

October 22, 2015

Dear Ms. Wagontall:

Re: Review of Alberta Newborn Metabolic Screening Program

The Network of Rare Blood Disorder Organizations, founded in 2004, is a coalition of national patient groups formed to share the best practices in health care delivery for people with a blood disorder and/or recipients of blood or blood products or their alternatives. We work, advocate and lobby together on key issues to ensure and maintain patient access to comprehensive care.

Your call for input into the provincial review of your newborn blood spot screening has been brought to our attention, and we would like to take the opportunity to endorse the expansion of the Alberta NMS program to include these additional conditions. In particular we write in support of newborn screening (preferably with parental informed consent) for Beta-thalassemia, Sickle Cell anemia, and severe combined immunodeficiency (SCID), on behalf of our member patient groups.

We are pleased to support this expansion of your screening program as it falls in line with the Canadian Organization of Rare Disorder's Rare Disease Strategy, particularly the goal of improving early detection and prevention, and as it is an important step in bringing Alberta up to the newborn screening program standards in other provinces such as Ontario and British Columbia, but mostly because it will help save lives and avoid needless suffering.

Thank you for the opportunity to weigh in on this matter. We look forward to your decision.

Sincerely,



Wendy Sauve
Interim Chair,
Network of Rare Blood Disorder Organizations (NRBDO)

Member Organizations:

Answering TTP (Thrombotic Thrombocytopenic Purpura)

Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)

Canadian Association for Porphyria (CAP)

Canadian Hemophilia Society (CHS)

Canadian Immunodeficiencies Patient Organization (CIPO)

Canadian Organization for Rare Disorders (CORD)

Fanconi Canada

HAE Canada (Hereditary Angioedema)

HHT Canada THH

Sickle Cell Disease Association of Canada (SCDAC)

Thalassemia Foundation of Canada (TCF)