



DATE: November 12, 2014

TO: Washington State Board of Health Members

FROM: Diana T. Yu, MD, MSPH

SUBJECT: NEWBORN SCREENING UPDATES INCLUDING ALD LETTER

Background and Summary:

In October of 2014, the Board received the following request from Mr. Zakes on behalf of the Zakes Foundation:

The Zakes Foundation requests that the State Board of Health commission the advisory committee to continue its full evaluation of ALD for potential inclusion on Washington State's mandatory newborn screening panel. In the event the advisory committee recommends and the State Board of Health votes in approval of adding ALD to the list of conditions to be screened, then the implementation of any future testing in Washington State would be conditioned upon the inclusion of ALD to the RUSP at the federal level.

At the Board's October meeting, the Board decided to begin an evaluation of the newborn screening (NBS) criteria used to determine whether a condition should be included in the NBS panel. The Board also made commitments to convene advisory committees to evaluate Critical Congenital Heart Disease (CCHD) and Adrenoleukodystrophy (ALD). During our discussion, I explained that we would retain our existing five NBS criteria but possibly add other criteria, and that we needed to create a framework for evaluating potential NBS criteria which could include an ethical/medical framework and assumptions.

I would like to honor the spirit of the Zakes Foundation request and recommend that Board staff work with Department of Health (DOH) staff to examine the ALD research pertaining to the five existing NBS criteria in parallel with the Board's project work to evaluate of the NBS criteria. This will allow us to move the process forward more quickly.

I also need to clarify that we have yet to convene an Advisory Committee, but that an internal group made up of Board and DOH staff have met to tease out the issues that the ALD research review will need to address. Given our October motion, I believe we also need a parallel research process for CCHD.

I think it is premature to determine whether or not possible inclusion of ALD in the NBS panel be pre-conditioned upon its inclusion in the Recommended Uniform Screening Panel (RUSP). At this stage, we do not know exactly how the RUSP will fit in the NBS evaluation framework.

Recommended Board Actions:

***Motion:** The Board requests that Board staff work with DOH staff to examine ALD and CCHD research pertaining to the five existing NBS criteria in parallel with the Board's project to evaluate the NBS criteria.*

Staff Contact: Tara Wolff