



Lydia Clarke, age 7

Suffering from
Wolf-Hirschhorn syndrome

ENFANT SOLEIL FROM LES ÎLES-DE-LA-MADELEINE

From the earliest moments of Lydia's life, your generosity has been there with her in her fight. Whether she was at her regional hospital, where specialized equipment allowed her to receive essential care for her survival, or at the Centre mère-enfant Soleil at the CHU de Québec, where she was regularly treated, Opération Enfant Soleil was there for her. For Lydia and her family, two words sum up the cause: gratitude and hope.

Laura's pregnancy and childbirth took place normally at their regional hospital. However, when Lydia was born, the doctor was alarmed by her small size. A few hours later, the baby and her family flew to the Centre mère-enfant Soleil in Quebec City. After many tests, the heavy diagnosis was given: she was suffering from Wolf-Hirschhorn syndrome, a very rare genetic disorder characterized by a developmental disorder with facial abnormalities, delayed pre- and postnatal growth, intellectual disability, severe psychomotor delays, epilepsy and hypotonia. First-time parents Dale and Laura were dismayed by the news. They felt overwhelmed and were wracked by worry... Lydia's condition made her very susceptible to infections. Cold and flu season was a risky time for her. Often ill, she had to be frequently transported to the Centre mère-enfant Soleil at the first sign of respiratory distress. At age 2, after a bout of pneumonia, she was discovered to have an inhalation disorder that was making her very sick. Surgery was

performed to install a gastrostomy tube that prevented her from inhaling liquid into her lungs. At age 4, a virus hospitalized her for 6 weeks, including 2 weeks in intensive care, where she was intubated for 10 days.

Now age 7, Lydia is in grade 1. Since she does not speak and shows some developmental delays, she is pursuing an academic path where she learns at her own pace. She loves people and school is a precious place for socialization. Last November, she underwent orthopedic surgery on both feet to help the development of her muscles and bones. Despite her difference, she is a positive, very strong young girl. She greets every day with a smile.

Lydia's parents join us in thanking you for being there for her and all sick children in Quebec.

Laura Rankin and Dale Clarke

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

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