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Santa Claus holds Alaira Widener, 3, recently at Children's Hospital in Colorado with her mother, Patricia looking on. Alaira told Santa all she wants for Christmas is to go home. Friday morning, doctors confirmed Alaira's diagnosis of Rasmussen's Encephalitis, a rare inflammatory neurological disease most often contracted by children age 15 and younger.

Facing brain surgery, 3-year-old just wants to come home

By RACHEL COLEMAN

• Leader & Times

Like a lot of 3-year-olds in Liberal, Alaira Widener is a Disney Princess kind of girl. She's hoping Santa Claus will bring her a Cinderella doll for Christmas. That item isn't at the top of the spunky 3-year-old's list, though.

What Alaira wants most of all is to come home. She told Santa, and she told the doctors at Children's Hospital in Colorado — and she told them with a bit of sass.

"She's argued with them," said her mother. "Just this morning, she told the doctor, 'I 'AM' going home,' and when he tried to explain she'd have to stay a little longer, she said, 'Stop it! I'm going home.'"

Alaira has ample reason to lobby for a homecoming. Along with her parents, John and Patricia Widener, she's been at CHC all month.



Friday morning, doctors confirmed Alaira's diagnosis of Rasmussen's Encephalitis, a rare inflammatory neurological disease most often contracted by children age 15 and younger. The news came after months of out-of-town trips as her parents tried to find out what was causing their daughter's seizures and periods of unresponsiveness.

"This started back in September," Patricia said. "She was acting funny, she'd just stare off into the distance and she wouldn't respond."

When her parents took her to the emergency room, doctors thought at first that Alaira was having a seizure. Three months, three hospitals and nine different medicines later, Alaira's condition had worsened. She was having between 30 and 60 seizures a day; nothing seemed to stop the attacks. A week ago Friday, the family was flown to Denver, where doctors finally identified the problem.

“We’re glad to get answers,” Petricia said. After a long silence, she added, “but they weren’t the answers we were hoping for.”

The recommended treatment for Alaira’s condition is removal of the right half of her brain — as soon as possible.

“Then we’re looking at anywhere of six months to a year of rehab and physical therapy,” Petricia said. Before recovery, though, the surgery will extract a high cost. Alaira will probably always have a limp on the left side, her mother said. She’ll be permanently blind in her left eye. She won’t be able to use her left hand. The doctors don’t think the surgery will affect her speech or her cognitive thinking.

“They say that after six months to a year of rehab, she might be able to function normally,” Patricia said. “They say that if they don’t take care of it now, if we put it off too long, it could affect the other side of the brain.”

Receiving the prognosis for the couple’s only child, and the only granddaughter on both sides of the family, seemed profoundly unfair.

“I’ve already had my cry, my upset,” Patricia said, just hours after doctors delivered the news. “When we found out this morning, I went into hysteria, crying, bawling. It’s not fair. She’s three. What did I do wrong?”

By afternoon, she said, “I’m at the point where I’ve gotta be calm. I can’t scare her.”

According to her mother, Alaira, who will be 4 years old in May, doesn’t scare easily.

“She’s not one to sit still,” she said. “She’s a very active little girl. If you can climb it, she’ll climb

it. She loves to run and play. She's very smart. She already knows that if she gets lost, to tell her parents' names and her name.

"She's very sweet, very polite. She says please and thank you, you're welcome. She loves giving hugs and kisses. My daughter doesn't know a stranger. Everybody's a friend."

That includes the medical staff that have become part of her daily life in Denver.

"She's really good with them," Patricia said. "They do a really great job here, bringing toys in to the kids so they don't get bored, trying to make it more like Christmas. She got to see Santa Claus, and she was so excited. She gave him a big hug, and asked him not to leave."

With grandparents Tommy and Tracy Clay of Forgan on hand for daily support, along with both parents, Alaira didn't really need Santa's company. Patricia said she understood why her daughter wanted the visit to last, though.

"It's Christmas, she's three, and it's all about presents," she said wryly, adding that "everyone is working hard to make sure she has a great Christmas."

Amid the gratitude, Patricia said, there's a bittersweet element.

"It's the parents' job to make your kid's Christmas special, you know?" she said. "If we weren't here at the hospital — if things were different — I'd be out there working, trying to get as much done as possible, decorating the house, wrapping the presents."

As it is, Patricia lost her job after missing two weeks of work. The family's Kansas Medicaid insurance plan has provided coverage, but it isn't as generous as private insurance. Her husband, who works at O'Reilly's Auto Parts, is using what vacation time he has to be with the family in Denver.

At their empty home back in Liberal, no one has been around to put up a Christmas tree.

“Nope, not yet,” Patricia said. Then she added, “but it looks like we might make it home next Wednesday.” Since Alaira moved from the Pediatric Intensive Care Unit to the regular floor this week, the possibility is real. That means Christmas with her entire family, including grandparents Leroy and Jonna Black, uncles and their fellow Knights of Columbus members, and friends who are already organizing a fundraiser for Dec. 20.

Nancy Anderson, who’s known Alaira since her birth, helped organize the benefit, hosted by St. Anthony’s Parish Hall at 1510 N. Calhoun.

“Patricia and I worked together at JC Penney, and we called Alaira ‘The Penney’s Baby,’” she said. “I’ve babysat her since she was born.”

The Friday fundraiser will run from 5 to 9 p.m. A raffle with items from local merchants features a children’s table and chair set, handcrafted by Anderson’s husband, theater tickets from Southgate 6, a Best Market gift card, oil certificates from Stu Emmert’s, a year’s supply of pizza from Little Caesar’s, a 12-volt drill from Sears and merchandise and gift cards from Penney’s.

“So far,” said Anderson. “We’re hoping for more people to step up and help.”

A chili dinner will sell bowls for \$3, with chili dogs priced at \$2 and Frito chili pie at \$4. All proceeds will be donated to the Widener family’s medical and travel costs.

It’s not clear whether or not Alaira will dig into the chili. Her favorite these days is macaroni and cheese and chicken strips.

“I think we order that almost every night — or pizza, pepperoni pizza,” Patricia said.

Those moments of regular life with a girl who loves her mac-n-cheese are something to treasure, Patricia said, whose focus now is keeping a cheerful, confident attitude in the face of the year that lies ahead.

“Everybody keeps telling me, hope for the best, prepare for the worst,” she said. “Right now, all I can really think about is the first part. That, and Christmas.”

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