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'He's a special little guy'

Ruby Gonzales, Staff Writer

Aiden Waters likes watching DVDs of the television show "Boohbah." He enjoys being tickled and is a big fan of Cookie Monster, too. But what is unusual about this 4-year-old Azusa boy is that he has had 15 laser treatments on his face and an operation for glaucoma. He's scheduled to undergo brain surgery Aug. 21 at Ronald Reagan UCLA Medical Center.

Aiden has a rare neurological disorder called Sturge-Weber Syndrome that causes him to have seizures. Like others with the syndrome, he was born with a large birthmark on his face called a port wine stain. In his case, it appears on the right side and covers part of his forehead and his right eyelid, which caused the glaucoma. Laser treatments have lightened the stain from purple to pink.

"It's not only a cosmetic issue, but a medical issue," said his mother, Rachel Waters, 31. The birthmark is caused by an overabundance of blood vessels around the trigeminal nerve. If left untreated, nodules will develop. What causes Sturge-Weber is unknown. It is characterized by the birthmark and neurological abnormalities. The brain underneath the birthmark is also affected, according to Anne Howard, director of communication for the nonprofit Sturge-Weber Foundation which is based in Randolph, N.J.

Aiden will be undergoing a hemispherectomy, in which the damaged parts of the right side of his brain will be removed. He needs donated blood for the upcoming surgery; a blood drive is scheduled for Saturday in Azusa. Dr. Charles Imbus is one of Aiden's neurologists, but is not part of the UCLA team that will be performing the hemispherectomy. He said the surgery will control Aiden's seizures and the child will have better use of the left hemisphere of his brain.

"Sometimes, we do better with half a brain" than a whole brain with a good half and bad half, Imbus said. "I really do have high hopes he will recover and be a self-sustaining individual in life."

Right now, Aiden takes medication for the seizures and for the glaucoma.

"I'm worried about the surgery," Waters said. There's "no way of knowing he will be better or worse. But without the surgery, he will have a life-long battle with seizures. He deserves to have a chance."

Aiden, Waters' only child, was born the day after Valentine's Day 2004. The birthmark on the baby's face was large and vivid. Her doctor identified it as a port wine stain. At the time, they lived in Arizona. She did research online and found that because the birthmark involved the forehead and the right eyelid, it was likely her son had Sturge-Weber Syndrome. Waters was told to take her son to an ophthalmologist, who found there was increasing pressure within the right eye. Aiden was put on prescription eyedrops and then had eye surgery when he was 2 1/2 months old.

At 3 months old, he had his first seizure and ended up in an emergency room. There, he was diagnosed with Sturge-Weber Syndrome. It was frightening, but not completely unexpected.

His first laser treatment to lighten the birthmark was when he was 4 months old.

Not everyone born with a port wine stain birthmark has Sturge-Weber. Between 8 percent to 15 percent of those with such a birthmark are at risk of having the disorder, according to the Sturge-Weber Foundation.

There are no exact numbers on how many people have Sturge-Weber Syndrome. Howard said the foundation can document 3,000 cases and those are people who notified them.

"When people call us, we ask them to register with the foundation because that's the only way we can get statistics," Howard said.

Each case varies in the degree of the symptoms exhibited. "The isolation is a big problem for families" who deal with a rare disease, Howard said. A rare disease is anything with fewer than 200,000 cases. "We can provide contact and support," Howard said.

Because Sturge-Weber is rare, Waters wants to spread awareness about it. "I know there are families out there like us," she said.

The foundation's Internet support group helped connect Waters to other local families dealing with the same issues. Waters said she knows of four others in Southern California, including a Long Beach family whose daughter went through a hemispherectomy a year ago.

Waters, who is divorced from Aiden's father, lives with her mother, Fran Pulokas, stepfather John Pulokas and boyfriend Jason McCormack, 33.

Waters works from home, selling safety signs and identification products. She takes Aiden to twice-weekly physical therapy, speech therapy and occupational therapy to teach him fine motor skills and hand-eye coordination. Since he doesn't know how to chew, he also attends therapy to learn feeding skills. He cannot say words, but he babbles. "Right now, he is 8 to 12 months old developmentally," she said.

She said Aiden's left side is partially paralyzed. He can move his left hand but won't use it to hold anything. His left foot tilts inward.

But Waters doesn't rail at the cards that fate dealt her son.

"It makes me sad more than anything else for a little guy to be born with all these problems right off the bat," she said. "I don't feel angry. I feel blessed. He's so loving."

But she has seen the stares and heard the callous remarks tossed their way by strangers. "I wish people would be a little more sensitive."

She actually prefers it when people ask her about her child. She would like to tell them about Sturge-Weber Syndrome. "It's just an unfortunate disease," she said. "I think Aiden has much potential but he's being hindered by it. But with medical technology, there's hope."

Waters wants Aiden to have a normal, happy life, to be able to go to regular school and to play and communicate with other children.

"He's more than his syndrome. He's a special little guy. I would like people to think of him as a person," she said.

ruby.gonzales@sgvn.com
(562) 698-0955, Ext. 3026



Four-year-old **Aiden Waters** kisses his mother, Rachel, while waiting at the Beckman Laser Institute facility in Irvine on Friday, July 25, 2008, where doctors use lasers to fade the Port Wine Stain birthmark from his face. Waters has a rare disease called Sturge-Weber syndrome which causes seizures and other neurological symptoms. He is scheduled for a hemispherectomy, a surgical procedure in which half his brain will be removed, on August 21.