

I thank the Committee for inviting me today. I also thank Representatives Moore, Hererra Beutler and Cole for introducing Scarlett's Sunshine on Unexpected Death Act in the House of Representatives and Senators Casey and Isakson for their leadership in the Senate. I know this issue is one the Chairman and Ms. Moore, in particular, have cared about and worked on for many years.

As grateful as I am, I hope you will understand why I wish I weren't here. This legislation is named after my daughter, Scarlett Lillian Pauley, and I am here because she cannot be. Today is the third anniversary of the worst day of my life – the day when the girl you see with big, blue eyes and an angelic face left this earth when she was just 16 months old.

Scarlett lit up our world from the moment she entered it. She loved to read. Her favorite book was *Barnyard Dance* by Sandra Boynton. Her face would light up when I would read it to her as she sat on my lap, and my husband Ryan would do a dance that matched each line. Scarlett also loved music. Her favorite song was "You are My Sunshine," which is the inspiration for the legislation's name.

Scarlett loved to smile. She was known for her "serious face," which led many to think she didn't like them. But we always knew it was just because she was studying them. Once she learned how much she loved to smile and make others smile, Scarlett was never happy until she could get everyone around her smiling.

Scarlett loved life and made the most of her short one.

January 7th, 2017 Scarlett came down with a mild cold and had a slightly elevated temperature.

Three years and approximately 16 hours ago, Scarlett enjoyed playing in her bath and a final performance of *Barnyard Dance*. I nursed her to sleep, gave her warm cheek some final kisses and put her in her crib.

Three years and 11 hours ago, I checked on her as parents often do before heading to bed. I opened the door to her room, expecting to hear the sweet noises of her sleeping peacefully. If you have children, I'm sure you remember holding your breath waiting for your child to take their next one. If it took a bit too long, your heart would sink into your stomach until you heard that next sweet inhale and your heart bounced back to your chest. Three years and approximately 11 hours ago, that next breath never came for Scarlett.

The next hour is a blur of EMTs, police officers, ambulances, sitting on the bathroom floor praying to God for a miracle, a police car ride to the hospital and being escorted into a room of doctors and nurses, one of whom I recall wiped away tears as we entered.

Three years and 10 hours ago, a doctor told us there was nothing more they could do and my Scarlett, the very reason for every beat of my heart and every breath I took, was gone.

To this day, we do not know what took Scarlett from us. We agonized for five months and six days waiting for the results of her autopsy. Even participating in research being conducted at New York University on deaths like Scarlett's did not give us answers on why she is not here.

Scarlett's death is considered Sudden Unexplained Death in Childhood, or SUDC. SUDC is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation,

including an autopsy. At this time, we do not know what causes SUDC, how to predict it or how to prevent it.

Since losing Scarlett, we have been blessed with our second daughter, Eliana. Because we don't know what happened to Scarlett, we live every day in fear we will lose Eliana as well. We also don't know it won't happen to your children or grandchildren.

According to the Centers for Disease Control and Prevention, SUDC occurs in about 400 children in the U.S. each year, but because of the lack of a specific way to record sudden and unexplained deaths in children that have been thoroughly investigated, it is impossible to know how widespread the problem is. And there are more than 3,600 infants lost annually to Sudden Unexpected Infant Death, or SUID, which is the sudden death of an infant under one year of age that, when first discovered, did not have an obvious cause.

Research into the potential causes of SUDC and SUID is desperately needed. Facilitating and standardizing data collection and analysis as this legislation seeks to do is an essential step in one day preventing these tragedies.

Losing a child is the single greatest pain we could ever imagine. And to be without answers as to why magnifies it exponentially. We read parenting books, followed all recommended safe sleep guidelines and made sure Scarlett received good medical care. Yet, we still lost our healthy, thriving, precious baby girl. It is an unimaginable tragedy no parent should have to live with, and there are thousands of us who do it every day.

We have done far too little for far too long to try to stop these tragedies. We have to change that, in memory of all the children who are deeply loved and dearly missed and for the future of all children.

Scarlett's Sunshine on Unexpected Death Act will help us take steps to solve this medical mystery and prevent future deaths, and I thank the Committee for their support of it.