



Léa Rose Villemaire, age 2

Suffering from Treacher-Collins syndrome

“Léa Rose has taught us to see beauty in difference. She has made us appreciate the simplest moments and the little things. She has taught us that every victory, no matter how small, deserves to be celebrated.”



Léa Rose is suffering from Treacher-Collins syndrome along with her mother Joannie. This syndrome is characterized by an embryonic malformation of the lower face, eyes and ears. Very early in her pregnancy, Joannie and her husband Charles-André were monitored by the experts at CHU Sainte-Justine. Various tests revealed that Léa Rose was carrying the disease, but the effects were predicted to be mild, as is the case with her mother.

It was a real shock for her parents at the baby's birth because the effects were more severe than had been expected. Devastated, Joannie felt tremendous guilt and anxiety. Due to a mandibular hypoplasia, Léa Rose's trachea and the esophagus were compressed. When she was just a few days old, a tracheotomy and gastrostomy had to be performed so that the baby could breathe and eat properly. A long hospitalization followed.

At four months old, she could finally come home, but she and her parents would face many challenges. Charles-André and Joannie had to learn to master caring for their child. The grandparents also took training courses to be able to take over from time to time. A caring team is devoted to the little one even at home. At night, Léa Rose is connected to a machine so that her saturation can be monitored. Fragile and vulnerable to viruses and infections, Léa Rose will not be able to attend daycare for a long time.

To help her develop speech, Léa Rose now wears a phonation valve—that is, a nozzle added to her tracheal tube—which has allowed her to emit her first sounds and stutters in recent months. This is a victory for the family! The process will be long, but Léa Rose is monitored by a speech-language pathologist, who helps her greatly. Still fed by gastrostomy, Léa Rose has started eating by herself, however, and a few foods have been integrated into her routine. Feeding will also be a long road for her, but she is supported by the love of her family and the generosity of each of us. Surgeries are planned in the years to come—bringing her jaw forward, constructing her ears and performing facial fat grafting. Because of the location of her tracheotomy, Léa Rose cannot make a sound. She will have to travel a long road again, carried by the love of those around her and the generosity of each one of us.

“The donations raised have a direct impact on hospitals' ability to provide quality care through the availability of specialized equipment. When parents feel supported and well equipped, they can do their very best for their children.”

*Léa Rose's parents join us in thanking you for being there for her and all sick children in Quebec.*

**Joannie Dupré-Roussel and Charles-André Villemaire**

Little miracles don't happen on their own...

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