Form 1: Nomination of a Condition for Consideration for Addition to the Newborn/Child Screening Panel in Ontario

Part A. Identification, contact information, nature of interest in nomination

1. What condition do you nominate?

2. Who nominates this condition?   a) Please list names of all individual/s who wish to be included on the nomination. Even if the nomination is on behalf of one or more groups, individual names are needed here.   b) Please provide complete contact information for one of the individuals listed above, who can represent all of the nominators in communications with the screening committee.

3. Are you nominating the condition on behalf of one or more groups or organizations?   a) If so, please indicate the name of the group/s or organization/s. Please also state the capacity in which the nominators represent the organization (e.g., JD is Director, RW is Medical Advisor, FS is a Member, etc).   b) If not, please specify the nature of your interest in nominating the condition (e.g., personal or family experience, health care professional, etc).

4. Please indicate any possible financial interests in nominating this condition for screening, for each of the individuals listed in your response to question 2a.

Part B. Additional information

5. What group of physicians provides care for patients who have the condition (examples: endocrinologists, hematologists, don't know)?

6. Do you know of a patient or family support group that has an interest in this condition?   a) If yes, please give the name of the group or groups. Is the group aware of this nomination (i.e., have you contacted them)?

7. Do you know if there is a test for this condition? If so, what is the test?
8. Is there a treatment for this condition? If so, what is the treatment? Do you know if the treatment is available in Ontario?
9. Do you know of any other jurisdictions (in Canada or internationally) that screen for this condition in newborns or children (if so, please list)?
10. Do you have any other comments you would like us to consider or any questions for us?