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Alaira sits in her hospital bed with a large teddy bear and a favorite blanket. She is learning to use the left side of her body after part of her brain had to be removed to save her life. Courtesy photos

Left-side learning After brain surgery, 3-year-old starts from scratch

By RACHEL COLEMAN

• Leader & Times

Alaira Widener is out of the woods. Her journey back to normal life, however, is just beginning.

Surgeons removed the right half of the spunky three-year-old's brain on Jan. 7 in an effort to stop the spread of Rasmussen's Encephalitis, a rare inflammatory neurological virus, to the left half of the brain. The life-threatening disease also causes chronic seizures, which was fortunate for Alaira: in September 2013, it was those periods of unresponsiveness, alarming "blank-outs" eventually identified as abnormal brain activity, that alerted doctors to her condition.

"The day we flew back to Children's Hospital of Colorado, she was having a seizure every three minutes," said Patricia Widener, Alaira's mother. "We spent the entire day at Dr. (Mariana) Lucero's office, until she could arrange for a flight to Colorado."

Alaira's surgery, though successful, took nearly 12 hours and left the usually active 3-year-old unable to move the left half of her body. As Patricia waited for her daughter to regain consciousness, she wasn't sure how to feel. Gratitude for a life saved mixed with a sense of loss.



"It broke my heart," Patricia said. "She was alive, but she couldn't move half her body. She couldn't do it. And I don't think she really understands what happened. She knows she had an 'owie' but she doesn't know why things don't work like they used to."

Shortly after recuperating from surgery — and an impromptu haircut to trim hair that had become hopelessly matted during a mandatory period of no movement and no shampooing — Alaira began the grueling work of recovery. Husband and father Steve Widener works full-time in Liberal. Meanwhile, Patricia stays at CHC with her daughter, where the pair put in full-time hours with therapists and trainers.

Up early, Alaira arrives at speech therapy for a 9 a.m. session, followed by exercise on a stationary bicycle. Next is physical therapy and occupational therapy. At 11:30 a.m., mother and daughter head back to the room for lunch and naps. They're back at work by 2:30 p.m. for a second round of PT and OT. That's the Monday-to-Friday schedule; on Saturdays, they get a break, Patricia said: "We only have physical and speech therapy once."

Frequent sessions are necessary if Alaira is to recover the use of the left half of her body; the right side of her brain, which controlled most of those functions, is gone. Her nervous system will have to reroute, finding new neural pathways to accomplish the tasks of daily activity.

"We're starting to get it back," Patricia said. "At first, there was no feeling and when it did start, it was like a pins-and-needles sensation."

More than a month of steady therapy has helped Alaira relearn to walk, if a bit stiffly. A new brace to stabilize her left leg will help, along with strength training and daily therapy sessions. The professionals focus on preventing her from developing bad physical habits, like hyperextending her knee, that could lead to cumulative problems in the future.

"She's very stubborn," said mother Patricia Widener. "She wants to do it her way, at her pace, and sometimes she gets real frustrated with the therapists."

When Alaira starts to cry or hit her therapists, Patricia said, she's expressing frustration about problems far too big for her 3-year-old world.

"There are times I have to leave the room," Patricia said. "She doesn't want to be here. She wants to be back at home."

In that, Alaira is on the same page with her team.

“We don’t really set goals about her therapy, but our main focus right now is getting her well enough to go home,” Patricia said. “She’ll still have to use the wheelchair for a long time, but once she can walk more, if the testing goes well, we will be headed back to Liberal.”

Both Patricia and Alaira are especially eager for the trip — about 10 days off — because their freedom within the hospital is limited. A staph infection required Alaira to be isolated from other patients, “and unless the weather is warm enough for us to go outside, we’re stuck in the room,” Patricia said. “I love this hospital, and they’ve been so good to us. But it gets long.”

In the meantime, Alaira hasn’t let the challenges dim her spirit.

“She’s still as active as ever,” Patricia said. “She’s not letting this whole, left-side thing bother her. She can scoot on her right hip quicker than anybody I’ve ever met. She’s determined.”

HOW TO HELP

Liberal community members, starting with Patricia’s co-workers at JC Penney, have already stepped up to support the Widener family. A December fund raiser at St. Anthony Catholic Church raised money for medical bills. A fund at Bank of Beaver City’s Liberal location continues to gather donations.

“It’s amazing,” Patricia said. “National Beef helped with our rent through April.”

Care packages have also helped ease the strain of a long hospital stay. To send mail to Patricia and Alaira, use the following address:

Children's Hospital Colorado — Sixth Floor

13123 East 16th Ave.

Aurora, CO 80045

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