

Mondamin girl's sore arm leads to cancer diagnosis

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Reporter

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Paige Perry felt like being a doctor for a day as she played with a stethoscope during a recent hospital visit. Photo submitted

"It was just a fluke thing," he said. "We'd just found out she had a tumor and then she coded and was in the ICU."

Andrea said that while Paige was in the ICU, she went in and out of consciousness.

"She would open her eyes now and then," she said. "They kept her pretty sedated."

On March 23, doctors at the University of Nebraska Medical Center in Omaha, Neb., performed a bone biopsy on Paige so they could determine the nature of the tumor. She later underwent CT and bone scans April 2, which showed that the cancer had not spread.

Ewing's sarcoma often spreads to the lungs and other bones, according to the MedlinePlus Medical Encyclopedia, a service of the U.S. National Library of Medicine and the National Institutes of Health. Metastasis - the spread of a cancer from the original tumor to other parts of the body by means of tiny clumps of cells transported by the blood or lymph - at the time of diagnosis is present in approximately one-third of children with this cancer.

The results of Paige's bone biopsy came back April 5 and confirmed that she has Ewing's sarcoma. She

Ken and Andrea Perry thought their daughter just had a sore arm.

The Mondamin couple was with their bright and bubbly 20-month-old daughter, Paige, March 14 in Blair, Neb., to have her left arm examined. Ken and Andrea noticed the day before that Paige was holding her left arm like she had a slipped ligament or Nursemaid's elbow.

Five days later, the Perrys took their daughter to her pediatrician in Omaha, Neb., who was concerned enough to send them on to Children's Hospital & Medical Center the same day. While they were there, X-rays showed a tumor in and around a bone right above the elbow on Paige's left arm.

The Perrys didn't know this at first, but the small tumor turned out to be Ewing's sarcoma, a malignant, aggressive bone cancer that typically affects older children, especially boys, from the age of 10 to 18, according to what they were told by doctors. But before Ken and Andrea found this out, Paige had a bad reaction to the anesthesia while she was sedated during an MRI and ended up in the hospital's intensive care unit (ICU) on a ventilator for 20 hours starting March 20.

Ken said Paige quit breathing for a minute and a half.

has a 70 to 75 percent chance of surviving the cancer, according to what doctors told the Perrys.

Ken said that before he and Andrea knew what was wrong with Paige, they were unbelievably stressed. Once they found out her diagnosis and heard about treatment options, they had to accept their daughter's dilemma.

"Yeah, it was pretty bad," he said. "We had some pretty low times when we first found out. Then we moved on and became more focused on treatment, and that seemed to help. But before we knew what we were going to do and what the treatment was, it was kind of up in the air."

Andrea said all she and Ken thought was Paige might've had a fracture in her arm, but once they found out about her cancer, everything changed.

"We were just slammed with that," she said. "Then she has to go to the ICU. All that happened in one day. It was a long time before we heard any good news."

Ewing's sarcoma can occur anytime during childhood and young adulthood, but usually develops during puberty, when bones are growing rapidly, according to the MedlinePlus Medical Encyclopedia. It may arise anywhere in the body, usually in the long bones of the arms and legs, the pelvis or the chest and may also develop in the skull or the flat bones of the trunk.

There are few symptoms, according to the MedlinePlus Medical Encyclopedia. The most common is pain and occasionally swelling at the site of the tumor. Children may also break a bone at the site of the tumor after a seemingly minor injury (this is called a "pathologic fracture"). Fever may also be present.

Ken said doctors had a hard time diagnosing Paige's tumor. He and Andrea hoped it was benign.

"They couldn't really believe what they were seeing," he said. "It took 10 to 12 days for the pathology to come back."

On April 8, doctors at Children's Hospital performed a bone marrow biopsy on Paige to determine if the Ewing's sarcoma was in her bone marrow, but it's not. Since the cancer had been caught early, it hasn't spread from her elbow and treatments of it are fairly successful, the Perrys have more hope Paige will survive the tumor.

Ken said doctors don't know why Paige has Ewing's sarcoma. He and Andrea were worried that their two sons, 10-year-old Trevor and eight-year-old Jeffery, were at risk for the cancer.

"They basically told us that our other kids are fine and don't even bother checking them because it doesn't run in the family," he said.

Paige then started chemotherapy April 9. She receives treatments every two weeks at Children's Hospital, but they alternate between two-day and six-day sessions. She'll have her third overall treatment of six starting, Friday, May 7; it's only two days versus the six days she just finished up April 28.

Ken said Paige didn't feel well between her first two treatments.

"She was in the hospital for three days with a fever," he said. "As soon as she gets a fever now, we have to take her in and get her admitted."

Once Paige is done with chemotherapy, the next step is most likely radiation therapy to the tumor site because Paige is too young for surgery to remove the tumor, according to what doctors have told the Perrys. Depending on what the chemotherapy and radiation do, doctors could have to amputate her arm, or if the treatments work, they would surgically remove the tumor, which is embedded in the bone, once Paige is older.

Ken said he believes that the surgery doctors would perform on Paige when she's older would cut out the complete bone.

"That would leave her without as much of her lower arm," he said. "She's so young that now they're thinking of just doing radiation on it, but that would kill the tumor and the bone, so she'd end with complications with her bone not growing. But that's unavoidable.

"They're thinking they're going to kill it with radiation and then, when she gets older, do some surgery to lengthen the area out so it doesn't look out of whack with her other arm."

Ken, a full-time farmer and part-time technician at Cargill in Blair, Neb., and Andrea, who works part time for Little Sioux as the city clerk, are just beginning to deal with how expensive cancer treatment can be. They do have health insurance, but the bills, which will probably be in the thousands of dollars, are piling up fast. The Perrys have to give Paige one \$100 shot a day, but they recently had to throw some out because they were expired.

Ken said no amount of money will stop him and Andrea as they fight to keep Paige alive.

"We've got to spend what we've got to spend to save her life," he said.

Ken and Andrea's family members have been both helpful and supportive. Paige's brothers, Trevor and Jeffery, are quite protective of her and wash their hands often because they understand the seriousness of her situation. They're talking about shaving their heads this summer as a show of support. The children's grandparents live in the area and have been assisted tremendously. Ken's brother, a farmer from North Dakota, even came down for a week when the Perrys first found out about Paige's cancer.

The Perrys' neighbors have brought them food. So have members of Country Bible Church in Blair, Neb., where the family goes every Sunday.

Ken said he and Andrea are overwhelmed by the support they have received.

"Our freezer is full of just ready-to-bake lasagnas," he said. "All I have to do is put something together and we're eating a good meal. It helps so much."

Much to Ken and Andrea's surprise, the 4 Rivers Riding Club is going to hold a Poker Run to benefit Paige on June 5. People can register from 11 a.m. to 1 p.m. at Sour Mash in Modale. The ride ends at the Magnolia Event Center; an auction and prize drawings will start at 7 p.m., followed by live music and food. For more information or tickets, call 402-516-2332 or 402-250-8814.

Andrea said the fundraiser surprised her and Ken.

"It's humbling," she said. "We're thankful."

An account has also been set up at all Community Bank branches where donations can be made on Paige's behalf. Community Bank has locations in Dunlap, Logan, Modale, Persia, Pisgah, Soldier and Ute.

Currently, Paige's relatives and friends are caring for her the best they can as she fights the Ewing's sarcoma in her left arm. She has a central line that runs from her chest under her skin up to a vein in her neck, which is used by doctors to take blood and give medicine; her parents flush it for her. When people come to their home, a sign on the front door tells them to please wash their hands.

The Perrys have had to cancel camping and fishing trips they had planned for late spring and summer, but those are small sacrifices they're willing to make so their daughter can get better.

And they can't stop saying how thankful they are for the help they're receiving, Ken said.

"It's really amazing," he said. "It's just comforting to know that there are so many people out there willing to help out when they hear about something like this."

To leave Paige an online message and follow her story, go to www.caringbridge.org/visit/paigeperry.



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