



Mey-Lin Gonson, 3 years old

Diagnosed with Beckwith-Wiedmann syndrome with hyperinsulinism

“We have seen the limits of current knowledge and the difficulty that physicians face in finding solutions for rare diseases.”



As soon as she was born, Mey-Lin was in distress. Doctors determined she was hypoglycemic and placed her on a drip. Within hours, she was transferred to the intensive care unit at the Montreal Children's Hospital, where a team of specialists was waiting for her, while her mother waited at St. Mary's Hospital. Over the next few weeks, the doctors detected abnormalities in Mey-Lin's liver and noticed that one kidney and one arm were larger than normal. This led geneticists to suspect she had Beckwith-Wiedmann syndrome, a condition that stunts her growth and predisposes her to cancerous tumours.

Mey-Lin's parents were devastated and overwhelmed; being in the middle of a pandemic and lockdown did not help. Isolated, Mey-Lin's mother and father take turns between home and the hospital to facilitate daily life and spend time with their two children. They gradually realized the risks that the disease posed to their little girl and the difficulties that lie ahead.

Mey-Lin underwent an initial treatment in an effort to stabilize her blood sugar. However, the side effects were disastrous and led to pulmonary hypertension. One evening, when Mey-Lin was in bed, she was lethargic and in respiratory distress. She was rushed to the pediatric intensive care unit at the Montreal Children's Hospital. “We called the emergency room in a panic. We thought we were going to lose her,” says Annie.

The second treatment was equally ineffective, and Mey-Lin's parents had to seriously consider the possibility of a pancreatectomy (removal of part or all of the pancreas) in Philadelphia. The little girl's parents were terrified and had to confront the urgency of the situation. After speaking with the medical team, they decided to try a final treatment. The treatment included medication and continuous feeding. Finally! The results were positive. A few days later, while her mother was holding and playing with her, Mey-Lin reacted with her first giggle, a burst of laughter that rekindled all hope.

The tube feeding, constant blood sugar monitoring, the pump she has to carry in a small backpack, the painful gel injections she receives every four weeks, the oncology follow-ups because she has to be monitored for tumours, the anxiety that comes with waiting for results: life isn't easy for Mey-Lin and her family. However, Mey-Lin is developing well and seems to have adopted her family's philosophy: move forward no matter what.

“Every donation helps make the lives of sick children and their families easier and more ‘normal.’ Every donation allows us to learn, laugh and play.” Donating creates hope for the future.”

Annie Sechao, Olivier Gonson and Quentin (7 years old)

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