DOZENS OF RARE DISEASES DISCOVERED EACH YEAR

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According to the Canadian Organization for Rare Disorders (CORD), Stephanie isn't alone. The national network reports that one in 12 Canadians has a rare disorder, and approximately three million people and their families face a debilitating disease that severely impacts their lives.

CORD says there are over 7,000 known rare diseases, and dozens more being discovered each year.

While she's had potential diagnoses of ailments like lupus and multiple sclerosis in the past, tests have ruled out those conditions, so doctors continue to treat her individual symptoms with a cocktail of medications, including low-dose chemo therapy and steroids.

Watching what Stephanie endures with her condition is particularly challenging for close friend Valentina Cvetic as she works in the medical field.

"It has been extremely difficult seeing Stephanie go from a healthy, active young woman with a bright future ahead of her to a woman who has to fight to make it through ev-

ery day, and who often asks me if it's worth it to continue fighting," she said. "She was going to university and enjoying hobbies like reading and photography. She always planned to have a family and travel. I feel that this disease has taken all that away from her. It has stolen her future."

The renowned obstetrician/gynecologist said she feels the health-care system has failed Stephanie as she was often dismissed in the early days of her symptoms as being "too young and healthy.

"It took many years until she found a few good doctors that took her symptoms seriously and started investigating her properly," she said. "If there is a medication or treatment that may have helped her, how much better off would she have been had they taken her seriously in the beginning and started the treatment sooner?"

Peter said he would also like to see more support for

people with "invisible" illnesses like his daughter's condition.

'Not everyone has a missing limb - some people are dealing with illnesses inside," he said.

For now, Stephanie keeps fighting, and hoping that a doctor out there holds the answer that will end her suffering.

"I don't know what's happening, and that's the most frustrating part," she said. "I want someone out there to see my story and hopefully have input on what this might be."

For her support network, a solution can't come soon enough.

"I know there are days when her pain is so bad, she would do anything to make it stop. I know there a days when she's so scared about what her future holds that it paralyzes her," said Cvetic. "However, despite all this, she keeps moving forward. She keeps fighting, and that bravery is what amazes me."

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