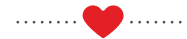




Milo Leblanc-Morin, 3 years old

Suffering from an unknown genetic neuromuscular disease

“Milo offers us a lesson in perspective, in relativity, that cannot be learned anywhere else. Despite all his obligations and limitations, he remains resilient. Only he can teach us this, by example, without any words.”



During his first week of life, Milo had trouble drinking and was losing weight at an alarming rate. Seven days after he was born, his parents decided to take him to the Hôpital de Saint-Eustache. After being hospitalized for two days, the healthcare team realized that Milo needed special care and decided to transfer him to the Montreal Children's Hospital Neonatal Intensive Care Unit. “That day, the metaphorical rug was pulled out from under our feet. We found ourselves in free fall before snapping back to reality,” recalls Aude.

Milo was hospitalized for eight days. During this time, doctors discovered several conditions, including an abnormally small head, multiple muscular diseases, developmental delays and the inability to eat. Milo was suffering from a genetic disease that's still unknown to this day. Doctors also discovered that Milo had difficulty swallowing. The milk he drank ended up in his airways. They decided not to feed him anything by mouth. Instead, they fed him through a nasogastric tube until he was four and a half months old. After this time, Milo underwent thoracic surgery at the Montreal Children's Hospital to have a G-tube* inserted. “Milo has always had the best care, thanks, in large part, to the equipment at the Montreal Children's Hospital. Whether it was the isolette and stretcher, the electric beds or the monitors,” explains his mother.

The next years were punctuated by countless medical appointments, to try to discover what was wrong with the young boy and find solutions to the many problems he was facing. As he required constant care, Milo's mother had to leave her teaching career in order to devote herself to her son.

Today, Milo is three and a half years old. He can sit with supervision and stand with assistance. He takes medication every day to control his epileptic episodes and attends regular physiotherapy sessions. He can now eat smooth purées and drink thickened water. His entire family has been deeply affected by his condition. Respite is rare. His older sisters' childhood was turned upside down by the arrival of her little brother, who needs so much help and care. They love Milo unconditionally and willingly accept the constraints and compromises imposed by his illness. Every day with Milo is a lesson in resilience. As his dad says, “Everything is put into perspective. What are the real issues? There are no long-term plans. The only things that matter are the present moment, which we learn to appreciate, Milo's progress, which we celebrate, and the moments of happiness, which we seize with our hands.”

*A G-tube is inserted directly into the stomach. It exits through the skin of the abdomen between the ribs and the belly button.

“We'd like to say thank you to all the donors who have given their time or money to make a difference in the lives of so many people. A real difference, not the one at the bottom of a sheet or list. More smiles at home, a moment of respite, a laugh, a real difference. Thank you.” — Aude

Aude Cadieux-Leblanc, Philippe Morin, Lou (7 years old)
and Charlie (5 years old)

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