



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

TERMS of REFERENCE for MEMBERS

1.0 PURPOSE

Network of Rare Blood Disorder Organizations (NRBDO) / Réseau des Associations Vouées aux Troubles Sanguins Rares (RAVTSR) is a pan Canadian coalition of 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.

The NRBDO's vision is high quality, effective, accessible, interdisciplinary care for all Canadians affected by rare blood disorders.

The mission of the Corporation is to support rare blood disorder organizations in achieving comprehensive care for their communities.

Our mandate is to improve the healthcare delivery for people affected by rare blood disorders by: i. working together to ensure the best comprehensive care, ii. ensuring a safe and secure blood system, iii. supporting the members by sharing best practices in governance, iv. developing skills in health care advocacy, and v. avoiding overlap and inefficiencies.

2.0 MEMBERSHIP

Membership in the NRBDO is open to Canadian 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. There is one class of Members with Membership available to one group per disease, with preference given to groups with a national presence. Each member shall be entitled to receive notice of, attend and vote at all meetings of the members of the NRBDO.

Membership in the NRBDO shall be available to organizations interested in furthering the NRBDO's purposes and who have applied for and been accepted into membership in the NRBDO by resolution of the board.

The NRBDO and each organizational member agree to the following terms:

- Members agree to support the mandate of the NRBDO as outlined in this Terms of Reference.
- Members receive a report annually on NRBDO activities.
- Members receive a work-plan outline for NRBDO activities in the coming year.
- Members commit to making every effort to send 2 representatives to the semi-annual Face-to-Face Member Meetings, with all expenses related to the meeting being paid by the NRBDO for 2 representatives. Any member organizations can send additional representatives at the expense of their organization.



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- Members are encouraged to nominate representatives from their organization to vacant positions on the Board of Directors.
- The Board commits to gain the support of member representatives prior to initiating public/external action, such as but not limited to meeting with or writing to elected government representatives or launching advocacy campaigns, through the process outlined in the **NRBDO Policy – Advocacy Letters**. NRBDO members are encouraged to promote our activities with their own members to generate additional support.

3.0 STRUCTURE

The NRBDO's work-plan is set and stewarded by the Board of Directors, which is made up of 3-7 member representatives elected to 1 year terms. While membership is open only to organizations, board members are elected as individuals, not to represent their organization on the board. Board member selection occurs as described above in section 3.0, as well as in the Board of Directors Terms of Reference.

4.0 DISCLAIMER

Membership in the NRBDO demonstrates an alignment with the mandate in Section 2.0, and wherever possible the NRBDO operates in full consensus. However it is understood that from time to time, the NRBDO may express views that are not endorsed by one or more member organizations. Similarly, member organizations may from time to time take a different stance than that of the NRBDO.

Approved: September 26, 2016

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