

TESTIMONY OF MRS. EMILY STENSON
BEFORE THE SENATE COMMITTEE ON APPROPRIATIONS
APRIL 30, 2025

Good morning Chairwoman Collins, Ranking Member Murray, and distinguished Members of the Committee.

My name is Emily Stenson, and I am here today with my five-year-old daughter, Charlie, to share our family's story and speak to the critical importance of pediatric medical research. I sit before you not only as a mother of three, but as a witness to what federally supported research can make possible—and what it would mean to lose it.

Charlie was diagnosed with Stage 4 germ cell cancer in November 2022, when she was just three years old. After more than a year of unexplained fevers, constipation, and bladder issues, doctors discovered a five-inch tumor in her abdomen that had unknowingly developed in utero and had already spread to her liver.

Our family's life changed overnight.

We began treatment at a local hospital, but when we realized Charlie needed specialized care, we transferred to Seattle Children's. There, Charlie received some of the most advanced pediatric cancer care in the country, including high-dose chemotherapy and stem cell transplants. In March 2024, we got the news every parent prays for—Charlie was cancer-free.

But just a few months later, in August 2024, routine scans revealed a relapse. Charlie now had two small nodules on her lung. Her baby brother was only two months old when we learned the cancer had returned.

Relapse treatment was grueling. It was the hardest stretch yet. Charlie lost weight and muscle mass. She needed a feeding tube to stay nourished, hydrated, and medicated. But through it all, she never lost her smile. Her strength became ours. And while we juggled caring for a newborn and two other children, often while separated, we held onto hope—because science gave us a reason to.

To try to provide a picture of the devastating challenges cancer families in our country face, I want to share some hardships that we are still healing from. We experienced firsthand a nationwide chemotherapy drug shortage, not knowing if or when Charlie would receive the carboplatin she needed to survive. We moved our entire family to Seattle for a summer to be closer to the hospital for her safety during intensive treatments. At one point, we were told Charlie might require a full hysterectomy or live with an ostomy bag for the rest of her life—possibilities that were devastating to sit with. Thankfully, neither became reality.

Throughout treatment, infection was a constant fear. With a port and Hickman line in her chest, the risk was incredibly high, and even a minor fever could become life-threatening. There were many nights when my husband and I took Charlie's temperature every 30 minutes, bracing ourselves to rush to the emergency room within half an hour if it crossed a dangerous threshold.

Early on, Charlie suffered an anaphylactic reaction to one of her medications, triggering a code call that sent the entire floor rushing into her room. In the Pediatric ICU after a major liver surgery to remove her tumors, she endured a failed extubation that left us terrified. That same surgery had another complication—liver bile leaking into her chest cavity—causing her immense pain and prolonging her recovery.

These weren't just medical complications—they were moments of deep fear and heartbreak, made survivable only through the expertise, care, resources provided by our incredible care team and by witnessing Charlie's incredible bravery.

Today, I am proud to say Charlie is once again cancer-free. She started preschool in February and is back to the joyful chaos of five-year-old life—coloring, playing dress-up, and chasing her siblings. These moments are not guaranteed for kids like Charlie but they are made possible by the research Congress chooses to prioritize and invest in.

Because of Seattle Children's leadership in pediatric clinical trials, Charlie was able to receive treatments that simply wouldn't have been available elsewhere. She participated in three clinical trials. Her first regimen tested an alternative to a chemotherapy drug known to cause severe hearing loss. That trial helped preserve her hearing. She was also able to have access to stem cell transplants, fertility preservation, and expert care from a leading germ cell cancer specialist—all because of the infrastructure and innovation that only research can provide.

The truth is, every option we had, every decision we made, was built on the courage of families who came before us—families who participated in studies, who fought for funding, and who advocated so that children like Charlie could have a chance.

Because of their efforts, we had options. We had hope. And we had a fighting chance.

Not every family gets that. I know parents who were sent home at diagnosis and told simply to go make memories. That is a devastating reality—and one that federal investment in research has the power to change.

To show just how critical real-time advances in research are to Charlie's future, I want to share one more example. Charlie's cancer went undetected for so long because she's in the 10% of patients whose tumors don't show up on standard blood tests. But now, researchers are developing a groundbreaking test using mRNA from her original tumor to detect any circulating cancer cells through a simple blood draw. Catching a relapse early

could be life-saving. We first learned about this test in 2023, and knowing it's almost within reach brings us so much hope. It's real proof that continued research doesn't just change lives—it saves them.

There is nothing that makes my family more deserving of hope than yours. We are no different. And if you were in my shoes, you would want to know that everything possible was being done to save your child or grandchild.

We cannot afford to slow down. Not now. Not when so many lives hang in the balance. Cuts to medical research are not just numbers on a spreadsheet—they are stolen chances, unfinished stories, and futures left unrealized.

Progress in pediatric research is not a luxury—it is a lifeline. And for families like mine, it is deeply personal.

That is why I am asking you today: please continue to fund and prioritize pediatric medical research. Every investment you make saves lives, protects futures, and gives children like Charlie a fighting chance to grow up and thrive.

Thank you for the opportunity to share our story—and thank you for your continued commitment to saving the lives of our nation's children.