opération enfant soleil

MONTÉRÉGIE'S ENFANT SOLEIL

Liam Dubois, 8 years old

Diagnosed with triple H syndrome

"At 14 months, Liam was admitted to the emergency room. After examining my little boy, the ER doctor looked at me and said, "We're transferring Liam to the ICU because we don't know how this will turn out..." It was just like in the movies, I felt the blood drain from my body and had to sit down."

Liam is an energetic young boy, a ray of sunshine in the lives of those around him. Behind the eyes of this lively little guy lies a rare disease that requires the utmost vigilance: triple H syndrome, an inherited, metabolic genetic disorder that affects the urea cycle. Without undergoing treatment and following a strict diet, the disease can cause irreparable damage to Liam's liver and brain.

When Liam was 10 months old, his parents noticed that he was uncharacteristically sullen. He was frequently vomiting, and his growth had faltered. Soon after, Liam refused to eat at all. His mother and father were at their wit's end and asked their pediatrician to run a series of tests. The results were worrisome, and Liam was rushed to the CHU Sainte-Justine.

The tests revealed that Liam was suffering from liver failure. His small body was not digesting proteins properly and he was becoming intoxicated. Liam had to be rushed to the intensive care unit at 2 a.m. His liver enzymes were nearly 7,000 when they should have been around 30.

It took twelve days to get Liam back on his feet. Twelve days during which his parents were introduced to the disease, its constraints and the significant risks that accompany it. From then on, Liam had to be put on a strict diet of no meat, fish, eggs, dairy products, nuts or legumes; everything had to be weighed and calculated to the exact gram.

Family life had to be reorganized around Liam's needs with a complete change in routine (night feeding, Liam's mom had to take a leave from work to care for him, moving to a smaller home, etc.). When Liam was about two and a half years old, he was given a feeding tube. Three hours a day are spent preparing his food and feeding him. Liam must lie down for two hours every day. Over time, Liam's neurological problems became apparent: developmental delays, language problems, sensory issues and ADHD. The slightest infection requires increased vigilance because it can upset his fragile metabolic balance. Therefore, Liam's emergency physicians must follow a strict medical procedure developed by a team of geneticists. "I worked in the field of research for 11 years and never imagined my child could be affected by a rare disease. Donations are essential to advance research and treat little-known diseases," explains his mother.

Despite all this, Liam lives every day to the fullest. He is a role model for those around him. The future? We don't know what lies ahead for Liam, but he can count on the love and support of his family to reach his full potential.

"With Opération Enfant Soleil, we are not alone. There are thousands of people supporting us whose impact is direct on the future of our children."

Audrey Thibodeau, Éric Dubois, Justin (12 years old) and Nathan (9 years old)

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