



PROTECTING, MAINTAINING AND IMPROVING THE HEALTH OF ALL MINNESOTANS

April 18, 2016

Jan Larson, JD
Committee Chairperson
Advisory Committee on Heritable and Congenital Disorders

Dear Mr. Larson:

Thank you to the Advisory Committee on Heritable and Congenital Disorders for ensuring Minnesota's Newborn Screening Program is exemplary and leading in national efforts to be on the forefront of changes and additions to newborn screening panels.

I would like to commend the advisory committee on its process, work group efforts, and evidence-based discussions regarding the benefits and harms of newborn screening for X-linked Adrenoleukodystrophy (X-ALD) and six lysosomal disorders, including Fabry, Gaucher, Krabbe, Mucopolysaccharidosis type I (MPSI), Niemann-Pick A/B, and Pompe.

As you know, the Secretary of the Department of Health and Human Services has recently added MPS 1, Pompe, and X-ALD to the Recommended Uniform Screening Panel (RUSP). I have reviewed the package of materials provided to me which included:

- Materials provided to the Advisory Committee members regarding condition discussions, including written testimonies;
- A table summarizing the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) progress and time lines regarding relevant condition nominations;
- Long term follow-up considerations;
- Materials summarizing the ACHDNC's stance on these conditions; and
- Brief clinical histories on those disorders that have not been nominated to the ACHDNC or those without evidence based reviews.

Following review, I accept the Advisory Committee on Heritable and Congenital Disorders recommendation to expand the Minnesota newborn screening panel to include MPS I, Pompe, and X-ALD.

The Advisory Committee also recommended that conditions added to the RUSP would be presumed to be added to the Minnesota panel pending a vote by the Advisory Committee, and without the need to commission a workgroup. While I feel that addition to the RUSP is an important factor to consider when deciding whether to add disorders to our Minnesota

screening panel, I found the thoughtful assessment performed by the workgroup on the lysosomal and leukodystrophy disorders to be very helpful to me as I made my final decision to add MPS I, Pompe, and X-ALD to the screening panel. Therefore, I prefer to reserve the option to request that a workgroup conduct a review of future disorders being considered for the Minnesota screening panel.

With regard to the recommendation that the Department of Health ensure long-term follow-up to parents and providers of children diagnosed with one of the disorders on the newborn screening panel, I look forward to future discussion about the needs and opportunities for enhancing follow-up and education about outcomes and long-term management of these children.

Please accept my personal thanks to you and the members on the committee for your valuable work to improve the health of Minnesota newborns.

Sincerely,

/s/

Edward P. Ehlinger, M.D., M.S.P.H.
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