

## **Canada's rare disease caregivers under immense stress, struggling with mental health issues, isolation and financial burden**

**National survey of patients and their caregivers indicates both feel vulnerable and unsupported**

**Toronto, Ontario, Apr. 3, 2019** – According to survey results released today, two-thirds of Canadians caring for loved ones living with a rare disease feel unsupported by Canada's healthcare system. The vast majority (87 per cent) have had their family finances negatively impacted as a result of their responsibilities, and three out of four are socially isolated. These results are particularly timely given the celebration of National Family Caregiver Day this week.

"As Canadians, we must do better. National Family Caregiver Day offers an opportunity not only to honour this vital group but also to commit to addressing these issues that impact their physical, mental, emotional and financial well-being. We owe it to them; we owe it to us," says Durhane Wong-Rieger, president, Canadian Organization for Rare Disorders (CORD).

"Nowhere are family caregivers more critical than in the rare disease community. Two-thirds of rare diseases affect children; it often takes years to get a diagnosis; and there are few specialists, no standards of care, and almost no effective treatments. Family caregivers provide the bulk of care and support. Our national healthcare system would collapse without their volunteer commitment, and our neglect of their needs is not only unethical but counterproductive," says Wong-Rieger.

Other key findings of the survey include the following:

- Almost 80 per cent of rare disease caregivers suffer from mental health issues as a result of their caregiving responsibilities
- 68 per cent reported that caring for someone with a rare disease has negatively impacted their work performance
- 63 per cent have taken on debt because of their caregiving responsibilities
- 70 per cent feel that their caregiving role has put a strain on their marriage/intimate relationships

According to their responses, rare disease caregivers in Canada are often challenged to find the time and resources necessary to meet the needs of both themselves and those they care for.

Forty-one per cent of caregivers reported missing six or more days of work a month as a result of their caregiving responsibilities. Due to an inability to find flexible employment opportunities, caregivers are often left in financially stressful and unstable situations.

The survey also illustrated that caregivers of individuals living with a rare disease feel incredibly socially isolated as they are often unable to make time for hobbies, physical activity or social engagements with friends and family. Seventy per cent of caregivers reported that caring for someone with a rare disease has negatively impacted the quality of their relationships and half say they are only able to engage in social activities less than once a month.

“As a caregiver, it is often difficult to make time for yourself. I wish more people understood the time and energy it takes to keep the one you are caring for even reasonably healthy,” says Katie Schulz, a mother of a young child living with Cystic Fibrosis.

“As a parent of two children born with rare conditions, I know we do what we do out of love. But as president of Canada’s rare disease network, I want to ensure that we do not continue to neglect this precious but highly vulnerable group,” says Wong-Rieger. “CORD has called on Canada to implement a national rare disease strategy and the findings of this survey compel us to ensure we include resources, support and treatment for those who provide the care as well as those who receive it.”

### **About Rare Diseases in Canada**

- Approximately one in 12 Canadians, two-thirds of them children, are affected by a rare disease. But because each disease affects only a small number of individuals, understanding and expertise may be limited and fragmented across the country.
- An estimated three million Canadians and their families face a debilitating disease that severely impacts their lives.
- Right now, only 60 per cent of treatments for rare disorders make it into Canada and most get approved up to six years later than in the USA and Europe.
- People with rare disorders in Canada are missing out on treatments that could save or significantly improve their lives. This needs to change.
- About 80 per cent of rare diseases are caused by genetic changes. Twenty-five per cent of children with a rare disease will not live to see their 10<sup>th</sup> birthday.
- A rare disease is a condition affecting less than 1 person in 2,000 in their lifetime.
- There are over 7,000 known rare diseases and dozens more being discovered each year.

### **About the Survey**

CORD, in collaboration with NATIONAL Public Relations and funded by Vertex Pharmaceuticals (Canada) Incorporated, conducted a survey of the rare disease community in Canada to explore and gauge the experiences and perspectives of both patients and caregivers, as it relates to their mental, physical, financial and emotional well-being.

Three-hundred forty-two participants responded to the survey conducted online between February 11 and March 8, 2019.

### **About CORD**

CORD, the Canadian Organization for Rare Disorders, is Canada’s national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada. For more information, visit: [www.raredisorders.ca](http://www.raredisorders.ca)

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