

# Smiles amid the struggles

## Five-year-old St. Albert girl born without eyes

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They want her to be able to look forward to a bright future.

But the catalogue of surgeries a little St. Albert girl has been forced to endure – the legacy of a rare condition that means she was born without eyes – has left her parents wondering how much of her life has already been lost to the past.

"She's sleeping, she's eating, it's all wonderful and then she goes for surgery and everything changes," said Ariel Boutette's mom Lori. "She used to say her own name a lot two years ago but after the surgeries she just shut down."

"Every time she goes in it's hard, it's really hard. It's just like 'here we go again. Let's see, what are we going to lose this time?'"

Ariel was born with her eye sockets empty and her eyelids fused shut due to bilateral anophthalmia – a condition that affects about one in 100,000 babies.

The brave girl, who celebrated her fifth birthday earlier this month, also suffers from a mild form of spina bifida. Since she was born, she's had to endure five major operations and close to 100 hospital visits.

"She's got the best smile, the best laugh," said Lori.

"But when she comes out of hospital she's usually madder than a wet hen."

In June, Ariel had a "tissue-expanding" operation aimed at filling out the gap in her eye sockets, which in turn should help her face and skull to grow properly.

A special gel that expands in water was inserted into her eye sockets and her eyelids, which were still partially fused, were sewn together.

"Your eyes are like spaces. They are there for a purpose," said Lori. "It's really important for Ariel to have this done."

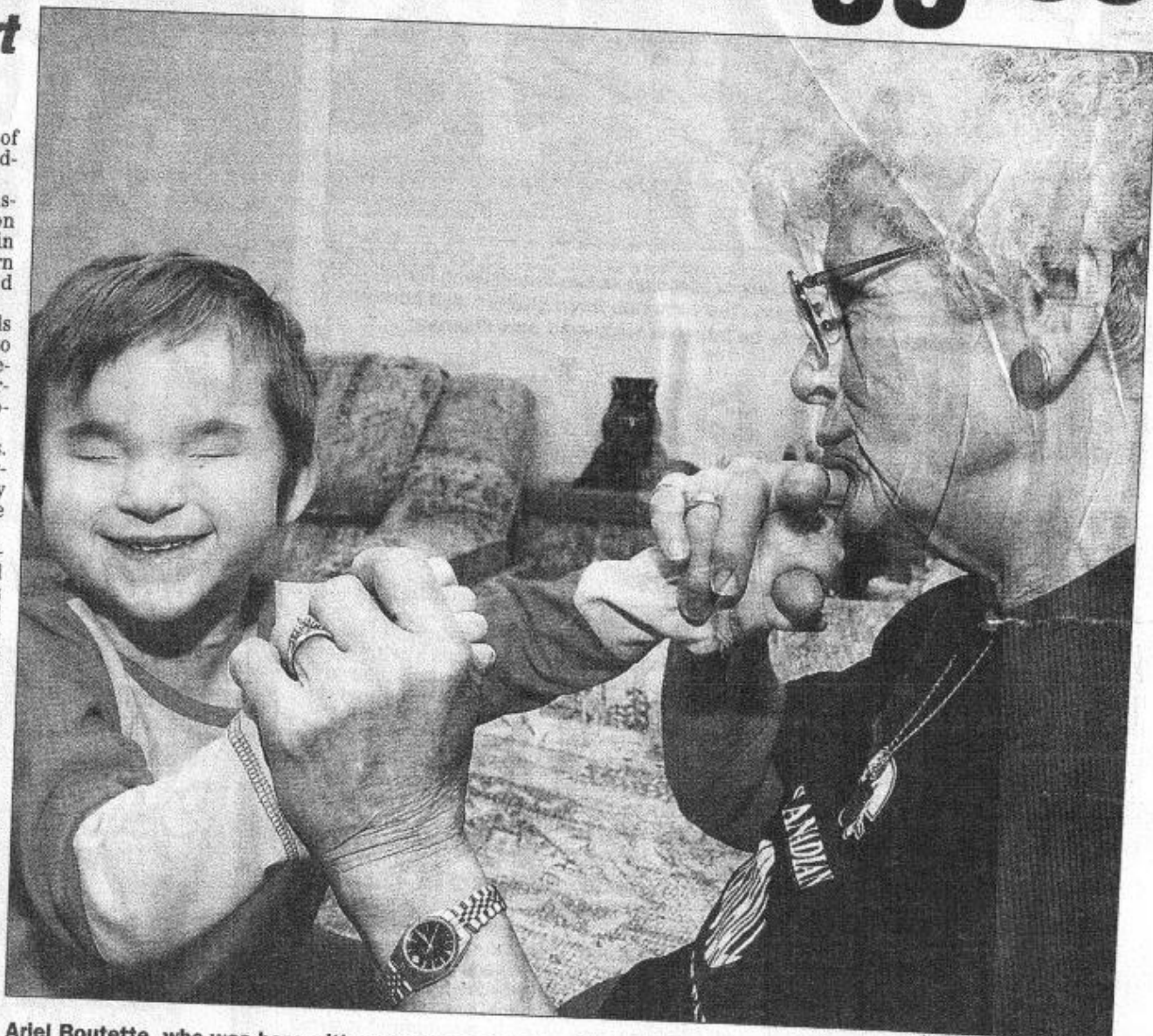
The operation wasn't without its challenges. Gel poured out of Ariel's eye sockets whenever she cried, said Lori. The gel will have to be repeatedly reapplied, but for now no dates have been set.

Although Ariel will probably never be able to see, doctors are hoping her eye sockets will grow enough to be able to support two prosthetic eyeballs.

"The eyes are ready – it just takes time," said Lori. "They have kind of let her be for now and she's doing really good. She's in kindergarten this year and her speech is getting better."

"My wish for the new year is that I would really like her to say her name more."

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Ariel Boutette, who was born with empty eye sockets, plays with her grandma Beryl Lukaniuk in St. Albert.

— WALTER TYCHNOWICZ, Sun