

Stouffville tot may be only person in Canada with lung condition

# Fighting for their princess

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**W**hen Alaina Priore turned a year old Nov. 6, it was a bittersweet celebration.

It was a happy day for the Priores because, despite the odds, Alaina was alive. But it was tough because, as her parents and older brother Thomas ate cake and celebrated with Alaina in their Whitchurch-Stouffville living room, the rest of their family and all their friends had to watch from outside.

"She looked out the glass window, staring and waving at everyone," said her mother, Michelle.

Alaina's immune system is so compromised, the few visitors allowed into the home must wear a gown and be masked. When Rocco, Michelle's husband and Alaina's dad, comes home to Ballantrae from work, he undergoes a routine of changing his clothes and sanitizing before he can say hello to his daughter.

*Alaina also suffers from interstitial lung disease, pulmonary hypertension, a hole in her heart and extreme failure to thrive.*

Alaina, now 18 months old, has surfactant deficiency. Surfactant is like soap in that it washes out secretions within the lungs so they can freely expand.

Because Alaina is surfactant deficient, her lungs are like a sticky balloon that you try to blow up but some parts don't easily separate.

Alaina also suffers from interstitial lung disease, pulmonary hypertension, a hole in her heart and extreme failure to thrive.

Her condition is so rare, Alaina is believed to be the only one in Canada with surfactant deficiency.

"It's not something that you treat. It's not curable," Mrs. Priore said.

Alaina was born at 32 weeks gestation. Mrs. Priore was induced into labour because doctors discovered her placenta was deteriorating and stunting Alaina's growth.

When born, Alaina weighed two pounds, 11 ounces, roughly the size of a 28-week-old.

"(The doctors) were pretty certain she was an OK size," Mrs. Priore said. "A 32-weeker is not one they usually worry about. But naturally it's the fear of the unknown.

"I was guaranteed, by one of the doctors, there was nothing wrong with my baby. They didn't know. It was something so rare they didn't test for it."

At first, Alaina's only known medical issue was chronic lung disease of a premature baby, which caused the newborn to spend her first four months of life at Mount Sinai Hospital in Toronto, on and off ventilators.

At one point, Alaina went into respiratory distress. It was then her doctors realized she needed the type of care only available at Sick Kids Hospital.

A feeding tube was inserted into Alaina's tiny, frail body because doctors discovered she was at risk of inhaling food into her lungs.

The Priores were ready to finally take their newest family member home on Easter Sunday last year, but Alaina spiked a fever and ended up with paraflye, which is the common cold for the non-immune compromised.

She spent two-and-a-half weeks in ICU on life support.

"She wasn't taking a breath on her own - from a common cold. It was touch and go. It was tough," Mrs. Priore said choking back her emotions.

Less than a month later, on Mother's Day, Mrs. Priore received the greatest gift she could have asked for - Alaina came home.

Since then, Mrs. Priore describes their lives as chaotic, stressful and an emotional roller coaster.

"Trying to keep everyone's life normalized is the hardest thing to do," Mrs. Priore said.

Prior to Alaina's birth, Mrs. Priore taught at a Montessori school and brought Thomas with her to its daycare centre.

Now, Thomas is being home-schooled until Alaina's immune system strengthens.

"It's a decision no mother should have to make. It's not good for Thomas. But it's detrimental to Alaina. ... He'll get over it. She won't," Mrs. Priore said.

Although Alaina was allowed to come home at six months of age, she was repeatedly admitted to Sick Kids for respiratory distress caused by aspiration pneumonia.

In a last ditch effort to determine the cause of Alaina's medical distress, she underwent testing that is available only in the United States. It took 12 weeks for the results to come back.

That is when the Priores learned Alaina was surfactant deficient, which is a genetic disease.



Ballantrae's Alaina Priore, 18 months, is, to her parents' knowledge, the only Canadian with surfactant deficiency. To bring attention to Alaina's condition and the Priore family's plight, friends are helping the couple organize the Princess Alaina Benefit July 17 at the Grand Baccus in Toronto.

"It's so rare that Alaina, from what I know, is the only one in Canada of her kind," Mrs. Priore said.

Doctors gave Alaina a year to live. She's now 18 months old.

In an effort to bring attention to Alaina's condition and the Priore family's plight, friends are helping the couple organize the Princess Alaina Benefit, which takes place July 17 at the Grand Baccus in Toronto.

"We want to open up someone's eyes in the research department," Mrs. Priore said. "Hopefully raise awareness so we can open our own research wing in Canada.

"It just takes one person. A few people or one family to try and raise awareness and I just hope we can do that."

Luisa Amabile, who has known Mr. Priore since they were chil-

dren, wanted to help the family, but just couldn't come up with anything she felt to be significant. She decided to take the lead on the fundraiser.

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"Event planning is my passion. It's something I've always wanted to do so I'm going to donate my time," Ms Amabile said.

"It puts my life in perspective. How fortunate I am to have two healthy children."

Proceeds from the event will also help pay for Alaina's medical equipment and nurses.

Alaina's last surgery was Feb. 14. It was to help alleviate the aspirating into her lungs. She came home four days later and has not been back to the hospital since. She has also gained four pounds.

Developmentally, Alaina is a normal 18-month-old girl. The only challenge, according to her mother, is keeping her stimulated because the hospital stays weaken her to the point she has to learn to crawl and walk all over again.

A car wash, also in support of the Princess Alaina Fund, is June 24 from 8 a.m. to noon at the Stouffville Auto Wash, 37 Winona Dr.