



March 21, 2017

Rep. Jason Brodeur, Chairman  
Health and Human Services Committee  
412 House Office Building  
402 South Monroe Street  
Tallahassee, FL 32399

**RE: Support for HB 963**

Dear Chairman Brodeur and Members of the Committee:

The National Organization for Rare Disorders respectfully requests the committee to pass HB 963, an act to improve Florida's newborn screening program (NBS) by enabling the state to screen for every condition recommended by the Department of Health and Human Services (HHS).

Newborn screening is one of the most successful public health programs ever enacted, saving millions of lives in its 50 years of implementation. Screening enables physicians to catch a heritable disease early and start treatment almost immediately following a child's birth. In many instances, this early intervention can profoundly benefit a child's mental and physical development.

Florida has been a leader among states when it comes to the rapid implementation of new recommendations and technologies used to implement NBS for new diseases. However, the state currently does not screen for all conditions on the HHS Recommended Uniform Screening Panel (RUSP).<sup>1</sup> This is because the process of adding new diseases to the state's NBS program can be arduous, requiring separate legislative approval for each condition.

HB 963, introduced by Representative Fitzenhagen, addresses this issue by streamlining the process by which the state may adopt new RUSP recommendations. The bill enables the state to adopt screening for new conditions added to the RUSP in a timely manner, while also accounting for the need for state agencies to adopt new procedures and meet other requirements.

Thank you for the opportunity to comment on HB 963. If we can supply additional information, please do not hesitate to let us know. Tim Boyd, NORD's Director of State Policy, is available to assist as needed and can be reached at [tboyd@rarediseases.org](mailto:tboyd@rarediseases.org).

Sincerely,

A handwritten signature in blue ink that reads "Peter L. Saltonstall".

Peter L. Saltonstall, President and CEO

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<sup>1</sup> NORD 2016 State Policy Report Card, available at <http://rareaction.org/resources-for-advocates/state-report-card/>