



Network of Rare Blood Disorder  
Organizations  
Réseau des Associations Vouées  
aux Troubles Sanguins Rares

## 2018 Pre-Budget Consultation Submission

### Minister of Finance Honourable Charles Sousa

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Thank you for the opportunity to contribute to the 2018 provincial budget through this pre-budget consultation submission.

The Network of Rare Blood Disorder Organizations (NRBDO) is a pan-Canadian coalition of eleven not-for-profit organizations representing people with rare blood disorders and/or people with a chronic condition 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.

#### Executive Summary

**The NRBDO recommends, starting with the 2018 provincial budget, that the government establish permanent funding to implement the priorities and recommendations as defined by the Ministry-appointed Rare Disease Working Group, and specifically to invest in Rare Blood Disorder “Centres of Reference” that can improve healthcare services for those living with rare blood disorders throughout the province.**

#### Rare Disease Working Group Recommendations

In February 2016, Health Minister Hoskins set up a Working Group to develop Ontario’s Rare Disease Strategy. The Working Group Report, released in March 2017, included 19 recommendations, and in October 2017 Minister Hoskins put in place an Implementation Working Group. We are encouraged that the Minister has set a deadline of June 2018 for an implementation plan.

As stated in the report from the Rare Disease Working Group: “In Ontario, various clinical programs and services have developed over time to address the diagnosis and management of rare diseases, however patients and clinical experts report that services are not comprehensive or well-integrated. This has led to uneven delivery of care for this patient group. This is a reality for both paediatric and adult populations. Availability of clinical programs and services in non-urban areas is particularly limited.”

Given Ontario’s existing (though often disjointed) assets in rare disease diagnosis and care, this province is poised to deliver a world-class rare disease program. Core to that program will be “Centres of Reference” – clinics that can facilitate improved coordination of care and access to specialized knowledge for the management of rare diseases.

## **Rare Disease Centres of Reference**

The NRBDO feels it is a timely request that the Ontario government, in this coming 2018 budget, establish permanent funding to implement the priorities and recommendations as defined by the Implementation Working Group, and specifically to invest in Rare Blood Disorder “Centres of Reference” that can improve healthcare services for those living with rare blood disorders throughout the province.

There are established clinics with qualified specialists, such as the Hemoglobinopathy Clinic at Toronto General Hospital and the HAE/PID Clinic at Saint Michael’s Hospital, and with dedicated and appropriate financial resources they could be scaled up to address the needs of Ontario rare blood disorder patients and families and offer the full benefits of comprehensive care to both the patients and tax payers of Ontario.

## **Economic Benefits of Comprehensive Care Clinics**

When it comes to rare blood disorders, finding the balance between optimal patient care and efficient stewardship of healthcare dollars is a challenge felt by doctors, hospital administrators, and governments alike.

Blood and plasma protein products are a significant expense in the healthcare budget. At our 2017 NRBDO Comprehensive Care Conference, presenters shared their findings, including an example from hemophilia where the blood product budget in Canada made up 93% of the cost for those receiving blood products, and the care delivery budget made up only 7%. It was noted that these two systems operate with very little understanding or interest in each other, but that it is only by looking at both holistically that we can understand how relatively small investments in care delivery can have positive impacts on the overall budget, while also providing much improved care for patients.

A growing body of evidence suggests that comprehensive care clinics:

- improve patient and caregiver experiences and outcomes,
- improve safety through tracking of product use,
- increase cost effectiveness,
- result in shorter and fewer hospital stays, and
- reduce product waste

## **Conclusion**

The NRBDO is pleased with the attention being given to rare diseases by the Ministry of Health and Long-Term Care in recent years. In order for Ontarians to benefit from the recommendations of the Rare Disease Working Group, resources will be required. Specifically, we hope the Honourable Minister will consider the economic benefits of investment in comprehensive care Centres of Reference for rare blood disorders. Thank you again for the opportunity to participate in this consultation.

*The Network of Rare Blood Disorder Organizations (NRBDO) is a coalition of national patient groups, formed to share the best practices in health care delivery for people with rare blood disorders such as hereditary angioedema; aplastic anemia, Fanconi anemia, paroxysmal nocturnal hemoglobinuria (PNH), and myelodysplasia; primary immune deficiency; porphyria, sickle cell disease, thalassemia, thrombotic thrombocytopenic purpura (TTP), hereditary hemorrhagic telangiectasia (HHT), hemophilia, and von Willebrand disease.*