My name is Liesl Broadbridge and I am the Policy Fellow 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 present comments here today.

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

This year, our Foundation's newborn screening policy work has continued to focus on efforts to align federal RUSP recommendations with state implementation, and to support stakeholder's preparation for RUSP nominations through capacity-building efforts.

With respect to our RUSP Alignment legislation, I am pleased to share that - with broad legislative and executive support - this spring the Governors of Georgia, Ohio and Arizona have signed into law legislation that will require the states to screen newborn babies for any disorder on the RUSP. In addition, North Carolina's House of Representatives passed similar legislation in May and it is now pending Senate action. We are in the planning phase for 2022 state efforts and look forward to working with the community to enact additional life-saving legislation next year.

With respect to supporting stakeholder engagement and capacity building, the EveryLife Foundation is again delighted to partner with Expecting Health to host the 3rd annual Newborn Screening Bootcamp this fall. Our virtual program will again provide resources and unique opportunities for cross-sector engagement to community stakeholders about the overall newborn screening system, the RUSP review process, opportunities for addressing racial inequities within newborn screening, and much more. We appreciate the time and dedication of the expert speakers and community members who will be a part of this event.

As you have heard previously, the Foundation is proud to serve as a convener of the Community Congress Newborn Screening Working Group. In addition to the Community Congress comments you *(heard/will hear)* from Ms. Elisa Seeger today, we would like to share that our membership urges continued emphasis and attention to the resources and communication efforts that will be necessary to help relay updates from the Committee's condition nomination, evidence review and decision-making processes.

As you know, revisions to the evidence review process will impact stakeholders across the newborn screening system. Changes to data requirements will impact the design of studies conducted for a RUSP nomination package. Any review of current RUSP conditions will require additional oversight and data reporting for state newborn screening programs.

For these reasons, we suggest the Advisory Committee create a suite of educational materials for newborn screening stakeholders, identifying changes to the evidence review process and how those changes impact specific components of the newborn screening system.

To accomplish these educational goals, we encourage the establishment of a multi-stakeholder working group – including representatives from the patient community – to inform the development and dissemination of these materials. Thank you again to the Advisory Committee for your tireless efforts on behalf of our nation's newborns. We are encouraged by all the great work that is occurring within the newborn screening space and look forward to continuing to help advocates effectively navigate and engage within the community.

Thank you