



HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

January 10, 2018

HB 1783-FN

Relative to Newborn Screening for Krabbe Leukodystrophy

Testimony

Good morning, Mr. Chairman and members of the committee. My name is Paula Minnehan, VP, State Government Relations with the New Hampshire Hospital Association (NHHA), representing all 26 of the state's community hospitals as well as all of our specialty hospitals.

The NHHA has concerns about HB 1783-FN. The main concern we have is one of process. RSA 132:10-a established the newborn screening program and requirements for which disorders should be screened at birth. As part of the program requirements, a Newborn Screening Advisory Committee was established. The Department of Health and Human Services, Division of Public Health Services, manages the program and convenes the Advisory Committee, on which NHHA has a seat, in addition to appointing a designee from a hospital to participate. We understand the emotional aspect of this issue, and as such, we remain committed to following the process that enhances newborn screenings.

The Advisory Committee is responsible for studying additional disorders to be added to the screening panel. That is the process established in law, and we ask that the committee allow for that process to be followed with regards to the consideration of adding Krabbe Leukodystrophy, or any other disorder, to the screening panel.

When a similar bill to the one before you today was introduced in 2015, the result of the deliberations at that time was that the Newborn Screening Advisory Committee did review the current science, medical and ethical evidence for adding the disorder to the newborn panel. We ask that the committee allow for that same process to occur now.

Thank you for the opportunity to provide our comments. I am happy to answer any questions.