



STATE OF WASHINGTON
DEPARTMENT OF HEALTH

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September 11, 2007

To: Newborn Screening Advisory Committee members

From: Michael Glass, Director
Newborn Screening Program

We are very happy that you will be serving on the Washington State Newborn Screening Advisory Committee. The committee will consider several candidate conditions for adding to the mandated panel. Sixteen of the candidate conditions are recommended in a report commissioned by the Federal Health Resources and Services Administration. An additional candidate condition was recommended by a sub-committee convened earlier by the Board and Department of Health to consider technical issues related to the availability of effective treatment and screening tests.

The conditions to be considered are:

- Isovaleric acidemia (IVA)
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
- Long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHAD)
- Trifunctional protein deficiency (TFP deficiency)
- Glutaric acidemia type 1 (GA-1)
- Methylmalonic acidemia – mutase deficient – vitamin B12 non-responsive (MUT)
- Methylmalonic acidemia – Cbl A,B – vitamin B12 responsive (CblA,B)
- Propionic Acidemia (PROP)
- 3-hydroxy-3-methylglutaric aciduria (HMG)
- Beta-Ketothiolase deficiency (BKD)
- Citrullinemia Type 1 (CIT)
- Argininosuccinic Acidemia (ASA)
- Carnitine Palmitoyl Transferase 1 Deficiency (CPT-1) *
- Holocarboxylase synthase deficiency (HCS)/Multiple carboxylase deficiency MCD
- Carnitine uptake deficiency (CUD)
- 3-methylcrotonyl-CoA carboxylase deficiency (3-MCC)
- Tyrosinemia type 1 (TYR-1)

We hope to cover the first five to eight conditions at the meeting on September 24, 2007.

Obviously there is a lot of information that needs to be shared. To assist, we have put together two sets of fact sheets for each candidate disorder:

* Not included in the recommended panel, added by Technical Advisory Committee

1. Technical fact sheets – These sheets contain information we prepared for the technical sub-committee and a summation of the sub-committee’s findings. Note: the sub-committee categorized the conditions into three groups: Most, Intermediate, and Less Concordance with the testing and treatment effectiveness criteria.
2. Parent fact sheets – Texas’ newborn screening program created all but one of these sheets, designed to give parents information about these rare conditions. The other sheet is from Alaska.

In addition we have assembled some family stories – we searched the internet for a representative sample of the types of experiences that families have with children that have these disorders. These unedited stories are intended to convey the human, emotional perspectives that compel many of these families to advocate for screening.

You can access these materials at the [2007 advisory committee website](#). If you would like paper copies, please call my assistant Juli Terao-Fast at 206-418-5537 or email: juli.terao@doh.wa.gov.

You may note some inconsistencies between these resources regarding the ‘facts’ about some conditions. In large part this reflects the spectrum of current knowledge regarding the conditions, their manifestations, and the most effective approaches to treatment.

Thank you for your willingness to serve on this committee. Please contact us (see letterhead) if you have any questions. We look forward to meeting with you on September 24th.