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Fundraiser established to help toddler attend CdLS conference

July 9, 2015 - News - no comments

By Kimberly Snickles



Her name is Aubrey Garigen. She's only 2-years-old, but she's stealing hearts all around Western New York.

"She really is an inspiring kid, I must have to say," said Nicole Garigen, Aubrey's mom.

Aubrey is a beautiful and happy little girl who loves learning new things and spending time with her parents. But although she's a typical toddler at heart, Aubrey's life isn't so simple. She was diagnosed with Cornelia deLange Syndrome (CdLS), a rare genetic syndrome that affects only one in 30,000 births. Garigen explained the chances of conceiving a baby with CdLS are the same as anyone else's because the syndrome happens during conception and there's no way of telling beforehand that a child will have it.

"We found out within 24 hours of Aubrey being born that she had Cornelia deLange Syndrome and we didn't know much about it, so we started researching and found out that it was going to be a rough road," said Garigen.

Cornelia deLange Syndrome affects every child differently. Some children have symptoms that aren't even diagnosed for CdLS and others, like Aubrey, have many symptoms. Aubrey was born premature weighing only two pounds, 15 ounces. She had to spend four months in the NICU and her parents had to become certified to care for her before she was even allowed to go home. Aubrey now weighs 13 pounds and has a tracheostomy tube to help her breathe. Her parents also have a suction machine handy at all times to help remove anything that may be blocking her airways. And, while it's definitely not easy, Garigen says her daughter is a strong little girl that surprises her more and more each day.

"She's doing the best she could possibly be doing right now," she said. "We have to wait until she grows and her airway doesn't collapse. It could be six months to two years, but we have our fingers crossed that we will be able to get this tracheostomy tube out."

As Garigen and her husband both work full-time and care for Aubrey, keeping in touch with family and friends in regards to Aubrey's progress was not always easy. While Aubrey was in the NICU, another mother suggested that Garigen start a Facebook page to help keep everyone in the loop. It was entitled 'Prayers for Aubrey' and it's helped Garigen receive prayers for her daughter all over the world.

"She has 2,000 people that support her now," said Garigen. "She brings a lot of happiness to a lot of people and she's a fighter – that's for sure."

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Through the Prayers for Aubrey Facebook page, Garigen was able to make friends with other mothers who had babies similar to Aubrey with CdLS. She also found out that there will be a CdLS conference in Orlando, Florida June 23 – June 26, 2016. The conference would allow Aubrey’s parents to meet with other families that have CdLS children and attend seminars with specialists and doctors that can answer any questions they may have.

“Attendees receive a head-to-toe consultation with experts from a range of medical and educational fields,” said Garigen. “We will also be able to attend work shops on legal concerns, educational issues, and medical/behavior challenges.”

However, the trip would be a costly one as an admittance fee, possible plane tickets, gas, food and a hotel stay could add up. Not to mention Aubrey will need an oxygen tank, so the family would have to make arrangements through a vendor in Florida, an expense that insurance may not cover. While the Garigen’s don’t normally like to reach out for help from the community, Aubrey’s mom says this conference is vital to care for Aubrey and to learn more about CdLS.

“It will only make her care better if we attend the seminar because then we can share with her doctors what we learned,” said Garigen. “Right now it’s a learning game for the doctors at home because they learn from us. No syndrome is the same, so it’s a learn as you go situation.”

A YouCaring fundraising page has been established to help raise money to send Aubrey to the CdLS conference. If you would like to make a donation to help Aubrey, visit www.youcaring.com/aubrey-elizabeth-363236 You can also visit her Facebook page www.facebook.com/aubreyprayers to learn more about her syndrome.

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