



RESPONSE TO PETITION

Prepare in English and French marking 'Original Text' or 'Translation'

PETITION No.: **421-02609**

BY: **MRS. CAESAR-CHAVANNES (WHITBY)**

DATE: **SEPTEMBER 19, 2018**

PRINT NAME OF SIGNATORY: **MR. JOHN OLIVER**

Response by the Minister of Health

SIGNATURE

Minister or Parliamentary Secretary

SUBJECT

National day

ORIGINAL TEXT

REPLY

Rare diseases are life-threatening, debilitating or serious and chronic conditions that shorten life spans, reduce quality of life, and place significant challenges on patients, caregivers and the healthcare system. It is estimated that as many as 1 out of 12 Canadians is affected by a rare disease. However, some of these diseases are considered ultra-rare and may affect fewer than 10 Canadians.

The Government of Canada engages directly with patients and patient groups concerning drugs for rare diseases. We recognize the value of information that can be gathered from patients as the direct users of the products. This is especially true for rare diseases given the limited information available and the fact that patients and/or their caregivers may be experts on their own diseases. Consequently, the Government of Canada continues to work with all its partners and key stakeholders to improve access to drugs for rare diseases by encouraging the development and availability of safe and effective products.

Rare Disease Day is an observance created by the European Organization for Rare Diseases to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families. The first Rare Disease Day was held on February 29, 2008, a date chosen as it is a "rare day". The Government

of Canada acknowledges and commends the efforts of the Canadian Organization of Rare Disorders (CORD) in recognizing this observance and raising awareness about rare diseases.