On behalf of the EveryLife Foundation for Rare Diseases, thank you for providing me with the opportunity to the Committee today.

The EveryLife Foundation for Rare Diseases is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures. Today, I want to update you on our recent newborn screening initiatives intended to support the Advisory Committee and expand the reach of newborn screening programs recommended by the Committee.

At the federal level, we have been leading rare disease community coalition efforts with our Newborn Screening and Diagnostics Working Group members to support the passage of the Newborn Screening Saves Lives Reauthorization Act. We are pleased that the House and Senate both introduced legislation earlier this year containing identical language, an update from last session in which the House and Senate bills differed. The legislation currently holds bipartisan support in both chambers. In addition to working directly with Congressional champions to advance the bill, the Foundation convened a virtual advocacy event in March that included nearly 700 rare disease community advocates and 373 Hill meetings. Known as 'Rare Across America', this event enabled advocates to educate their representatives and senators about the importance of newborn screening and to seek their support of the legislation. We will continue to work with the rare disease community to ensure that policy makers understand the importance of reauthorizing and funding critical newborn screening programs as proposed in the bill.

We also remain focused on shortening the timeline between when a condition has been added to the RUSP and when it is screened for at the state level. The RUSP Alignment legislation works to ensure that a state must screen for all RUSP conditions within a specified amount of time following a condition's addition to the RUSP. The legislation would also ensure that there is a long-term funding source for the newborn screening program to facilitate implementation of new conditions. The current process of state-by-state implementation requires significant resources and many more years of waiting for the patient community. Years that newborns go undetected and lack access to potentially life-saving therapies and interventions.

The EveryLife Foundation previously led the passage of this legislation in California and Florida. This year we are pursuing similar legislation in Arizona, Georgia, Ohio, and North Carolina. To date, our legislation has been introduced in all four states. In Georgia, the legislation unanimously passed the State Assembly and is currently waiting for the Governor's signature. In Arizona and Ohio, the legislation passed out of one chamber and is currently waiting for passage out of the full Assembly. In North Carolina, the legislation was recently introduced into the State House of Representatives. None of this is possible without the great work of dedicated rare disease community advocates in each of these states working to ensure that the importance of this legislation is understood. Your work as a Committee to build a trusted and comprehensive review process for the RUSP conditions has also contributed to the success of the legislation as states understand the value in leveraging the work you have done to evaluate the appropriateness of each new condition.

We are grateful for all the work that is occurring within the newborn screening space and are committed to continuing to empower advocates to effectively navigate the existing newborn screening system and engage meaningful within the community.