Via Courier/Email/Post

Name:
Date:
Address

Dear (Insert MP, MPP and Mayor here)

CC (Insert) names and titles of additional MPs, MPPs and Mayors here)

**Subject: CORD 2017 Rare Disease Strategy**

**I Care for Rare is a social advocacy campaign, designed to give individuals, families and caregivers living with rare diseases an opportunity to achieve a collective voice for systemic healthcare AND community care support reform.**

**I Care for Rare is asking both the Federal Government to adopt and the Province of Ontario Government to amend the Health Protection and Promotion Act to include the needs of those suffering from rare diseases and immediately adopt the Private member Bill 129 and its recommendations set out in CORD’s 2017 Rare Disease Strategy as presented in 2017.**

Care for Rare Disease | Disorders crosses many different ministries from education to employment and long-term care and municipal housing to the department of red tape. Rare disease, although more often diagnosed at younger ages, does not fit into an “age” category. **Transition from the “children’s system” to the “adult system” can be like falling off the transition cliffside, leaving families without proper medical and community care support for years.**

Spending more money on the same system is not the solution.

**Families are not equipped to navigate today’s complexity in accessing medical and community care supports. The “system” is flawed, and families and caregivers are struggling daily to manage the care of their loved ones alone and in silence. Often, they must leave the workforce to support their patient family member in isolation.**

* Rare diseases are one of Canada’s biggest public health challenges on par with diabetes and cancer.
* Provincial ministries manage access to community supports and healthcare services.
* About half of those with rare diseases are children.
* Unnecessary delays in testing and wrong diagnoses are often missed opportunities to be effectively treated.

CORDS Canada’s Rare Disease Strategy lays out a five-point action plan:

* Improve early detection and prevention.
* **Get the right care to patients as early as possible.**
* **Enhance community support.**
* **Provide sustainable access to promising therapies, and**
* Promote innovative research.

The evidence is here: <https://www.ipsos.com/en-ca/canadian-rare-disease-patients-and-direct-caregivers-experience-major-hurdles-timely-diagnosis-care>

I would be happy to sit down with you at anytime to speak to you about why this is an urgent need for families and patients.

Best Regards,

(Insert signature here)

I Care for Rare, Social Advocacy Campaign