

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

June 15. 2018

Pamela Fralick President, Innovative Medicines Canada 55 Metcalfe Street, Suite 1220 Ottawa, ON K1P 6L5 pfralick@imc-mnc.ca

Dear Ms. Fralick,

The Network of Rare Blood Disorder Organizations (NRBDO) / Réseau des Associations Vouées aux Troubles Sanguins Rares (RAVTSR) is a pan-Canadian network of patient organizations, working together for those affected by rare blood disorders.

We are writing to you today to express our concerns about the impact of Innovative Medicine Canada's restrictions on patient groups when it comes to using funding from pharmaceutical companies to reimburse the domestic travel expenses of health care providers.

Health care providers, including physicians, nurses and other members of the integrated care teams, who treat rare conditions are often the only ones with expertise in their province. It is imperative that they share best practices with colleagues across Canada. Patient organizations, with financial support from pharmaceutical partners, play an integral role in bringing these HCPs together in national congresses or conferences.

Alternate sources of funding, for example, hospitals or health authorities, rarely provide support for attendance at such out-of-province meetings where competence is shared and developed. In many cases, nurses and other members of the care teams work only part-time to treat a specific rare condition and, not only are they not supported by their institutions to travel, but they must often take personal leave to do so.

Prohibiting reimbursement for travel and accommodation effectively bars the organization of such learning activities. We urge you to reconsider the domestic travel reimbursement restrictions on health care providers, and would welcome the opportunity to discuss this issue with you further at your convenience.

Sincerely,

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Gergana Sandeva Chair, NRBDO