Oral Testimony - Joye Mullis
Health, Education, Labor and Pensions Subcommittee on Children and Families Hearing
Newborn Screening Saves Lives: The Past, Present and Future of the Newborn Screening System
Thursday, September 26, 2013

Good morning Madame Chairman Hagan, Ranking member Enzi and distinguished members of the Subcommittee.

Thank you for the opportunity to share my story with you today.

As with all children, my son's story began well before his birth. I believe that every heart has a story and this is his.

My husband and I learned that we were expecting our first child on a hot July morning in 2008.

Our joy and celebration was tempered quickly by some early complications; however, we were overjoyed to see our baby's strong heartbeat on the screen in front of us during our first ultrasound.

From that point forward, my husband and I weathered the ups and downs of a complex pregnancy with optimism and hope.

In all, I had 5 ultrasounds and ultimately we learned that our baby would be born with two non-critical birth defects that would require surgical intervention. Our physician assured us, however, that our baby's heart was strong and the prognosis was good.

On March 8, 2009, our precious baby boy Ethan was born. My husband and I spent the first 8 blissful hours of his life with him, surrounded by family and friends. We prayed that he would be okay, but we had no idea that in just a short time, new challenges would be coming our way.

As the post-partum nurse was bringing Ethan back to our room after his newborn screening, she noticed that "he just didn't look right" and immediately wheeled him back into the nursery and hooked him up to a pulse oximeter.

Through that non-invasive screening, she discovered that Ethan's oxygen saturation level, which should have been at least 95 percent, was in the mid-60s percentile.

I will never forget hearing the words, "We have reason to believe there is something wrong with your baby's heart." Questions raced through my mind and fear coursed through my veins.

I asked myself, "How could there be something wrong with his heart? How did this go unnoticed before now?" I was angry and very, very scared.

Ethan was diagnosed with pulmonary atresia with a ventricular septal defect. While a pediatric cardiologist explained in great detail what that meant, the bottom line was that my hours old son would need to be rushed to Duke University Medical Center for his first open-heart surgery.

It wasn't until Ethan was 9 ½ weeks old that my husband and I walked out of Duke as a family of three and into our home with our son.

Four years later, Ethan's health is now stable. He has endured 14 surgeries and procedures, and an incident in which he went into full cardiac and pulmonary arrest taking a team of about 30 doctors and nurses, and 11 minutes of CPR to bring him back to us.

Despite his rocky start, we now have a boy on our hands who loves bugs, cars, and playing with his preschool friends. There may be more surgeries ahead, and we cherish the time we have together now.

Every heart has a story. The story of Ethan's is one of strength and resilience.

While pulse oximetry screening can't take away the heartache of surgeries and complications, it can be the start of a lifetime of success for a baby born with a congenital heart defect.

It has taken a lot of work to get Ethan to where he is today, and it all began with an observant nurse.

However, babies should not have to rely on a doctor's or nurse's intuition to diagnose potentially fatal conditions.

Ethan's story exemplifies the importance of comprehensive newborn screening, and *The Newborn Screening Saves Lives Reauthorization Act* will help ensure that infants throughout our nation are screened for treatable conditions – like Ethan's - at birth.

I urge all Members of the Committee to support this legislation and I sincerely hope it will be passed by the full Senate this fall.

Thank you for listening to my story today, and may God bless you.