On behalf of the EveryLife Foundation for Rare Diseases, I would like to thank the Committee for providing me with the opportunity to address you 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. A vital part of our effort is our continued advocacy for newborn screening, focusing on ensuring patients receive the earliest access to lifesaving diagnostic opportunities through newborn screening.

At the federal level, we have been leading rare disease community coalition efforts dedicated to the passage of the Newborn Screening Saves Lives Reauthorization Act. We are excited that the House re-introduced the legislation on January 25th, beginning the vital process of working to ensure that this important piece of legislation is finally signed into law. We look forward to advocates taking advantage of our Rare Across America event at the end of the month to ask their Representatives to support the legislation. We will continue to work with the rare disease community to ensure that the impact the passage of this legislation will have on patient communities is well understood by policy makers.

We are also 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. As those present are aware, patient advocacy organizations work for decades with community leaders to develop the evidence necessary to ensure that RUSP nomination packages are ready for review by this Committee. Once conditions have met the evidentiary requirements of RUSP addition, those same organizations and patient communities then face an additional hurdle of state implementation. A process that requires significant resources and many more years. Years that newborns go undetected and lack access to potentially life-saving therapies and interventions.

The EveryLife Foundation RUSP Alignment legislation ensures that the states must screen for all RUSP conditions within a specified amount of time following a condition's addition to the RUSP, while also ensuring that there is a long-term funding source for the newborn screening program to facilitate implementation. Within the states where this legislation has passed, we have worked with the state laboratories and legislatures to ensure that resources and timeline requirements meet the needs of each state program. Just last year, we saw California, the original state to pass this legislation, add SMA to their newborn screening panel within the specified two years of RUSP addition. This year, we are pursuing similar legislation in Arizona, Georgia, Ohio, and North Carolina.

We are excited for all the great work that is occurring within the newborn screening space and looking forward to continuing to help advocates effectively navigate and engage within the community.

Thank you