



## Léana Sabourin, 12 years old

Suffering from cystic fibrosis

“The dream of an idealized life for Léana and our family was lost with the diagnosis of this degenerative and fatal disease. But our lives are not just about the disease. We have made the choice to live positively and enjoy the present moment.”



Léana is 17 months old when she takes her first steps ... in her hospital room, with the help of her infusion pole. Hospitalized for pneumonia, the little girl does not realize that her life has suddenly changed. But for her parents, Marie-Ève and Joël, life stops when the diagnosis is announced: cystic fibrosis. It is the end of everything. With barely a moment to absorb the shock, they already have to learn. Learn about the disease, learn about the treatments they will have to provide Baby with, learn to manage the medication, learn to develop a new routine... learn how to live differently.

They already knew that something was wrong with Léana. Since her birth, infections had been multiplying, and breathing difficulties had taken them to the emergency room so many times! The thought of a serious illness is not one of the possibilities you consider for your child. And yet...

Because of the treatments, the clapping sessions, the menu that must be balanced on a daily basis for her, the thousand precautions that Léana's condition implies and the medical follow-ups, it takes a lot of imagination to combine everything. Each lung infection leaves permanent damage to Léana. Over time, her lung capacity will decrease. Since cystic fibrosis is a degenerative disease, Léana's condition will not improve with time...

It is important to be on the lookout for the slightest risk. A gardening session or an outing to the mall can hide a virus or a bacteria that will cause a new infection. A simple cold must be treated with great care. Léana is “lucky.” She has only been hospitalized twice: once for pneumonia before she was diagnosed, and once for the flu when she was seven years old.

But life has not said its last word, and neither has Léana! Léana's courage, kindness and wisdom at the tender age of 12 impress everyone around her. She is a bright, artsy, active teenager who plays soccer, volleyball and loves school. She is also, and above all, a happy girl who does not let the disease take over her life. She is a true inspiration to her family.

*Léana's family thanks you for being there for her and for all the sick children in Québec!*

**Marie-Ève Roy, Joël Sabourin and Élie**

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