

Support Lacking For Rare Disease Research

Stouffville family struggles to help ailing daughter

By Kinjal Dagli Shah

Five-year-old Alaina Priore was born with a genetic condition that affects her heart, lungs and stomach and puts her life at risk. She is the only person in Canada to be diagnosed with the combined health problems of Abca3 protein surfactant deficiency, pulmonary hypertension, atrial septal defect (a hole in the heart) and extreme reflex disease.

When Alaina was born, doctors told her parents, Michelle and Rocco, that she wouldn't live beyond a few months. Her case is so rare that her condition is not recognized. There is no foundation for her parents to find support and there is no research being done towards finding a cure.

"We offered the research department at Sick Kids Hospital \$20,000 to research her condition," said Michelle. "It was money raised from a benefit we had in Alaina's name. But the hospital declined the offer saying no one is interested in pursuing the research because Alaina's case is only one of her kind. It isn't worth their time."

When Alaina was 18 months old, Michelle set up a gofundme page in the hope that a crowd funding effort would draw attention to her daughter's rare condition, as well as raising money to offset the expenses the family were incurring in medical bills.

"We didn't receive a single donation. The only donation on the page was \$50 from an anonymous person, who in reality was me trying to just get people going," said the mother of two.

"I think people are reluctant to give because her condition isn't well-known and they don't see how sick she is. There's also some hesitation because we appear to be a family that isn't quite in need," added Michelle, who runs Country Casa Montessori Daycare in Stouffville.

The couple have learned to live with the fact that they may not raise much money in Alaina's support. But they are far from giving up.

"Over the years, we have stopped expecting (help) and learned to rely on ourselves. We just work harder in our business and try to keep up. But the fact is that things are very costly and nobody

should have to work to pay for their child's medical needs. We have stopped having too many fundraisers because we don't want to be heartbroken every time."

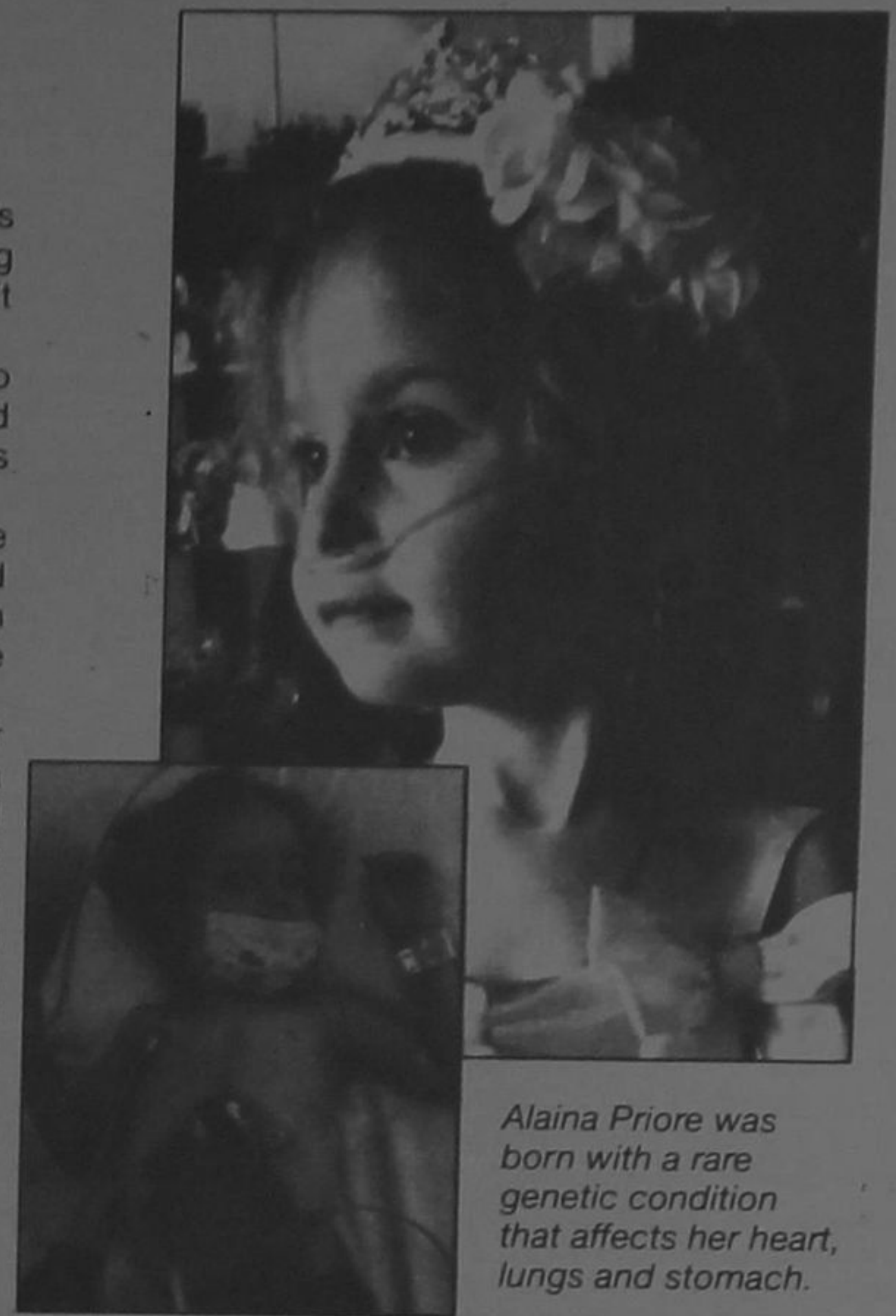
Michelle and Rocco just want people to recognize their struggles as a family and offer support by even sharing Alaina's story.

"We aren't asking for money all the time. Even if you click on her page and share it, maybe someone somewhere in research may look at it and want to give it a go."

Michelle and Rocco are putting their heart and soul into keeping Alaina alive, and all they need is support and recognition of the sacrifices they are making as a family. After all, if anyone saw Princess Alaina, all of 28 pounds, riding her jeep outside with the oxygen prongs that stay permanently in her nose, they would recognize her as truly one of a kind.

A well-wisher has created another gofundme page in support of Princess Alaina. To support, share or donate, visit <http://www.gofundme.com/sg4g2g>

Write to Kinjal at kinjal.dagli@gmail.com



Alaina Priore was born with a rare genetic condition that affects her heart, lungs and stomach.

The Great Brush-Off

On May 7, the Latcham Gallery hosted its first Art Battle, a live painting competition to celebrate the creativity of community artists ranging in age from 10 to 20. Twenty-three contestants, some working in pairs, were given a time limit to create a painting and the results were spectacular. The winner was Celina Lea.

Bruce Stapley photos



Howzat!

On May 27, Stouffville Cricket Club launched its 2015 season at Bethesda Park on Bethesda Road east of Ninth Line.

The club welcomes new players aged 18 and up and games will be played twice a week on a matted cricket pitch with the traditional hard ball. The cost is just \$100 for the season, which runs until Sept. 12. Contact Dave at stouffvillecricketclub@gmail.com or 416-708-6250 for more information.



Members of the Stouffville Cricket Club prepare for the 2015 season at Bethesda Park.

STOUFFVILLE I.D.A.

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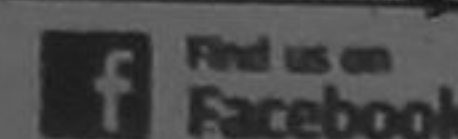
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