She can feel warmth and coolness, but not the more extreme temperatures that would cause anyone else to recoil in pain.

Tara and John weren't completely comfortable leaving Ashlyn alone in the kitchen, but it was something they felt they had to do, a concession to her growing independence. They made a point of telling stories about how responsible she is, but every one came with a companion anecdote that was painful to hear. There was the time she burned the flesh off the palms of her hands when she was 2. John was using a pressure-washer in the driveway and left its motor running; in the moments that they took their eyes off her, Ashlyn walked over and put her hands on the muffler. When she lifted them up the skin was seared away. There was the one about the fire ants that swarmed her in the backyard, biting her over a hundred times while she looked at them and yelled: "Bugs! Bugs!" There was the time she broke her ankle and ran around on it for two days before her parents realized something was wrong. They told these stories as casually as they talked about Tristen's softball games or their son Dereck's golf skills, but it was clear they were still struggling after all these years with how to keep Ashlyn safe.

A couple of nights after telling me the story about putting her hand in the boiling water, Ashlyn sat in the kitchen, playing with the headband that held back her long brown hair. We had all been drawing on napkins and playing checkers and listening to Ashlyn and Tristen sing "Call Me Maybe," when all of a sudden Tara gasped and lifted the hair away from her daughter's ears. She was bleeding beneath it. The headband had been cutting into her skin entire time we were sitting there.

**Ashlyn wears headbands** and flip-flops most days and also prescription glasses with black frames and bracelets that she makes with beads she keeps in an old Vlasic pickle jar. She sells her crocheted purses for \$5 to friends at Pierce County Middle School. When she smiles or laughs, you can see her Invisalign braces, which she wears because the metal ones might cut into her tongue and gums without her being aware. She has a medical-identification tag that she clips to a silicone wristband — she has eight in different colors, which she mixes and matches with her wardrobe. On the back of the tag it reads, "Cannot feel pain — sweats minimally."

At school, she was once asked if she was Superman. Could she feel a punch to the face? Could she walk across burning coals as if she were walking on grass? Would it hurt if she were stabbed in the arm? The answers are no, no, yes, no. She can feel pressure and texture. She can feel a hug and a handshake. She felt her best friend, Katie, paint her toenails. "People don't get me!" she said one night while we played checkers on her iPod. "Everyone in my class asks me about it, and I say, 'I can feel pressure, but I can't feel pain.' *Pain!* I cannot feel it! I always have to explain that to them."

When she was born, she didn't cry. She barely made a noise, staring out from her swaddling with a blank red face. When she developed terrible diaper rash, so raw that it made Tara wince to even wash her, the pediatrician gave

instructions to change her formula and put cream on the rash and keep it dry. “I kept thinking, But she’s not crying,” Tara said. “The doctors dismissed it, but we’re thinking, What’s going on?”

When Ashlyn was 3 months old, the Blockers moved from Northern Virginia to Patterson, Ga., where Tara has family. At 6 months, Ashlyn’s left eye was swollen and bloodshot. The doctor suspected pink eye, but Ashlyn didn’t respond to the treatment, so they went to an ophthalmologist, who found a massive corneal abrasion. “And Ashlyn is just sitting there, happy as can be,” Tara recalled. The ophthalmologist assumed she had no corneal sensation in her eyes, and referred them to the Nemours Children’s Clinic in Jacksonville, Fla. It took a while to get an appointment, and before they made it to Jacksonville, Ashlyn rubbed big red splotches on her nose and almost chewed off part of her tongue with her emerging teeth.

At the clinic, they drew Ashlyn’s blood and took scans of her brain and her spine, but the tests were inconclusive. Over the next 18 months, there were more tests. A nerve biopsy from the back of her leg left stitches that ripped when she was running. When the doctor finally gave his diagnosis, Tara was afraid she would forget the words, so she asked him to write them down. The doctor took out a business card and wrote on the back: “Congenital insensitivity to pain.”

“The doctor told us we were the only ones out there,” Tara said. “That it was so rare. He said to keep an eye on her and that they didn’t know much about it and couldn’t really be of any help. It was kinda like, ‘Good luck!’ ”

At home, Tara typed the words “congenital insensitivity to pain” into a search engine and started reading the results. There weren’t many, and the few there told of mutilations and early death. There was no comforting advice to be found.

“John and I had never heard of this condition,” she said. “It was mind-boggling. It was so frightening.” They received help from the people around them in Patterson, a community of fewer than 700 people. When Ashlyn started school, teachers watched her on the playground; one person was assigned to make sure she was O.K. at all times. The nurse washed her eyes and checked her shoes each time she came in from recess — what she called her “Nascar pit stop” — to make sure there was no sand that might cause another corneal abrasion or scratches on her feet. “It really sharpened our observation skills,” Tara said. “I learned to see something happen before it happened.”

The Blockers got rid of all their furniture with sharp corners. They lay down the softest carpet they could find. They didn’t let Ashlyn roller-skate. They didn’t let her ride a bicycle. They wrapped her arms in layers of gauze to

keep her from rubbing them raw. They used a baby monitor in her bedroom to listen for grinding teeth. When they still couldn't sleep, they brought her into their bed, and Tara held her hands over Ashlyn's, cupping them so she wouldn't chew on her skin or rub her eyes during the night.

**When Ashlyn was 5**, the Blockers decided the only way they were ever going to find another person in the world like her was to send up a flare. They contacted their local newspaper, The Blackshear Times, which ran an article about Ashlyn in October 2004. The Associated Press picked it up, and Tara remembers Ashlyn's picture next to George Bush's and John Kerry's on the MSN home page. Ashlyn's grandmother in Virginia saw it while she was at work and called Tara in Georgia. "Do you know Ashlyn's on the Web?" she asked. "The Girl Who Feels No Pain! Turn on your computer!" By that time, of course, the Blockers knew. "Good Morning America" had already called.

The Blockers were flown to New York City and appeared on "G.M.A." — and on the "Today Show" and "Inside Edition." They told and retold the stories about Ashlyn's injuring herself. When they flew back to Jacksonville, people recognized them in the airport. They were interviewed by a French news crew and by the BBC. A Japanese film crew brought bamboo chopsticks as a gift. They were called by Oprah but never made it on. They said yes to Geraldo Rivera and no to Maury Povich. Ashlyn was in the Jan. 24, 2005, issue of People, the famous one with Brad Pitt and Jennifer Aniston on the cover, under the giant yellow headline "Brad & Jen: Why They Split."

All the media attention finally put the family in touch with scientists who could help them understand her condition. Dr. Roland Staud, a professor of medicine and rheumatologist at the University of Florida, heard about Ashlyn and invited the Blockers to Gainesville, where for 15 years he has been conducting research into chronic pain. The implications of her condition were profound. She was an anomaly of nature. Over the next few years, Staud tested Ashlyn's genetic material and eventually found two mutations in her SCN9A gene. That same gene, mutated in a different way, led to severe pain and chronic pain syndromes. If he could understand how the mutation worked in Ashlyn, Staud theorized, he might be able to turn it off in people with chronic pain.

The connection between the gene and pain insensitivity was discovered in 2006 by a geneticist in Cambridge, England, named Geoffrey Woods. "I used to work in Yorkshire, where lots of Pakistanis had emigrated" and where there were a number of marriages between first and second cousins, Woods told me when we spoke this fall. "I'd see an awful lot of children with genetic diseases." An obstetrician who had come to England for training persuaded Woods to do some research in Pakistan. On one of his trips, he was asked to see a boy in Lahore who, they said, didn't feel pain. "I agreed to see him and went out," Woods said. The boy's mother and father greeted him but told him the boy had died.

“For his birthday, he’d wanted to do something for his friends — he’d wanted to jump off the first-floor roof of his house,” Woods told me. “And he did. And he got up and said he was fine and died a day later because of hemorrhage. I realized that pain had a different meaning than I had thought. He didn’t have pain behavior to restrain him. When I came back to the U.K., I found three more families with kids in the same condition — with multiple injuries, biting lip, biting tongue, biting hands, fractures, scars. And in several cases, parents almost had their children removed because of suspected child abuse.”

Woods and his colleagues began their search for the genes that caused this disorder, eventually zeroing in on SCN9A. Pain-sensing nerves along the body’s surface normally fire more frequently when we touch something hot or sharp, sending electrical signals to the brain, causing us to react. These electrical signals are generated by molecular channels produced by the SCN9A gene, says Stephen G. Waxman, a professor of neurology at Yale University School of Medicine. Ashlyn’s mutation prevents the gene from making the channel, and the electrical impulses are never produced.

“It is an extraordinary disorder,” Woods said. “Boys die at a younger age because of more risky behavior. It’s quite interesting, because it makes you realize pain is there for a number of reasons, and one of them is to use your body correctly without damaging it and modulating what you do.”

**When I visited** Roland Staud’s office in September, he seemed reluctant to talk at first. As I described my week with Ashlyn, however, he began to soften, and eventually he spoke about her as if she were his own child. There was a picture of her on his bulletin board behind his desk. He had seen her throw paper airplanes in the clinic hallway after long days of testing, and he posed for pictures every year with the family. He had watched her grow up. “Her life story offers an amazing snapshot of how complicated a life can get without the guidance of pain,” Staud said. “Pain is a gift, and she doesn’t have it.”

When Ashlyn was 9, Staud asked John and Tara’s permission to conduct a series of physical tests to determine what range of sensation Ashlyn possessed. She could feel tickles and pressure and distinguish a soft touch from a pinprick, but she couldn’t perceive extremes of temperature. He also gave her a range of psychological tests to determine if she could feel emotional pain and empathy, and he found her to be a bright and friendly child.

Staud wondered what Ashlyn would be like as she became an older teenager, if she would begin to disobey her parents and what the implications might be for her health. “We know very little about this in the long term,” he said. “How will she be emotionally? How will she evolve?” We sometimes experience emotional pain physically — Staud

used the tried-and-true example of heartbreak, how the end of a romance can cause a physical pain — and he wondered if the relationship between the body and emotions also goes the other way; if a person lacks the ability to feel physical pain, is her emotional development somehow stunted? “It’s completely possible that some pain fibers work in her,” Staud said of Ashlyn. “That’s one of the reasons we follow her. She is going into a hormonal change now. Puberty. Estrogen receptors are associated with pain processing. Will she have fear? She is only threatened by emotional consequences. She is an easygoing girl, and she has parents who have learned how to influence her without additional means of physical contact.” He paused and then added, “I don’t think she cries very much.”

Ashlyn does cry. She cried when her dog ran away earlier this year, curling up with her mom and dad in their bed. “She can feel empathy,” Tara told me. “She does. I don’t know if they found that in their research. But I *know* she does, in my heart.”

**A hard rain** turned the red-dirt driveway in front of the Blockers’ house into a lake on one of the nights I spent there. John came in from work soaking wet and took a Mountain Dew out of the fridge. He works for the Alma phone company, and frequently drives his truck up and down Highway 84, past Georgia Bulldogs flags hanging from the porches and the two signs that promote Patterson as “One of America’s top 50 towns for raising kids.” Around town, he is known as the Phone Man, and it isn’t out of the ordinary for a customer to call the Blocker house at odd hours, rather than contacting the phone company, and ask John to come see about a problem.

“Something happened to me the other day,” he said, after he dried himself off. “I was at the school, and a guy was like: ‘Let me ask you something. Now, this might be grotesque, I just have to use it as an example. You mean to tell me if she was, like, to get her hand chopped off. . . .’”

“Oh, my *gab*,” Tara blurted.

“And I was like, Wow,” John continued. “And he’s like, ‘O.K., you mean to tell me she would not feel that?’ And I was like, ‘She would see it and be scared.’ And he was like, ‘Yeah, yeah, but she wouldn’t be hurt by it?’ And I was like, ‘No.’ And he was like, ‘That’s mind-boggling to me!’”

Ashlyn, who had her head buried in her palms, looked up laughing from the kitchen table and said, “*Why* would I cut my hand off?”

John and Tara had seen her say, “Ow!” when someone else was hurt. And Ashlyn yelled when her father described the time he put a nail straight through his thumb while he was building a chicken coop, but she had no idea why his face got red and his voice got loud and he held his thumb in the air. She said that over the years she studied the expressions other people made and learned to cringe when someone described something painful.

“Girl, what goes through your mind when you see someone hurt?” John asked her.

“I feel bad for them,” she said. “Because they go through the pain and I don’t. I would help them.”

“Define pain for you,” John said. “What does it mean for you?”

“I don’t know.”

“When you see someone else in pain, what do you associate?”

“That must really hurt.”

“What is *hurt*?”

Ashlyn squinted her eyes, as if in deep thought. She couldn’t answer him.

**One Saturday morning** last year Ashlyn awoke past noon — she likes sleeping late — and walked into the living room and announced to her mother, “I had a dream.” Tara expected her to start telling some fantastical story, but instead Ashlyn said, “In the dream we started a camp for kids like me.” She said there was a lake in the dream and boats, and she had a vivid image of children who otherwise don’t know anyone like them running around together.

Which is how Camp Painless But Hopeful got started. Tara called a place called Camp Twin Lakes in Winder, Ga., four hours from Patterson, and asked about holding a weekend retreat there for kids who feel no pain. The staff agreed. Tara would coordinate and pay for the cabins, insurance and food, and the staff would take care of the cooking.

The Blockers made T-shirts and put stickers on their cars. A local radio station gave them a free ad to promote a fund-raising barbecue in the parking lot of the Blackshear Rite-Aid. Ashlyn sold some of her purses and jewelry to her friends. Tara advertised the camp on a private Facebook page called “A Gift of Pain,” a support group for

families affected by insensitivity to pain: “Would anyone be interested in attending a camp for families like ours?” Eight families signed up.

The camp was held in early November, when the weather was starting to cool in Georgia and the temperatures were more agreeable for children who don’t sweat much. Researchers have identified three genes that are associated with congenital insensitivity to pain and suspect there are other genes that have not been found. Some of the children who came to the camp had a mutation on a gene, *NTRK1*, that is involved in the development and maturation of the nervous system and that is characterized by self-mutilating behavior, fevers, mental retardation along with insensitivity to pain. Roberto Salazar, an 11-year-old from Indianapolis who came to the camp with his mother, has this mutation, and in his short life he has bitten off part of his tongue, pulled out his teeth and crushed his ankles with his own weight. Once he jumped down an entire flight of stairs. For most of the year, he was confined inside an air-conditioned home, because he doesn’t sweat at all, and his body temperature could rise quickly and dangerously. Roberto’s mother, Susan, had seen Ashlyn’s name in an article a few years before and reached out to Tara; since then, they have stayed in touch, sharing stories about their children. When he showed up at camp, Roberto was getting around on a motorized scooter. He gave the other children rides for fun.

The Brown family from Mapleton, Iowa, drove to the camp with nine people in one van, including a 3-year-old boy named Isaac. When Isaac was small, he stuck his whole hand into his mother’s mug of hot coffee and didn’t cry. Then he put his hand on a hot stove burner and received third-degree burns and still did not cry. His parents took him to a neurologist who recommended genetic testing, which the family could not afford. After Isaac took toenail clippers and ripped out his eyelashes, his mother, Carrie, told her husband, “I can’t take this anymore.” In 2010, they took him to the Mayo Clinic in Rochester, Minn. The doctors there told Carrie that they believed her son had congenital insensitivity to pain, but they needed to find the particular gene that was mutated. They enrolled Isaac in a study and started the long process of looking for an explanation, which Carrie says they have not yet found.

Carrie Brown found Tara online, and the idea of actually hanging out with other parents who shared these terrifying experiences with unintentionally self-destructive children was too amazing to pass up. The Browns have seven children and live off Carrie’s husband’s income as a registered nurse. But they vowed to get to Georgia, even if it meant not paying other bills. A gift of \$400 from their church helped finance the road trip. They drove 18 hours, stopping for the night at a Motel 6 in Chattanooga, Tenn., where they tried unsuccessfully to persuade the desk clerk to let all nine of them stay in the same room.



The Browns were the first ones to arrive at the camp. When the Blockers pulled up, Tara got out of the car and rushed to hug Carrie, who was standing outside her van. They both wept.

“It was just . . . I don’t know how to explain it,” Carrie said. “I felt like I was finally meeting another mom who got me, who wouldn’t judge me for being overprotective, because she knows how important it is. She understood.”

The first night at camp, Ashlyn made s’mores and went on a hayride with the other children. She watched a puppet show. She rode the zip line. She danced. She especially gravitated to the little girls. She held them and gently rubbed their backs. She helped them decorate steppingstones with jewels and beads, little concrete slabs that will always be on the grounds, as part of the camp’s legacy project. “It was just awesome to meet people just like me,” Ashlyn said.

**Karen Cann’s life** had been full of wonder and pain, even if she had never been able to feel any. When she and her sister, Ruth were children in Scotland, no one could explain what was wrong with them. Like the Blockers, their parents lived in fear of their daughters’ inflicting harm on themselves, but rather than seek out people like them, the girls tried to blend in. “We didn’t want to be considered freaks,” Cann, who is 35, told me, and then she added, “I mean, we are freaks.” Neither Karen nor her sister can sweat very much, and neither has the ability to smell. (Ashlyn’s parents discovered she too couldn’t smell when she started spraying herself immoderately with perfume; it turned out she liked the way the mist felt.) Growing up, they always had burns and scars and limbs in casts, and their mother faced the suspicious questioning of doctors.

“We didn’t even know what we had, what to call it,” Cann said. It wasn’t until she was in her 20s that Cann began to search for answers in earnest. “I thought, I’m going to start e-mailing doctors up and down this country and try and find an answer. Me and my sister Ruth went to see a doctor in the Liverpool pain institute. And I sent a letter to Addenbrooke’s Hospital. They passed the letter to Dr. Woods.”

Karen Cann was 29 when Woods first met with the sisters. “We just exploded with everything that happened to us,” she said of that first meeting. “It was almost like a counseling session. Poor Dr. Woods!” They wanted to know if they really couldn’t smell. Growing up, they weren’t sure if they could smell or not because they could taste. He blindfolded them and put oranges and coffee under their noses. Nothing. He drew their blood and soon confirmed that they both had mutations on their SCN9A gene.

“People regard you as hysterical, or strange, when you tell them you can’t feel pain,” Woods told me. “It might not be something you want people to know about. We find families are careful who they tell their diagnoses to. We’ve

found there is a grouping of pain families, and they keep secret.” Because of this, Woods suspects the condition is less rare than has been recognized. “I think it’s more common than one in a billion,” he said, “or even a million. The adults with the disorder often go unnoticed because they don’t share it.”

Tara met Cann online in 2009 and sent an e-mail telling her how happy she was to have found someone to talk to, someone who could be a guide for Ashlyn. Tara also wanted to know more. What had Cann’s life been like? Could she feel hot and cold? Did she sweat? Tara knew that Cann had a husband and a child. What was it like to be a mother who couldn’t feel pain?

“I sent her quite a lengthy e-mail back, as I wanted to reassure her that the condition hadn’t held my sister and I back in life,” Cann said. “I knew Ashlyn was quite young, and I knew it would be a worrying time for Tara.”

When Cann was Ashlyn’s age, she started puberty and was interested in boys, but she remembers being embarrassed about her scars and hiding her legs with long dresses. She felt intensely self-conscious about her condition. She remembers holding other girls’ hands, and feeling how soft and dainty they were, comparing them with her own, which were rough and scarred. But it had gotten easier, she told Tara, and she and Ruth both made it through school and received university degrees. They each had loving partners and great friends and full-time jobs. When she made love with her husband, she could feel pleasure, or at least she thought she could. “Intimacy is enjoyable,” she told me. “I probably don’t feel it the same, but it feels good.” She had learned to live with her condition, she said, and had become aware of things that could hurt her — a process that took most of her life — but that growing awareness has allowed her to get on with the business of being an adult.

Cann had her first child at 31 through an emergency C-section. The child was a healthy baby girl, but in the aftermath, Cann felt a sensation she could only describe as a stiffness down her right side. She went home and walked around on it for weeks, the stiffness becoming more intense — though not painful — until eventually she could hear a clicking inside her body and it became difficult to walk. When she went to her doctors and explained that she couldn’t feel any pain but that she knew something was wrong, and would they please take an X-ray, they said she was probably experiencing postpartum depression and should seek treatment. She persisted, and eventually it was revealed that she had shattered her pelvis during childbirth and was bleeding internally. For the next six months she stayed in the hospital unable to walk.

Because of the way her pelvis healed, Cann's left leg is now shorter than her right, and she wears an elevated shoe to correct it. Beyond that, though, there were no lasting effects, and in 2011 Cann had a second child, a son, again by a C-section. This time she was X-rayed immediately after the birth and suffered no damage.

Tara still corresponds with Cann. "She gave me an insight into what we could expect from Ashlyn down the road," Tara said. "Anything comes up that I'm not sure about, I know I have a lifeline to see if she has experienced it."

Before Cann met Tara and heard about Ashlyn, she didn't like telling people about her condition. "She has inspired me," Cann said. "My sister and I have viewed the condition in a negative way, obviously due to the physical damage the condition has caused, and the emotional pain and stress it's brought for our family. I now, however, have decided it's time to try and get something positive from it. I want to spread awareness. It's also inspired me even more to push doctors to use me as a guinea pig to find out more about pain and the drugs that could be created from mimicking my condition."

For all the reassurances over Facebook, the photos they swap and the feeling that Cann and Ashlyn are linked by their experience, Cann has never met the Blockers or talked to them on the phone. When I asked her why, she said, "I think I would have done so by now, if it wasn't for what I went through a few years ago." She meant the despair she felt after breaking her pelvis, the realization that not being able to know her own pain meant not just that she might endanger herself but that she might not be able to care for her child. "I'm still quite emotionally fragile, and I wouldn't want to get upset on the phone and frighten Tara about Ashlyn's future," she went on. "Not that the same thing will happen to her. But parents worry, don't they?"

**Sometimes it seemed** as if the entire town of Patterson were a network of external pain receptors, feeling for the hazards that might injure the girl who feels no pain. "One time she cut her foot," said Michael Carter, her band teacher at Pierce County Middle School. "I don't know if it was the stand that came down on her, but there was blood on her foot." You could sense when talking to many of the people around Patterson that Ashlyn was a strange and special presence in their lives, that they were proud of her and worried for her. "Middle school can be traumatic for some kids," Carter said, "but I think she's kind of tackled this thing. She says, 'This is who I am.' She'll tell you about it. She loves to hug — she's a joyful person."

Her art teacher, Jane Callahan, talked about her imagination, how she sees things a little differently than the other children around her. She has a good eye for detail. Her homeroom teacher, Corey Lesseig, explained how important

it was that she lived in a place like Patterson, where everyone knew her and understood her, and she could be comfortable being herself. “You wonder as she gets older, how all that’s going to be,” he said.

Watching her heave her backpack onto her back and walk down the halls, watching her at a weeknight football game or painting in art class or playing her clarinet in band, I found it hard to think of her as one of a handful of people in the world whose body might contain secrets that could unlock the mystery of pain itself. As Staud said when I met with him in Gainesville, they had only scratched the surface of what they could learn from Ashlyn. She would most likely be tested for years to come, and she and her family had reconciled themselves to that, to the tests and also to the realization that, like Karen Cann, she could never totally protect herself. With each day she became that much more aware of the world, that much more cognizant of what she had to look out for and anticipate. Most things became easier, and the possibilities for her life became greater. But it’s not possible to imagine all the threats in advance, so she has to enlist everyone around her to help her watch out for the present.

“She’s our normal,” her mother said. “People are like, ‘I don’t know how y’all do it, don’t you have to protect her?’ And we’re like, ‘I dunno, come on over to the house and tell me if we do anything different.’ ”

*[Justin Heckert](#) is a writer in Indianapolis. This is his first article for the magazine.*

*Editor: [Joel Lovell](#)*