**Healthcare Questionnaire for Ontario Provincial Candidates**

**Spring 2018**

The Network of Rare Blood Disorder Organizations (NRBDO) / Réseau des Associations Vouées aux Troubles Sanguins Rares (RAVTSR) is a pan-Canadian coalition of 10 not-for-profit organizations representing people with rare blood disorders and/or people with chronic conditions who are recipients of blood or blood products or their alternatives. We speak with a unified voice on issues of blood supply and safety, and the healthcare of individuals living with rare blood disorders.

This questionnaire can also be completed on line at:

<https://www.surveymonkey.com/r/M8NQ9TV>

**Candidate Name:**

**Candidate Party:**

**Candidate Riding:**

1. Health Canada has an accelerated review process to evaluate promising new drugs for serious and unmet patient needs. This cuts the regulatory approval time in half. No such rapid review process exists for decisions on reimbursement of such drugs by the provinces and territories, including Ontario.

**Are you in favour of creating an accelerated review pathway so that patients with serious, unmet needs can have access to novel therapies, including blood products and their substitutes, more quickly?**

(pick one) 🞏 strongly support 🞏 support 🞏 oppose 🞏 strongly oppose

2. The Ontario Government established an Ontario Rare Disease Working Group, which released a [report](http://www.health.gov.on.ca/en/common/ministry/publications/reports/rare_diseases_2017/rare_diseases_report_2017.pdf) with 19 recommendations in 2017. Among these recommendations were the creation of “Centres of Reference” for the specialized treatment of rare disorders, and patient registries that would help with research as well as management and treatment of rare diseases. This would improve patient care, and, in the case of rare blood disorders, contribute to optimal use of blood products.

**Would you support Ontario funding Centres of Reference and voluntary patient registries for rare blood disorders specifically?**

(pick one) 🞏 strongly support 🞏 support 🞏 oppose 🞏 strongly oppose

3. The Ontario Technology Advisory Committee (OHTAC) recommendation is that “home-based subcutaneous infusion of immunoglobulin (IG) be publicly funded for treatment of patients with primary and secondary immunodeficiencies.” The Committee accepted the findings of Health Quality Ontario that home-based treatment was similar to hospital-based treatment in efficacy, while being preferred by patients and caregivers, providing a cost-savings to the health care system, reducing nursing time, and increasing hospital capacity.

**Do you support the OHTAC’s recommendation to implement a home-based IG infusion program in Ontario?**

(pick one) 🞏 strongly support 🞏 support 🞏 oppose 🞏 strongly oppose

4. Recent proposals on pharmacare include measures that would make efficacious, expensive drugs for rare disorders affordable to patients with serious, unmet needs.

**Do you support a pharmacare program that would increase access to such efficacious drugs for patients with rare disorders?**

(pick one) 🞏 strongly support 🞏 support 🞏 oppose 🞏 strongly oppose

5. Distribution and reimbursement of the cost of plasma protein products and their recombinant substitutes has always occurred via Canadian Blood Services (CBS). This has resulted in fair and equitable access to an optimal supply of these essential therapies to citizens of Ontario and indeed all of Canada.

**Are you in support of continuing the practice of having all blood products distributed by CBS?**

(pick one) 🞏 strongly support 🞏 support 🞏 oppose 🞏 strongly oppose

6. Why would you support policy that improves the lives of people living with a rare blood disorder? Are you or someone you know impacted by a rare blood disorder? *(Optional)*

Thank you for taking the time to complete this questionnaire, and best of luck to you on June 7th!