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NEWS

Saving Raynah's brain: In a brutal year, a story of love and medicine unfolds in Wisconsin

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This Christmas, Raynah Bickle thinks of home, not the hospital, of friends and family, of presents she will give and receive. She's hoping for new slippers. And she can't wait to paint over her bedroom's "Frozen" theme; she's outgrown the snowflakes.

In this miserable year of heartbreak and anger, pandemic and polarization, the young girl from Racine completed her journey back from the brink of death. Her brain, once under siege from a massive abscess, is free.

Today it rests secure inside a new skull that is a medical and technological marvel.

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Late in 2019, quite unexpectedly, she reached the pivotal moment of her young life.

Her mother, Reannyn Bickle, had finished a late-night nursing shift in the intensive care unit of Ascension All Saints Hospital, and was home resting with 2-year-old Amelia, the youngest of the family's four girls.

At around 10 in the morning, as they lay in bed together watching the animated movie "Sing," a loud shriek came from upstairs.

Reannyn sat bolt upright. She looked toward the second floor. The sound seemed to be coming from the bedroom of 11-year-old Raynah, who was home sick from school and had just finished showering.

Reannyn ran toward the cry.

As she reached the top of the stairs, she saw Raynah sitting on the edge of her bed, head tilted oddly.

“Was that you?’" the mother asked, struggling to calm her voice.

Raynah said nothing. Her eyes didn't move. They were locked in a thousand-mile stare.

Reannyn called a second time, then snapped her fingers inches from the girl's eyes. No response.

“Then I got really scared," Reannyn recalled. "I got right in her face: 'Raynah! Can you hear me? Show me two fingers.' She just kept staring. She was not even trying to form words."

On that morning, Oct. 29, 2019, Reannyn hustled Raynah and Amelia into the family van and set off for nearby Aurora Medical Center Kenosha. Reannyn, nurse and mother, was still wearing the pajamas she'd slept in.

From the road, she called the emergency room and told the voice on the other end, "I'm coming in hot," a term medical staff use to signal urgency. "I'm not trying to be pushy," she explained. "I'm an ICU nurse. My daughter is 11 years old." She explained that Raynah looked as if she'd had a stroke.

"OK," the voice answered. "We will be ready."

Next Reannyn phoned her husband, Ethan, a former emergency medical technician.

"I don't know what's wrong with Raynah. She won't talk to me. It looks like she's had a stroke."

Ethan was logging off his computer before she finished the last sentence. "I'm on my way."

Still driving, Reannyne called a good friend, a fellow nurse, and explained that she was rushing Raynah to the ER. She asked her friend to come pick up Amelia.

The Bickles were not accustomed to worrying over Raynah. She had always been healthy, an easy-going child, a peer mediator at school, "super chill" in her mother's words. Teachers told the Bickles that Raynah was always helping the other children.

She was the kid who couldn't wait to turn 7 so she'd be old enough to go down a waterslide. Then, when the slide was closed for cleaning on her birthday, she brushed it off. "It's OK. It'll open next week."

From their medical backgrounds, the Bickles knew the various conditions that could cause a person to become unresponsive, and they hoped for one in particular.

If their daughter was experiencing hypoglycemia, low blood sugar, it would not be such a big deal. She'd be back from the hospital in maybe four hours.

At the hospital, a nurse poked a lancet needle into one of Raynah's fingers to check her blood sugar level. It was not low.

Ethan's heart sank.

The hospital took a scan of Raynah's brain. The Bickles took one look at the image and knew something was terribly wrong. A long black pool snaked down between the skull and the left side of the brain.

"Literally you could see fluid pushing the brain," Ethan said.

The hard bone of the skull fits snuggly around the brain leaving little room for movement. Inside Raynah's skull, a large abscess had squeezed her brain, causing it to shift a quarter inch to one side, a significant disturbance.

The Kenosha hospital gave Raynah seizure medications and antibiotics, and decided to transfer her 40 miles to Children's Wisconsin Hospital — Milwaukee. Around 3:30 in the afternoon, the ambulance sped off. Something one of the doctors had said stuck in Ethan's mind.

"It's possible that she could be looking at some surgeries."

From deaths to miracles, they'd witnessed it all

Unlike most parents in the pediatric intensive care unit, the Bickles knew what to expect.

They knew the look doctors get when they're worried. They knew the code medical teams use during an emergency.

They had watched others enter that heart-clutching state, known only to the parents of a deathly ill child. Ethan never forgot how awful it felt to reach the hospital in an ambulance with a patient who was dead on arrival.

"Health care is a war against death," he said. "And you lose a lot."

As an ICU nurse, Reannyn knew what it felt like to extinguish a family's hope, to tell a mother and father, "There's nothing more we can do."

In that moment, a nurse must hold back personal emotions. "You don't want someone to have to comfort you," she said. "You have to be this silent phantom."

Reannyn and Ethan had also witnessed amazing recoveries that defied logic.

Reannyn recalled a very old woman, sick and on a ventilator. She had a "do not resuscitate" order.

"We turn off the medication," Reannyn said. "We take the ventilation off. This woman wakes up and starts talking."

MORE: 40 years ago, we wiped out smallpox. Is eradicating COVID-19 possible?

Two years later, the nurse recognized the woman's daughter walking in the hospital hallway and asked how things were going. The old woman was still alive.

Most of the time there is a scientific explanation for what happens in the hospital, "but I definitely believe in miracles," Reannyn said.

It looked as if the Bickles might need one. The fluid inside Raynah's skull was a massive collection of pus between the brain and the dura mater, the membrane surrounding the brain and spinal cord.

On the way to Wauwatosa, the parents — Reannyn in the ambulance; Ethan following — informed family members of the situation and asked them not to call the hospital for updates. They would update family members.

Ethan and Reannyn wanted the hospital staff left alone to take care of their very sick patient.

A life-threatening condition that began with a severe sinus infection

Raynah made no sound in the ambulance.

When it reached Children's, the nurse who'd been caring for her in the back of the ambulance told Reannyn that the girl had moved her left arm and was making eye contact. These were small, but encouraging signs.

It did not take doctors at Children's long to establish what had happened to Raynah.

She had a raging sinus infection that had caused the life-threatening abscess pressing against the protective meninges layer and squeezing her brain.

Adults have eight sinuses. The frontal sinuses, located behind the forehead, do not develop until late in childhood. Sometimes their development triggers an infection called frontal sinusitis. Rarely, however, does the infection spread inside the skull, as it had with Raynah.

In order to relieve the pressure on her brain, doctors would have to cut open her skull, then drain and rinse away the pus. Too much pressure on the brain can lead to a stroke, brain damage, even death.

Reannyn phoned her grandmother and asked that she pick up one of Raynah's younger sisters, Quin, on the way to Children's.

Ethan called his father, who was driving up from Kenosha.

"Get Amelia here," he told him. "This is life or death. There's a two-hour window before she goes into surgery."

Doctors did not wait even that long. Raynah was in the operating room within the hour. The surgery would be performed by pediatric neurosurgeon Irene Kim, who'd worked at Children's for two and half years.

"I think she was moaning, but she wasn't really talking," Kim said, recalling Raynah's condition.

The surgery would navigate through a minefield of risks, especially bleeding in the brain, which that can lead to a stroke. Already, Raynah could not speak, or move the right side of her body. Without surgery she would likely lose those functions, but she also could lose them if something went wrong during the procedure.

As the Bickles waited, the rest of their family arrived. In the waiting room, they turned the television to a children's show.

Ethan paced. He was aware of people talking to him but it was all just sound, distant and indistinct, like the nasal drone of Charlie Brown's teacher. A surgeon was opening his daughter's skull. What else mattered?

Reannyn felt as if she were drifting through a fog. She'd cried to the point where she could not cry anymore. She was hungry, but could not eat. She was exhausted but could not sleep. *Just get through the surgery,* she remembers thinking.

The Bickles received occasional texts from the operating room; it felt as if they arrived every 90 minutes or so.

Raynah's been sedated. We're about to begin.

Everything's going well. She's stable.

We're about to start closing. Everything went well.

Around 11 p.m., Kim came from surgery to the room where the Bickles were waiting.

The neurosurgeon said: Everything that could go right did.

More surgeries needed

Although the procedure had gone well, Kim had to remove almost half of Raynah's skull in order to relieve pressure on the brain and clear away the infection.

The surgeon had not reattached the portion of Raynah's skull that had been removed. She left it off to allow the brain room to swell.

A flap of skin was all that covered the missing chunk of Raynah's skull.

From the beginning, Kim had told Reannyn there was a good chance they would need to operate more than once.

A single surgery doesn't always clear the entire infection. Any remaining infected material can keep growing, requiring doctors to re-operate and wash out more pus.

In Raynah's case, a very small amount had collected outside the brain in an area between the two hemispheres. Kim hoped that antibiotics would knock out the remaining infection.

Almost a week after the first surgery, however, the infection had begun to grow back. Raynah required a second operation to drain more pus.

Four days later, on Nov. 9, 2019, surgeons had to go back into her skull for the third time to deal with the infection.

"It was concerning that it was not responding to the antibiotics in the way we'd hoped," said Kim, who is also an assistant professor of neurosurgery at the Medical College of Wisconsin.

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While the surgeries were hard on the Bickles, so were the periods in between. Reannyn's eyes stayed glued to her daughter's vital signs on the monitor, willing them to improve. The child's blood pressure, in particular, was low.

Raynah's fever — once as high as 105 degrees — hovered for days between 100 and 103. She would shake and shiver. She suffered multiple seizures, for which doctors gave her a strong medication.

The anti-seizure drug left her "zonked 90% of the time," Reannyn wrote on the Facebook page she had created for her daughter, "BrainahStrong."

Although her breathing tube had been removed, it would be a month before Raynah could talk.

"We are scared, but trusting in God," Reannyn wrote on Facebook on her daughter's 11th day in the hospital. "She is still unable to move her right side and can't speak, but she is trying very hard with all her therapies. She is fighting hard."

Doctor who made headlines in 2004 joins Raynah's team

The team of infectious disease doctors at Children's meets every Wednesday to discuss their patients, and on Nov. 6, they talked about Raynah and her stubborn infection.

One of the doctors asked to weigh in was Rodney Willoughby Jr., who'd come to Children's and the Medical College of Wisconsin 15 years earlier from Johns Hopkins Hospital in Baltimore.

Willoughby, who'd once worked at a two-room clinic in the high savanna of Cameroon, had made international headlines in 2004, his first year at Children's. He and a group of colleagues saved the life of a 15-year-old Fond du Lac girl named Jeanna Giese, the first person in the world to survive rabies without a vaccine.

Giese, who had contracted rabies after being bitten by a bat in church, came within hours of dying. Willoughby and the other doctors placed her in a medically-induced coma to protect her brain, and treated her with a cocktail of drugs, a therapy that became known as the Milwaukee protocol.

Giese survived and gradually recovered the ability to walk and talk until she showed little trace of her medical ordeal. In 2011, she graduated from Lakeland College in Sheboygan. In the years since, she has gone on to marry, raise three children and race sled dogs.

In the years since 2004, Willoughby had endured trials of his own, following a path that would lead him to a second desperately ill young woman.

An epiphany leads to insight on a lethal gas

The Milwaukee doctor spent years fielding criticism from researchers who'd devoted their careers to working on rabies and were skeptical that the new treatment had saved Giese.

Willoughby, a professor of pediatric infectious disease at the Medical College of Wisconsin, patiently refined the therapy and posted it online so that doctors around the world could use it.

Early attempts on other patients were unsuccessful; Willoughby believed doctors often started the treatment when the rabies virus was too far along for the patients to be saved. Gradually, though, Giese was joined by a small procession of rabies patients who'd received the treatment and recovered. To date, at least 18 people have survived what was once a death sentence.

Willoughby continued caring for patients at Children's. The intensely curious doctor also pursued research interests of his own.

One involved hydrogen sulfide, a colorless gas produced by decaying material and known for its rotten egg smell and devastating toxicity. The gas, a hazard farmers deal with when they work around manure pits, is so lethal it knocks out the smell nerves before the brain can react.

"It's like throwing a grenade," Willoughby said. "Everything in range of the shrapnel gets hit."

In 2016, a farmer from Amherst, Wisconsin, died along with 16 of his cattle after he stirred a manure lagoon. There had been a crust on the manure and when the farmer broke it, hydrogen sulfide was released. He was overcome in seconds.

Willoughby had become interested in the gas a few years earlier after treating a 4-year-old boy who'd become very ill with the bacterial infection meningitis. Despite being treated with powerful antibiotics, the boy declined over the next two weeks.

The answer emerged, as it had with Jeanna Giese in 2004, through a detailed search of medical and scientific papers. Willoughby ended up reading about 200 papers related to hydrogen sulfide.

He found that the type of bacteria causing the boy's meningitis also produced hydrogen sulfide gas, which could impair brain cells. The gas, produced within seconds, gradually poisoned an expanding area of brain.

To rescue the brain, doctors used a treatment familiar to scuba divers: hyperbaric oxygen.

Divers who rise to the surface too quickly suffer decompression sickness or "the bends." The condition is caused by nitrogen bubbles that form in the tissue and blood, leading to a variety of symptoms including joint pain, dizziness and weakness.

A hyperbaric chamber delivers pure oxygen under pressure, which eliminates the nitrogen bubbles from the blood. The treatments are not used solely by scuba divers. Doctors use them for a variety of conditions, including aggressive infections. Hyperbaric oxygen therapy can kill or slow the growth of certain kinds of bacteria, reduce swelling and assist in wound healing.

In a desperate effort to reverse the decline of the boy with meningitis, Willoughby and his colleagues decided to treat him with hyperbaric oxygen. After six treatments, the boy's blood flow to the brain improved. He was more alert. His eyes were better able to track moving objects.

Although the boy suffered some brain damage, he fared better than expected. Willoughby would look back on the moment as an epiphany. He'd never understood why complicated frontal sinus infections — like the one Raynah suffered — caused such heavy damage to the brain.

Now he knew. It was the hydrogen sulfide, which can pass through the tissue protecting the brain.

"It's like falling into a manure pit," Willoughby said of Raynah's abscess. "Only the manure pit invades you."

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Hyperbaric treatments, Willoughby reasoned, could be used to deactivate the toxic hydrogen sulfide, allowing it to harmlessly exit Raynah's body in her urine.

When used to fight hydrogen sulfide, the treatments did have a shortcoming, Willoughby said. Patients felt better right afterward but would start to feel worse as the hydrogen sulfide levels gradually rose again before the next treatment.

But Willoughby's research had led him to a possible solution. A 1961 paper by a Russian researcher found that dogs suffering from circulatory shock could be stabilized with high doses of vitamin B12, a nutrient that helps keep the body's nerve and blood cells healthy.

The effects of B12 last between five and seven days, more than enough to serve as a bridge between the hyperbaric treatments.

After the weekly meeting of infectious disease specialists, Willoughby went to talk with Kim, Raynah's surgeon.

"Would you mind if I go talk to her parents?" he asked.

Then, with Kim's blessing, Willoughby knocked on the door to Raynah's room.

Saving Raynah's brain from deadly hydrogen sulfide

By this point, Raynah's parents were exhausted. Their daughter's high fevers had continued. Doctors said the most recent surgery to clear infected material from her skull might well have been the last she would need, but Reannyn would not let her hopes get too high.

"We all know, it is possible she'll need more," the mother wrote on Facebook.

Willoughby described the B12 and hyperbaric oxygen therapy and why he believed it would help Raynah recover. At that point, she was having major difficulties walking and talking, and was likely to need six months of rehabilitation in a long-term care facility.

If the treatment worked, within days it would clear away the hydrogen sulfide that kept leaching into her brain. She might regain her speech and movement skills much faster.

Ethan listened. He had met many doctors in the last few weeks and been asked to make many decisions. Too many. He was maxed out on decisions.

The Bickles would let the doctors decide. If Raynah's pediatric critical care doctor, Rainer Gedeit, supported Willoughby's treatment, then they'd try it.

Willoughby and Gedeit discussed the therapy and agreed to pursue it. Raynah received her first infusion of B12 on Nov. 10, 2019. An MRI scan the next day showed no fluid increase in her brain.

"Finally," Reannyn wrote on Facebook. "They may have got it under control ... PTL (Praise the Lord)."

Raynah's first treatment with hyperbaric oxygen took place two days later at Aurora St. Luke's Hospital, home to one of the nation's first programs in hyperbaric medicine.

The hospital still displays its first two treatment chambers, which were nicknamed "Bonnie" and "Clyde" after the bank-robbing couple immortalized in the 1967 movie. The two chambers look like mini-submarines with small portholes.

Raynah's 90-minute treatment took place in a far more modern setting. She sat inside a special room wearing a clear plastic hood and listening to the hiss of the pressurized air.

Laurie Gesell, an avid scuba diver and mother of three who specializes in hyperbaric medicine at Aurora St. Luke's, explained the process to the Bickles.

Hyperbaric oxygen therapy would help Raynah, not simply by getting rid of the hydrogen sulfide, but also in more traditional ways. The treatments would help her immune system engulf and kill bacteria. They would also reduce swelling in the brain, and help the antibiotics do their job.

The main potential complication with the treatment would be seizures, which can be quite serious.

Gesell would be watching over Raynah throughout her treatment.

"It was a very sad situation," Gesell said, "because my children are around the same age. That's when it hits you hard."

The first treatment left Raynah wiped out. A video taken the following day showed her in bed — drained, eyes closed, the left side of her head shaved from surgery.

"Hey," her mother asks on the video. "Can you say 'Hi'?"

Raynah turns toward her mother, opens her eyes.

"Hi," the girl whispers.

"Good job. Can you say Mom. Mo-mmm. Mo-mmm. Mo-mmm."

Raynah mouths the word each time, but no sound comes out.

Later that day Reannyn and Ethan checked into the Ronald McDonald House near the hospital. They'd had little sleep during the last two weeks. Settled into their room, they took a nap.

Over the next few days, Reannyn's Facebook posts described steady improvement.

Nov. 14: "We busted out of ICU today! We're now on the neurosciences rehab floor and it is AMAZING ... Still no talking or voluntary movement on the right side. BUT there is involuntary movement while she's sleeping and she has mumbled words in her sleep."

Whenever she left bed, Raynah had to wear a helmet to protect the area where part of her skull was missing.

Nov. 16: "My cousin painted Raynah's helmet and she smiled huge when she saw it."

Nov. 17: "Hyperbaric #5. Raynah had LOTS of visitors today ... After everyone left, we celebrated with ice cream."

Nov. 20: "Right leg is making a comeback people!!!! She can't be stopped now."

Nov. 24: "Raynah was super giggly today."

Willoughby, a father of three, checked constantly on her progress. "I was trained to treat all my patients as if they were my own children," he said.

Raynah still could not speak. She used an alphabet board to spell out words. It was approaching Thanksgiving and there was already a mini-Christmas tree in the room. Doctors doubted she would be home for the holiday.

Raynah looked at the tree and spelled out H-A-L-L-O-W-E-E-N. She did not realize Halloween had come and gone. Two of her sisters had celebrated birthdays during her time in the hospital; Quin turned 5, Amelia 3.

Raynah spelled out anxious messages to her parents. "What about my French horn?" In the last few weeks, she was to have started taking lessons on the instrument. "What about my toothpick bridge?" The bridge was going to be a project for school.

Instead, Raynah worked to relearn lessons from earlier in childhood.

She spoke her first word: "Ma-ma." For a while, that was the only word she could manage.

The Bickles spent Thanksgiving 2019 in the hospital. They worked hard with their daughter. Over and over again they stood, each supporting one of her shoulders, as she learned to walk again.

Down the hallway to the nurse's station, then a five-minute rest. Next, it was on to the children's playroom. Another rest. Then to the couches in the lounge at the unit's entrance. Rest.

At home, the Bickles had been given a "Days Till Christmas" countdown with numbers that could ripped off as the holiday grew closer. The Bickles taped a label over it that was more appropriate to their lives: "Days Till Home."

The funny thing was that Ethan and Reannyn had both grown accustomed to saying, "I'll see you at home," when they meant the Ronald McDonald House.

Raynah's MRI scans kept improving. For days she had tried to say other words but they always came out "Ma-ma." Then one day, a second word: "Dad." She began practicing the names of friends and family so she could say them when they visited.

She began to walk on her own, faster every day.

On Dec. 9, Raynah had her last hyperbaric treatment. Then, on Friday the 13th, far earlier than anyone had predicted, she was released from Children's and returned to Racine.

Ethan converted the living room into a makeshift bedroom for Raynah, replacing the couch with her bed and adding a set of curtains that pulled around for privacy. The family of her best friend Gabby Tignino placed a large sign on their garage: "#BrainahStrong."

Christmas 2019 was the first time in weeks the Bickles and their children had all been at home together, including Raynah's big sister, Mady, then 13.

"We kept it low key," Reannyn said. "They all got the gifts they wanted. Raynah got a Kindle. She just devours books."

Although everything felt settled again, 2020 began with Raynah still needing one more surgery. The doctors had never replaced nearly half of Raynah's skull removed during her first surgery.

There was a possibility that the section of skull removed contained infected material and therefore could not be put back in place.

Sculpting the implant to secure Raynah's skull

Until the missing section of skull was replaced, Raynah had to wear a helmet everywhere but in bed.

Raynah missed riding her bicycle, rollerblading, swimming. She would be unable to do any of those things until after her final surgery. On top of everything, the helmet got sweaty and uncomfortable.

Since doctors would not be using the original section of her skull, they would need an alternative. Today a substitute for human bone can be manufactured using a 3-D printer, then attached to existing bone by a neurosurgeon.

On Feb.13, Kim met with Raynah and her parents and told them it would take four to six weeks to get the implant made. Raynah's procedure would take place the first or second week in April, at the earliest.

As the Bickles left Children's that day, news organizations were reporting the 14th U.S. case of a new coronavirus. At that point, the virus had killed almost 1,400 people, most of them in China.

The surgeon at Children's sent a CT scan of Raynah's head to West Chester, Pennsylvania, to a company called DePuy Synthes, part of the Johnson & Johnson Medical Devices Companies. The images, which arrived in West Chester on Feb. 18, represented slices of the skull that fit together to form a three-dimensional image.

Kristina Collins-Watts would be the designer, creating a patient-specific implant fashioned from a high performance plastic called PEEK. Collins-Watts, 27, had worked with a 3-D printer in her previous job making bridal jewelry.

"I wanted to do something different," she said. "I have to say this is very rewarding. It's rewarding to know that what I'm doing is going to help a person move on to their own new normal."

There is an artistic element to the work. Designers sometimes compare it to sculpting clay. "Everyone's head is different," Collins-Watts said. "You need to have an artistic sense to make the implant so that it matches."

Raynah's took about three hours to make. Collins-Watts sat working on her computer listening to mellow jazz, and some classical music here and there. As she worked, sometimes she thought how the 3-D printing technology had once been so basic. Now people make soy-based ice cream using printers.

Her work was then reviewed by Kim, who suggested some small tweaks. The implant was then created and sent back to Children's hospital on March 3.

Raynah's surgery had been scheduled for April 6.

By then the world had changed. The number of U.S. COVID-19 cases had exploded to almost 31,000 on April 6. The virus, now a global pandemic, had killed more than 1,500 Americans.

Many states were under stay-at-home orders.

Hospitals were swamped. As they edged closer to capacity many, including Children's, began postponing surgeries that were not medical emergencies. That included Raynah's final operation.

Raynah seldom cries, but she did on April 6.

"I just want my bone on," she said. "I wish I could just have the surgery and be done."

As it turned out, Raynah did not have to wait long. Her surgery was rescheduled for the morning of April 20.

The weekend before, her neighbors in Racine formed a parade of cars honking their horns in support. On the day before the surgery, she was tested for COVID-19. She did not have the virus. Everything was set.

One last surgery for Raynah

The pandemic had changed hospital practices. Only one parent could accompany Raynah inside.

Around 8:30 a.m., Reannyn was waiting with her daughter, when hospital staff came to wheel her into surgery.

Raynah had slept well the night before. No nerves at all.

While she waited, Reannyn passed the time reading one of the Harry Potter novels. Raynah had watched all of the movies based on the books, and Reannyn wanted to discuss them with her.

Ethan stayed at home, pacing in his basement office. When his daughter left that morning he'd told her, "I love you. I'm glad you're at the end."

As he paced, he said, "I'm just hoping nothing goes wrong and there's no decision we have to make."

Later Ethan drove to the hospital, and he and Reannyn switched places. One stayed in the car in the parking garage, the other in the hospital.

The surgery, known as a cranioplasty, began with an incision. Kim gently separated the scalp from the dura mater, the thick membrane that surrounds the brain and spinal cord. The surgeon identified the edges of the skull, then positioned the implant.

"I had to trim the implant slightly with a drill to get the contour exactly the way I wanted it," the neurosurgeon said later.

Kim secured the implant with titanium plates and screws. Then she closed the scalp incision. A little after 1:30 p.m., the surgery ended.

Kim told the parents that it had gone well, better than expected. When Reannyn went to see her, Raynah looked up. "Hi, I'm awake," she announced.

Several of the nurses who knew Raynah from her hospital stay back in the fall, popped their heads in the door to say hello.

The surgery, Reannyn said, "brought a lot of joy to a lot of people in this dreary, dreary time."

'This is like our end point'

For Raynah, it was a great summer. The family went boating in northern Wisconsin. They visited the Great Wolf Lodge, an indoor waterpark in Wisconsin Dells.

Sometimes at home, Reannyn and Ethan heard their daughter and her sister Mady giggling in bed at night.

Raynah made rapid strides in speech and walking until she showed little sign of her medical crisis a year ago. Because her skull is already almost fully developed, she will not need a new implant when she gets older.

As the pandemic surged again in the late fall, Raynah's school went to virtual lessons. Like other children, she was disappointed.

One Saturday in December, Raynah sat on the couch wearing a T-shirt that said: "Brain Surgery. Been There. Done That."

"This is like our ending point," Ethan said. "There were times when I was falling apart and Reannyn was holding me up, and there were times when it was happening to Reannyn and I was holding her up."

Raynah was thinking about what the bedroom should look like when they painted over the "Frozen" theme. When she looks at the room now, the colors are too bright, "the snowflakes are too little kiddish."

She likes venturing out into the woods, seeing the birch trees. She imagines a bedroom that feels "like the inside of a cabin."

Warm and cozy.