



### Elyssa Lepage, age 3

Mosaic trisomy 9

Despite the rare disease that afflicts her, little Elyssa keeps defying expectations and fighting every day. She has given a real lesson in courage and perseverance to everyone around her. “We’re stronger than we think,” says her mother.



Elyssa weighed only three pounds thirteen ounces when she was born in January 2018. A few days after arriving at home, the little girl was unwell and needed to be hospitalized at the Gatineau Hospital. Analyses revealed that she had mosaic trisomy 9, a rare disease little known to doctors. In her case, the disease was characterized in particular by a global developmental delay, hypotonia and musculoskeletal abnormalities.

“I cried a lot. The hard part is not knowing what to expect,” says the little girl’s mother. Elyssa’s illness has many unknowns: we don’t know if she will ever be able to walk or speak. In addition, her condition means that her parents need to be organized, and Mom has had to set her university studies aside. “Grieving over not having a healthy child wasn’t easy for the family.”

In July 2018, the little girl was hospitalized at the Montreal Children’s Hospital due to breathing difficulties and aspiration problems. Twenty-five days later, she returned home, but her condition remained fragile; she endured one hospitalization after another. In January 2019, she underwent surgery to treat severe acid reflux and received a gastric tube.

Today Elyssa continues to be tube fed and must undergo oxygen therapy while sleeping. The young child is waiting for spinal cord surgery to make sure she does not lose the use of her legs. Despite her delayed growth, Elyssa is making good progress! In fact, she now travels short distances using a walker, which makes her parents so proud. “She is a real fighter; she has been fighting since she was born.”

“Thank you for giving. You don’t understand the importance of the cause until you need it. Thank you for being there and reminding us of the significance of one life every day.”

*Elyssa’s family joins us in thanking you for being there for her and all sick children in Quebec.*

**Sophonja Jacques, Michel Lepage and Loïk**

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

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