



March 20, 2017

The Honorable Brian Boquist  
900 Court St. NE, S-311  
Salem, Oregon 97301

The Honorable Knute Buehler  
900 Court St. NE, H-389  
Salem, Oregon 97301

The Honorable Lee Beyer  
900 Court St. NE, S-411  
Salem, Oregon 97301

The Honorable Julie Parrish  
900 Court St. NE, H-371  
Salem, Oregon 97301

**RE: SB 808 – Newborn Screening**

Dear Senators Boquist and Beyer, and Representatives Buehler and Parrish:

We write today to thank and commend you for your imperative leadership on newborn screening that is embodied in the senate bill, SB 808. Newborn screening has proven to be an essential tool for the long-term health and well-being of babies born in Oregon and across the United States. This bill provides a much-needed, practical, science-based approach to improving public health for these children through continuing improvement to screening best practices. Every year, millions of babies born in the U.S. are screened for a variety of diseases and conditions that might otherwise go undetected. These simple tests provide life-saving early warnings of conditions, allowing for the earliest diagnosis and access to critical treatments. In many cases, early detection can also avert costly and risky medical procedures later in life.

Under current practice, states take many different approaches to newborn screening. This patchwork approach creates wide variation in disease detection and access to treatment. Oregon's current process for reviewing and approving screening of additional diseases has created a lag behind current medical recommendations. Every day of delay in testing is another day of heartache for patients and their families that can be avoided with more timely action.

SB 808 would provide a forward-thinking approach to the expansion of newborn screening in Oregon. This bill would enable Oregon to screen for any disease on the Recommended Uniform Screening Panel (RUSP) within two years of the test's approval. The RUSP list is updated periodically through a thorough, deliberative review process involving a national committee of experts in newborn screening. By allowing Oregon to leverage the work done by these medical experts we can remove obstacles and minimize the suffering that comes from untreated diseases.

SB 808 would ensure that babies born in Oregon, particularly those that will be affected by debilitating and life-threatening diseases, are diagnosed and treated without delay. This is critical for improving health outcomes and providing the brightest future for all babies born in Oregon. For these reasons, we are proud to support SB 808. We are grateful for your leadership on this issue and look forward to working with you and your offices to ensure this bill becomes law.

Sincerely,

Max G. Bronstein, MPP  
Chief Advocacy & Science Policy Officer  
EveryLife Foundation for Rare Diseases

*No Disease is Too Rare to Deserve Treatment*