



William Bernard
6 years old

Suffering from Barth Syndrome

Estrie's Enfant Soleil

**“William teaches us about courage, loving life and patience!
Love gets us through the difficult times.”**

There have been plenty of difficult times for Jennefer and Sébastien. Their son William lives with Barth Syndrome, a serious genetic disease that makes him more fragile. William suffers from cardiomyopathy, delayed growth, scoliosis, a weakened immune system which leads to many infections, epilepsy, hypoglycemia and sleep apnea.

It all started when William was born. The medical team noticed that something wasn't right: the baby's blood sugar levels were very low and his lactic acid levels were abnormally high. William's life was in danger. His parents were overwhelmed with worry. William's condition was stabilized, but it would take a series of hospitalizations and tests to understand what was wrong.

William was 9 months old when he was diagnosed. The outlook was not optimistic, with a life expectancy of about three years. Grief, fear, dismay and incomprehension settled over the small family, but so did the desire to understand, support and care for William. They rearranged work schedules, reorganized themselves. They made sure that one parent was always with him during the hospital visits. There would be 25 over 6 years.

Despite the numerous treatments, hospitalizations and medical appointments that followed, William has remained positive even through the most difficult times. He is a timid, sweet and sensitive child. Opération Enfant Soleil was part of his life from the very first. As an ambassador, William wants to encourage other sick children “to not give up, to hope, to get better and to follow their dreams.”

William's family thanks you for being there for him and for all sick children in Québec!

Jennefer Lacroix, Sébastien Bernard, Byanka and Meryka

Little miracles don't
happen on their own

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