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. My name is Dylan Simon and I serve as the Newborn Screening Policy Fellow for the EveryLife Foundation.

I want to thank the multiple members of the Advisory Committee and the Evidence Review Group who spoke at last month's 2nd Annual Newborn Screening Bootcamp. We were thrilled to have your expertise and perspectives engage with a wide variety of newborn screening advocates to help empower patient communities working within the newborn screening ecosystem. The Bootcamp, convened in partnership with Genetic Alliance, was a five-week event designed to educate and engage newborn screening stakeholders. We were delighted with the success of our virtual event, with more than 280 individuals attending at least one week of the Bootcamp.

Over the course of first four weeks of the Bootcamp, discussions included a wide variety of newborn screening-related issues, from the importance of building a coalition to the challenges of state implementation. We were able to discuss important topics such as the benefits of patient registries, the evidence review process of the federal Advisory Committee, and how patient advocacy organizations and public health laboratories can work together to move the newborn screening system forward.

We closed the Bootcamp with three distinct discussion groups designed to provide an opportunity for attendees to dive deeper into information covered during the Bootcamp and how they can move their conditions forward in newborn screening. Advocates self-identified into one of three groups: Just Getting Started in Newborn Screening, On the Path to RUSP, and Beyond the RUSP. With community moderators helping to answer questions, participants shared ideas and best practices on how to address the common challenges that most face in the community.

Thank you again to the entire newborn screening community for your support of the Bootcamp. We appreciate that the COVID-19 pandemic has placed even greater demands on the precious commodities of time and resources of our newborn screening leaders, and we are especially grateful for your unwavering dedication to our rare disease patient communities. It is through your continued support that we can bring together a diverse group of stakeholders that share their unique perspectives on how to move newborn screening forward.

We are excited to announce that the 3rd Annual Newborn Screening Bootcamp will occur next October, hopefully in-person the Sunday before the APHL Newborn Screening Symposium in Sacramento, California. We are looking forward to seeing everyone in person at next year's event.

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