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[Home](#) > Cynthia - 11 years old

A new face for Cynthia

A young girl's face is stretched in innovative surgical procedure

Diagnosis Crouzon syndrome

Cynthia Maldonato is 11 years old. She loves to sing in her church choir and her favourite subject in school is math. Instead of sporting the usual 'tween wardrobe of jeans and a hoodie, Cynthia dresses a little more elegantly. During a recent pre-surgical visit to The Montreal Children's Hospital of the McGill University Health Centre, she wore a skirt, blouse, jacket and black pumps. She also carried a dainty handbag.

Cynthia's dad, Galby Maldonato says his daughter is a like a magnet, people just naturally flock to her. He credits this to his daughter's kind, gentle and beautiful soul.

While the vast majority of people are kind and friendly, and even protective towards Cynthia, there are always a few who, unwittingly or not, make insensitive and hurtful comments about the way she looks. Cynthia was born with Crouzon Syndrome, a rare genetic disease which causes premature fusion of a baby's bones. As a result, Cynthia's skull is completely misshapen, her eye sockets are too shallow so her eyes bulge and constantly tear, and she can't close her eyes completely even when she sleeps. She has difficulty breathing through both her nose and mouth; she has a significant underbite, which makes eating a challenge and eating hard foods such as apples impossible. Fluent in both French and Spanish, Cynthia also has a pronounced lisp.

"Her face is bowl shaped," says plastic surgeon Dr. Mirko Gilardino, one of two surgeons involved in Cynthia's care. "She has a very restrictive mid-face, it's almost caved in completely."

Diagnosed with Crouzon Syndrome at birth, Cynthia has already undergone four surgeries including one to advance her forehead to allow her brain to grow.

On January 25, Cynthia underwent a newer type of surgery, the first of its kind to be done in Quebec. The surgery, performed by neurosurgeon Dr. Jose Montes and Dr. Gilardino, will essentially allow her mid-face, orbits and forehead to be stretched forward, as much as 21 millimetres.

During the challenging six-hour surgery, the surgeons peeled off her face after making an incision from ear to ear. Then Dr. Montes used a special surgical saw, with a protector on one side to prevent injury to her brain, to remove her forehead exposing Cynthia's brain. At this point, Dr. Gilardino stepped in to continue the cutting. Using a surgical chisel and hammer, he cut the bone along both sides of her face and across the bridge of her nose so the whole face became mobile.

The next step was to fit Cynthia with what is called an external distractor halo. The semi-circular metal device looks like something out of a science-fiction movie. It was attached to the sides of her head with screws, just above and behind her ears. Dr. Gilardino also inserted four screws into Cynthia's face, two near her eyebrows and two on either side of her nose. Wires attach the screws to the halo.

The surgery went extremely well but due to the expected swelling, Cynthia was kept sedated and on a ventilator in the PICU for 48 hours. About a week after the surgery, Dr. Gilardino, with the assistance of Cynthia's parents, started the process of advancing her face, one millimetre per day. As the injured facial bones start to knit together both the bone and soft-tissues are "stretched" to generate new tissue with the distractor. The procedure is known as a monobloc distraction.

"Believe it or not, her parents are turning the four screws on Cynthia's face twice a day, morning and night," says Dr. Gilardino. "The stretching really doesn't hurt, but it will pull her face forward half a millimetre at a time over a period of three weeks." It works somewhat like braces on teeth.

As her face is stretched, her eyes will become less prominent as the orbits deepen, and her teeth will become more aligned. "I can adjust the alignment of Cynthia's face, pulling the bones of the face upwards, downwards, to the left or to the right. I can adjust it as we go," says Dr. Gilardino. "It is far from perfection, but it is a nice controlled gradual movement. During the distraction phase (stretching phase), I'm really focusing on her eyes—if I overdo this, she'll end up with beady eyes. I want to make sure this doesn't happen."

In fact, Dr. Gilardino is planning to overstretch Cynthia's face in order to account for Cynthia's continued growth. This way she'll grow in to her new face.

Once the period of stretching is over, Cynthia will have to continue wearing the halo for about two months to allow her bones to set and harden. After that it is a simple procedure to remove the halo and screws. She might need another small surgery down the road to fine-tune her bite.

Dr. Gilardino is Director of the MCH Craniofacial and Cleft Surgery Team. He joined the MCH in 2008, along with Dr. Broula Jamal, the team's specialized craniofacial orthodontist. Cynthia is the first MCH patient—and the first patient in Quebec—to undergo this new "monobloc distraction" technique. The new technique has

significant benefits in terms of post-operative infection. The traditional way of advancing a patient's face carries a nearly 50 per cent risk. With this new procedure, the risk of infection is reduced to virtually 0 percent. Dr. Gilardino estimates he may do as many as four of these surgeries per year.

During an interview prior to the surgery with Gazette health reporter Charlie Fidelman [1], Cynthia confided she was very much looking forward to the surgery, because she wants her eyes to look normal, and her teeth to come together. And she wants to look like her brother and sister. She also told the reporter that she is eager for the surgery because she wants to look good for her 15th birthday celebration, the Quinceañera, an important celebration in the life of a teenager – like the Latin version of a Sweet 16.

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Links:

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- [2] <http://www.thechildren.com/node/11749>
- [3] <http://www.thechildren.com/patients-families/patient-testimonials/missing-factor-growing-hemophilia>
- [4] [Http://www.thechildren.com/patients-families/patient-testimonials/missing-factor-growing-hemophilia](http://www.thechildren.com/patients-families/patient-testimonials/missing-factor-growing-hemophilia)
- [5] <http://www.thechildren.com/patients-families/patient-testimonials/living-lupus>
- [6] [Http://www.thechildren.com/patients-families/patient-testimonials/living-lupus](http://www.thechildren.com/patients-families/patient-testimonials/living-lupus)
- [7] <http://www.thechildren.com/tiny-patient>
- [8] [Http://www.thechildren.com/tiny-patient](http://www.thechildren.com/tiny-patient)
- [9] <http://www.thechildren.com/confrontingconcussion>
- [10] [Http://www.thechildren.com/confrontingconcussion](http://www.thechildren.com/confrontingconcussion)
- [11] <http://www.thechildren.com/patients-families/patient-testimonials/waiting-new-kidney>
- [12] [Http://www.thechildren.com/patients-families/patient-testimonials/waiting-new-kidney](http://www.thechildren.com/patients-families/patient-testimonials/waiting-new-kidney)
- [13] <http://www.thechildren.com/patients-families/patient-testimonials/growing-juvenile-arthritis>
- [14] [Http://www.thechildren.com/patients-families/patient-testimonials/growing-juvenile-arthritis](http://www.thechildren.com/patients-families/patient-testimonials/growing-juvenile-arthritis)
- [15] <http://www.thechildren.com/patients-families/patient-testimonials/starting-new-chapter-18>
- [16] [Http://www.thechildren.com/patients-families/patient-testimonials/starting-new-chapter-18](http://www.thechildren.com/patients-families/patient-testimonials/starting-new-chapter-18)
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- [18] [Http://www.thechildren.com/patients-families/patient-testimonials/waiting-eva](http://www.thechildren.com/patients-families/patient-testimonials/waiting-eva)