

***E&C Member Day Hearing
The Honorable Kelly Morrison (MN03)***

REMARKS AND QUESTIONS

Opening Remarks

Thank you, Chair Guthrie and Ranking Member Pallone, I appreciate the opportunity to testify before you today.

I'd like to begin by thanking the committee for advancing my bill, the Newborn Screening Saves Lives Reauthorization Act of 2025 out of the health subcommittee.

This bipartisan legislation would renew and strengthen vital federal support for newborn screening programs, helping ensure lab quality, inform parents, and expand screening.

Newborn screening has been an essential public health initiative that allows for life-saving early diagnosis and treatment.

Each year, approximately four million newborns are screened in the U.S. and about 12,000 infants are identified as having a condition and benefit from these critical early diagnoses.

The long history of bipartisan collaboration and support for the newborn screening program has been instrumental in helping improve diagnostic tools, expand screening access across states, and even support the development of rare disease treatments and therapies.

This week I had the privilege of meeting with the father of one of the many families personally impacted by a rare disease newborn screenings could help identify and treat.

Despite the tragic loss of their daughter Darcee in 1995 to MLD, Metachromatic Leukodystrophy and their devoted caregiving to their daughter Lindy also battling MLD,

Dean Suhr (Soo-er) and his wife Teryn have been dedicated to making sure other families do not suffer through the isolation and pain they faced during their nearly 7-years-long search for an accurate diagnosis for their daughter.

Thanks to the dedicated work of fierce champions like the Suhrs (Soo-ers) along with other rare disease advocates, researchers,

and physicians, we've seen incredible advances in the field of newborn screening.

I'm honored to represent Minnesota's third congressional district and in Minnesota, we're proud to be a hub for pioneering research and a leader in studying rare disease diagnoses and interventions.

Recent developments and advances in cell and gene therapies show how investing in these programs can transform long-term health outcomes.

When we invest in newborn screening, we are protecting the most vulnerable among us, giving babies the best chance at a healthy start, and helping spare families the pain and exhaustion of searching for a diagnosis.

Having cared for patients as an OBGYN for over two decades, I cannot emphasize enough how transformative and consequential it is to identify and when possible, treat conditions at the earliest possible moment.

Parents already face so many challenges when they welcome a new baby to their family. The peace of mind and clarity that life-saving newborn screening can deliver is priceless.

I've been so inspired by the courage and resilience of the advocate families I've cared for as a doctor and met with as a legislator.

They persist regardless of the at times all-consuming caregiving responsibilities they have, and despite the heartbreakin losses some endure.

They push past barriers, unwaveringly committed to getting every baby in America the access to the timely diagnosis and treatment they need.

The Energy and Commerce committee has the opportunity to continue the progress we've made over the last 22 years.

To help transform their dream of a world where every child has access to an accurate diagnosis and effective treatment into a reality.

To honor the dedication and sacrifice of these families and the memories of their loved ones.

I implore the committee to take the critical step of advancing this bill to full committee consideration (without delay).

In the spirit of recognizing devoted advocates, I would also like to request the committee's consideration of the ADINA Act.

While at sleep away camp in 2022, a constituent of mine, Adina Togal was rushed to the hospital following a severe allergic reaction to a prescribed medication.

Since the incident, Adina and her family have been fighting to make sure no other family has the same frightening experience.

The ADINA Act would require pharmaceutical companies to clearly label major allergens & gluten present in medications, bringing greater transparency, protecting patient safety, and delivering peace of mind to families like Adina's and so many others.

With an estimated 3.4 million Americans presenting to the emergency room annually for a food allergy reaction, this bill could help families avoid costly medical bills and alleviate emergency room case load.

Closing Remarks

I look forward to continuing to work with the committee to advance policies that protect our children's health and safety.

I yield back.