



1 June 2010

Helen Stevenson
Assistant Deputy Minister and Executive Officer
Ontario Public Drug Programs Ontario
Ministry of Health and Long-Term Care
Hepburn Block 80 Grosvenor Street, 11th floor
Toronto, Ontario M7A 1E9

Dear Ms. Stevenson,

On behalf of the Canadian Organization for Rare Disorders, I would like to express our appreciation for the report from the Ontario Citizen's Council with their recommendations from the January 2010 meeting to consider the question: "Under what situations and /or conditions should the Ontario Government (i.e. taxpayers) pay for Drugs for Rare Diseases".

We thank you for the opportunity to have provided a background document as well as suggestions for patients to present their stories. We were also able to have representatives from CORD had the opportunity to observe the presentations to the Council.

Overall, we believe the recommendations indicate that the Council members understood the challenges of patients with rare disorders as well as the unique issues presented for access to drugs that have been developed, tested, and approved for small patient populations, requiring different standards for drug approvals. We also appreciate the values perspective of the Council to recommending access if the drug is likely to benefit and even before final review has been completed. We are in agreement that patients receiving access to these therapies need to demonstrate responsibility in abiding by the treatment and monitoring protocols. Finally, we endorse the position that drugs that prove not to be effective, on an individual basis, should be discontinued for that patient.

Please express our gratitude to the Citizen's Council for their conscientious and compassionate discharge of their mandate with respect to this issue.

In addition, we wish you every success in your future endeavours.

Sincerely,

President

**151 Bloor Street West, Suite 600
Toronto, Ontario M5S 1S4**