

**Ministry of Health
and Long-Term Care**

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**Ministère de la Santé
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August 29, 2016

Durhane Wong-Rieger, PhD
President and CEO
Canadian Organization for Rare Disorders
151 Bloor Street West, Suite 600
Toronto, ON M5S 1S4

Dear Ms. Wong-Rieger:

I am writing to follow-up on the August 17, 2015, correspondence by Assistant Deputy Minister Patrick Dicerni. At that time, he wrote to you regarding the efforts of the Intergovernmental Newborn Screening Working Group to explore areas of pan-Canadian cooperation for newborn screening.

Before 2013, newborn screening collaboration in Canada was limited to certain geographic areas and clinician groups. The creation of the Intergovernmental Newborn Screening Working Group by Ministers provided program officials and jurisdictional clinicians the opportunity to come together, share information and improve screening practices in Canada.

Last year, the Working Group requested feedback from stakeholders in order to provide Provincial-Territorial Health Ministers (except Québec) with the most comprehensive information available and to ensure that the views of patient groups and advocates were included.

I would like to inform you that all feedback received was carefully reviewed and, where appropriate, included in the update to Ministers at their January 20, 2016, meeting in Vancouver, British Columbia.

I am also pleased to inform you that at their January meeting, Ministers received a recommended Canadian Newborn Screening List consisting of 22 diseases to inform and provide guidance to provincial newborn screening programs. Furthermore, national guidelines were endorsed for the retention and secondary use of newborn screening blood samples. (See below for additional information.)

As Patrick wrote last year, newborn screening is a key population-based public health initiative, with the goal of early detection and treatment so that better health outcomes for the given population are achieved.

On behalf of the Working Group, I would like to thank you and your organization for your support in this important initiative.

Sincerely,



Louis Dimitracopoulos
Acting Assistant Deputy Minister

CANADIAN NEWBORN SCREENING LIST

At the January 2016 Health Ministers' Meeting, a Canadian Newborn Screening List consisting of 22 diseases was accepted to provide guidance to provincial newborn screening programs.

Amino Acid Disorders / Urea Cycle Disorders

Phenylketonuria
Maple syrup (urine) disease
Tyrosinemia type I
Citrullinemia
Argininosuccinic acidemia

Fatty Acid Oxidation Disorders

Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency
Long-chain 3-OH acyl-CoA dehydrogenase (LCHAD) deficiency
Trifunctional protein (TFP) deficiency
Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency
Carnitine uptake defect

Hemoglobinopathies

Sickle cell disease

Organic Acid Disorders

Isovaleric acidemia
Glutaric acidemia type I
Methylmalonic acidemia (mutase deficiency)
Methylmalonic acidemia (Cbl A,B)
Propionic acidemia

Endocrine Disorders

Congenital hypothyroidism
Congenital adrenal hyperplasia

Other Disorders

Galactosemia
Biotinidase deficiency
Cystic fibrosis
Severe Combined Immunodeficiency

NEWBORN SCREENING BLOOD SAMPLES

Note: the recommended guidelines regarding newborn screening blood samples is that all blood spot cards should be stored for ten (10) years then destroyed in a safe and secure manner consistent with any applicable laws, the appropriate national guidelines and institutional policies. The primary purpose of retaining a newborn screening blood spot specimen is for analyses that will benefit the child. Other uses include:

1. Screening program quality assurance or screening program development purposes.
2. Additional analyses that could benefit the family of an affected child.
3. Research, provided the jurisdictional legal requirements (e.g., privacy, obtaining consent when necessary) and other requirements (e.g., Research Ethics Board approval) are met.