



Matéo Kenuajuak, age 3

Suffering from Duchenne muscular dystrophy

“Long before Matéo’s arrival, we had participated in numerous fundraisers for Opération Enfant Soleil, a cause dear to our hearts. Now that we are directly affected, we will continue—for Matéo and for all sick children.”



When a phone call announced that a small four-day-old Inuit baby was waiting for them at the hospital, Stéphanie, Michel and their two children were overjoyed. Mom rushed over and brought Matéo home, where he was greeted as a gift by his new family. It was love at first sight for his big brothers, parents and Matéo, who had been so long awaited.

Over the months, some concerns emerged, however: Matéo was unable to lift his head when lying on his stomach and cried a lot. At six months, pneumonia caused him to be hospitalized, and his parents shared their concerns with the doctor. A few days before his first birthday, the trouble affecting him was identified: The child was suffering from Duchenne muscular dystrophy, a disease that is characterized by the absence of dystrophin, an essential protein that allows the muscles to withstand exertions. Without it, they become damaged and degenerate over time. He is affected by a lack of muscle tone and significant pulmonary weakness, which increases the risk of infections, as well as a global developmental delay.

Although they had been expecting this diagnosis for months, his parents were in shock. But they quickly pulled themselves together and listened to the specialists describe the worrisome disease that was afflicting their child in its most severe form. The development, symptoms, ordeals to come

and delicate question of Matéo’s life expectancy were discussed. That day, Stéphanie and Michel promised their little one they would make every effort to make his life as normal as possible.

Unfortunately, last autumn, Matéo’s parents noticed that he was falling more often and that the disease seemed to have progressed. Matéo meekly submits to numerous medical follow-ups with his neurologist and physiatrist, as well as the treatments he needs, especially with his physiotherapist, with whom he works on his development. His vulnerability to respiratory infections often results in hospitalization; his lungs are also muscles to be developed. Despite everything, Matéo has never lost his beautiful smile.

Matéo’s family joins us in thanking you for being there for him and all sick children in Quebec.

Stéphanie Hébert, Michel Lepage, William and Simon

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

Visit operationenfantsoleil.ca to learn about the journeys of all the province’s Enfants Soleil through their profiles and videos.

Would you like to get involved? • Contact us: 1 877 683-2325 • oes@operationenfantsoleil.ca