



My name is Dylan Simon, and I am the Director of Policy for the EveryLife Foundation for Rare Diseases. On behalf of the EveryLife Foundation, I would like to thank the Committee for providing me with the opportunity to provide updates on our relevant Newborn Screening initiatives.

EveryLife's Newborn Screening initiative is focused on ensuring babies receive lifesaving treatment opportunities through early diagnosis with newborn screening.

As part of our initiative, the EveryLife Foundation is partnering with Expecting Health for the 4th annual Newborn Screening Bootcamp. The Bootcamp will take place in-person and virtually on Saturday, October 15th. Our program will provide attendees with the opportunity to learn about and discuss developments in newborn screening with experts and patient advocates currently navigating the newborn screening process. We will also focus a panel and breakout session on equity in newborn screening, discussing the recent research from APHL that was presented to the ACHDNC earlier this year. We will also work to determine proactive ways various newborn screening stakeholders can help to improve equity within newborn screening. We appreciate the time and dedication of the expert speakers and community members who will be a part of this event.

The EveryLife Foundation is also excited to continue working with the newborn screening community to determine how best to modernize the newborn screening system. Over the summer, the Foundation, in conjunction with other newborn screening stakeholders, organized the Newborn Screening Modernization Roundtables. These leading organizations included ASGCT, Biomarin, Expecting Health, NBSTRN, Orchard Therapeutics, PTC Therapeutics, Sanofi, Sarepta Therapeutics, and Traverre Therapeutics. The roundtables occurred over the course of two months and convened over 100 newborn screening stakeholders from various backgrounds, including patient advocacy organizations, state public health officials, industry representatives, academia, and physicians. The roundtables gave participants the opportunity to propose, analyze, prioritize, and identify the policy solutions most necessary to modernize the newborn screening system.

Throughout the roundtables, participants discussed and analyzed possible policy solutions, identifying four overarching modernization goals. These goals are:

1. Improve and expand federal support and oversight for newborn screening programs for all components of a newborn screening system, including research and pilot studies, screening implementation, data collection/reporting, and stakeholder communication.
2. Establish a regional lab network that provides state labs the opportunity to work together to ensure efficient and faster addition of newborn screening conditions.
3. Increase access to population-level data and facilitate the development and implementation of newborn screening conditions.
4. Integrate next-generation, evidence-based genomic testing into newborn screening in a manner that will be broadly endorsed and implemented in all states.

Moving forward, roundtable concepts will be shared in greater detail, along with proposed, actionable policy changes to achieve newborn screening modernization.

Thank you for the opportunity to speak with the Committee today, and for your tireless efforts on behalf of the nation's newborns and families. We look forward to sharing the community's newborn screening modernization policy solutions with you in greater detail.

Thank you.