

# Baby born with brain cancer surviving with chemotherapy

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Peering intently at the tiny white smudge in their baby's brain scan, Sue and Ben Erickson could see that the image did not reveal the miracle they had prayed for.

The cancer still lurked, though it had shrunken significantly after five rounds of chemotherapy. The news was as good as they could expect, realistically, and the doctor was upbeat.

"It looks good. It looks good. I'm happy," said Dr. Rishi Lulla, a [pediatric oncologist](#), as he reviewed the images at Lurie Children's Hospital in Chicago. "It's substantially, substantially better."

The results from last week's MRI marked a pivotal time for Matthew Erickson, who, at 8 months old, has charmed every nurse with his single-toothed grin. He was born Dec. 11 with an especially aggressive form of [brain cancer](#), a high-grade glioma that developed while he was still in his mother's [womb](#), even though it's most often diagnosed in adults.

The cancer, whose causes are unknown, had engulfed most of the [right hemisphere](#) of Matthew's brain. Only about five children nationally are born each year with such a rare, usually fatal, condition, his doctors said when the Tribune first chronicled the family's story in February.

At the time, doctors gave the Huntley couple a difficult choice: bring Matthew home with a hospice team, love him and keep him comfortable until the inevitable. Or, they could treat the cancer aggressively with

chemotherapy, a toxic cocktail with no certain outcome.

While used successfully with some other babies, chemotherapy could cause additional long-term damage or even hasten Matthew's demise, the doctors warned.

Matthew seemed determined to make the decision for the couple. He was a born fighter, his parents said, and he rarely cried, making the treacherous journey a bit less emotionally taxing on his parents.

Even when he throws up, he smiles, his mom said.

"You look at him, you look at his eyes, he has life," Sue Erickson said.

The couple arrived at the hospital at 6 a.m. Aug. 16, the day of Matthew's MRI, admitting they did not sleep the night before. For six months, the family had set their sights on this day, to find out how well their baby responded to the aggressive treatment.

"Too nervous. Too excited," said Ben Erickson who, like his wife and mother-in-law, wore a T-shirt that read "Grey Matters" with the family name on the back.

Since their decision to fight the cancer, the couple has also fought to maintain normalcy.

Matthew has spent at least two to three weeks each month in the hospital, dealing not only with the chemotherapy's side effects, but complications from diabetes insipidus, a kidney condition marked by excessive urination that can lead to dehydration. He also suffers brain seizures, which are likely caused by the tumor and surgeries, Lulla said.

Meanwhile, time marched on. The couple's son, Nolan, 5, just started

kindergarten. Their daughter, Sophia, recently celebrated her second birthday with a "princess party."

Matthew's saga splashes over into daily routines. Sophia one day picked up a calculator, held it to her ear like a cellphone, and said, "Dr. Lulla? Dr. Lulla?"

Sue's parents, Louise ("Nunny" to her grandchildren) and Bob Turner, help juggle child care and doctor appointments.

School also started last week for Ben, a teacher at South Elgin High School.

Hundreds of students surprised him last spring with a donation for Matthew, whose every visit to the hospital generates a lengthy bill. The most recent invoice was 69 pages long.

"Thank God for insurance," said Ben, who was not sure where the total stands.

After the MRI, Matthew awakened from sedation smiling, as usual.

Over prior months, he has undergone four brain surgeries, and received 30 to 40 transfusions for blood and platelets. At one point, he was left with only one long strand of hair clinging to his head. Within days of his last treatment, a soft layer of "peach fuzz" had begun to reclaim his head.

Developmentally, Matthew has made progress each month.

He babbles like other babies his age. He sits up, but finds it hard to stay there, or to hold a bottle, possibly because of the weight of a catheter in his left arm, Sue said. The peripherally inserted central catheter, or Picc,

is a semipermanent port used to deliver fluid and medications or withdraw blood.

As the family traipsed through the hospital, headed from recovery to a clinic where they would learn more answers, they stopped along the way to greet familiar faces.

"Where's your little baby?" said one nurse, noticing that Matthew's size has doubled, to 16 1/2 pounds, over recent months.

"Little dude, you're beating this thing," said another patient's mother, Deidre DeVance, cooing over Matthew in his miniature track suit. "You don't even know what you're beating, but you're beating it."

Sue, Ben and Louise huddled around a computer with Lulla, a physician in the hospital's Division of Hematology, Oncology and Stem Cell Transplant.

He pointed to the screen showing four images of Matthew's brain from MRIs taken in December, February, May and July.

The change was obvious, even to a layman.

Instead of gray brain matter, the scan taken eight months ago revealed a gaping dark cavern in the brain's right hemisphere, where excess fluid had collected in the oversized ventricles, or cavities that allow the flow of cerebral spinal fluid. The tumor was hunkered down in the middle, a small bright white spot.

By May, the tumor was "very subtle," Lulla said, pointing to a smidgen of white against gray. Brain surgeries to remove portions of the tumor and fluid had been successful, as well.

"What if we had decided to do nothing? What do you think would have happened?" Ben Erickson asked, as the couple sat quietly, absorbing the information.

"I don't know the answer. I think he would have died, not from the tumor but the (pressure of fluid-filled) ventricles," Lulla said. "Our goal is to stop the tumor from growing and get Matthew to grow around the tumor."

Sue Erickson asked the next big question: "Is there ever going to be a point where there is no cancer?"

Probably not, Lulla said. Even a few abnormal cells left behind may lead to the cancer's return, he explained.

While Thursday's scan showed even more improvement, the scary white smudge lingered and prompted debate among doctors during their weekly "tumor board" meeting.

During these sessions, oncologists, surgeons, nurses, radiologists, pathologists and social workers discuss new cases and patients whose treatments have reached critical points.

On Aug. 21, Lulla and Dr. Tord Alden, a neurosurgeon, laid out Matthew's case to the group of about 20 people. As they viewed brain images projected on a large screen, specialists questioned whether they were looking at scar tissue or tumor, and how fast, if at all, the cancerous cells would spread.

At 9 p.m. that night, Lulla called the couple and discussed options.

Some doctors felt that the chemotherapy should continue. Lulla and Alden recommended giving Matthew a two-month break, during which

time they could also treat his brain seizures with steroids.

"Ben and I, we almost knew the ball would be put into our court and we would have to make that decision," Sue Erickson said the following morning.

The couple decided to follow the advice of the doctors who know Matthew best, Lulla and Alden. The steroid treatment should be far easier for his body to tolerate than the chemo, said Lulla, the recent recipient of a nearly \$100,000 research grant from the St. Baldrick's Foundation, a charity that raises money to combat childhood cancers.

"Nothing is guaranteed," Sue said, recalling that there were those who doubted the couple's decision to proceed with chemotherapy in February. "There was a risk then. There is a risk now."

[Chemotherapy](#) administered to children younger than 3 with a high-grade glioma offers a 40 to 50 percent chance of survival for three years, Matthew's doctors have said. Yet they are treating other children who have beaten similar odds - who have shown doctors that nothing is certain.

Early on, the couple adopted a family motto: "Defined by God, not by cancer."

"Matthew has blown any statistic, any number out of the water," Sue said. "To keep on with chemo I know could help him, but I also know if we don't address the seizures, that could affect him a lot more. I am looking at Matthew as a survivor, and as a kid in 12, 14 years."

Since his [MRI](#), Matthew has been readmitted to the hospital twice after having trouble keeping food down. On Monday his condition had improved and he was prepared to start the steroid treatment, Sue said.

He will remain in the hospital under observation this week, she said.

If the tumor shows no change in two months, the doctors could continue the wait-and-see approach, Lulla said. Matthew will soon start occupational, physical and speech therapy sessions at home.

Meanwhile, his parents take great joy in the milestones that most take for granted.

After reviewing their baby's brain images, Ben looked closer at the scan and asked: "Can you see his teeth?"

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