Thank you, Chairman Chaffetz, Ranking Member Cummings, and Members of the Committee. My name is Tammi Carr and I am here today to share about my son, Chad Carr, and his battle with a form of pediatric cancer. September 23, 2014 is the day that forever changed my perspective on life, and on what is truly important. That day we took our three-year-old son Chad for an MRI after a fall: An MRI that we had to fight for; an MRI that we thought was simply to confirm a possible concussion. They told my husband Jason and me that the MRI would take a couple of hours, and not to be worried. Well after three and a half hours, we were worried. And when we saw the look in the anesthesiologist's eyes after the MRI was complete, we knew we were in trouble. She said they had found something -- and that something turned out to be a brain tumor.

So as a parent, what is your first reaction when you're told that your child has cancer? I can tell you that it is not to panic, it is to fight. You ask: How do we fix this, what is the treatment plan, when do we start, how do we get that tumor out? Your adrenaline starts pumping and you are ready for the battle ahead. So we asked those questions and we got answers that to this day I honestly can't wrap my head around: "I'm sorry, your son Chad has Diffuse Intrinsic Pontine Glioma (or DIPG). It is a tumor in the brain stem. We cannot take it out. There is really no treatment plan. There is a zero-percent survival rate and he has about nine months to live." I am sure mine is not the first story you have heard about a child being diagnosed with a deadly cancer. It pulls at your heart strings and it's sad. But stop, and really think about what I have told you. Think about the reality that we were given. We weren't given any hope; we weren't given a fighting chance. Our beautiful, spunky, healthy three-year-old was just given a death sentence. How is that possible? How could it be possible that Neil Armstrong's daughter was diagnosed with this same disease over 50 years ago, and the prognosis for our son was virtually the same as it was for her? How is it possible that we live in the most technologically advanced country in the world and nothing had been done to make progress? How is it possible that our son was going to die and there was absolutely nothing that we could do about it?

Well after pulling myself up off of the floor of the ICU where I lay flat on my face for what seemed like hours, I decided we were not going to take that for an answer. That was NOT going to be Chad's story. There had to be a first child to survive and it was going to be my son. So we did all of the research we could into clinical trials, since there actually are a few dedicated researchers working on this disease. What we found is that they are almost entirely funded by families like ours. They have committed their life's work to a disease that is basically unfunded, and they have to watch children die year after year. How can this be okay? These scientists do not receive any meaningful federal research dollars because, as we have learned, pediatric cancer overall receives only four percent of all federal research dollars, and this so-called "rare" disease DIPG doesn't make the cut for significant funding. Cancer kills about 2,000 children in this country every year, and about 300 of those deaths are from DIPG. That may not seem like a lot of people in the grand scheme of things, but when you think about that many children dying every year, over so many years, you start to understand the thousands and thousands of years of life that these children never see. How many more families need to be impacted, and how many more lifetimes lost, before something changes? We also learned that second only to accidents, cancer is killing more children than anything else. And what kind of cancer? Brain cancer. So why not focus on the hardest brain cancer to treat, the DIPG tumor that was slowly taking away Chad's ability to walk, talk, swallow, and ultimately to live? Surely if you make inroads with that most difficult type of tumor, wouldn't that open up the flood gates for the more treatable tumors? That made sense to us. So while we were in the midst of the fight for our child's life, we started the ChadTough Foundation to honor the toughest kid we knew, and to become part of that change. We are proud to work alongside of other foundations and families who are similarly driven to make a difference to children who are facing DIPG.

We created many memories as a family during Chad's battle. Chad spent every possible moment with his brothers CJ and Tommy, who are here today and who he loved with every ounce of his being. And we shared our story with anyone who would listen. We pushed Chad's physicians to think outside of the box, and fought as hard as we could. We refused to give up. Unfortunately, after fighting for 14 months, our son Chad took his final breath on November 23, 2015. That is a moment I relive over and over in my head. It is something I think about every day, and likely will for the rest of my life. It is a moment that no parent should ever have to go through. It is a moment that I would not wish on my worst enemy. But we are doing our best to survive. And we live each day trying to honor Chad and all of the other DIPG Angels.

The ChadTough Foundation raised over 1.5 million dollars in 2016 for DIPG research in honor of our son. Today our family is more focused than ever on being part of making progress against this disease, but it is just a drop in the bucket of what is really needed. Families who have lived a reality that no parent or grandparent or sibling would ever want to know should not be alone in this fight. And believe me, this can become reality for anyone. We sure never thought it would happen to us. No one knows who it will be today or tomorrow.

When I hear about potential cuts to the National Institutes of Health (NIH), it honestly hits me right in the gut. There have been such great strides made around pediatric cancers such as leukemia because bright minds were asked to focus on treatments and they were given the resources necessary to do so. Pediatric leukemia ─ which was once considered a rare disease and, 40 years ago, had a ten percent survival rate ─ now has a survival rate of nearly 90 percent. Chemotherapy was developed as a result of pediatric leukemia research. To think that the relatively small, four-percent research bucket for pediatric cancer research might be getting even smaller? The proposed eighteen-percent cut to the NIH budget would be devastating to all pediatric diseases, but especially so to rare diseases such as DIPG, and at a time when there has finally been some momentum and discoveries made about the genetic makeup of DIPG tumors. In the last five years, we have seen explosive advancements in genomic data and other tools for cancer researchers to open up the battle against the most challenging and deadly pediatric cancers. Without federal funding, we very quickly lose ground in the battle.

Federal funding is critical to recruiting the best and brightest scientists into pediatric cancer research, and no amount of fundraising by family foundations can replace that. These scientists are already choosing to take pay cuts to do research instead of seeking more lucrative private practice or industry jobs. Foundation fundraising may help to increase the pace of research, but NIH funding establishes the baseline to ensure that the research is pursued in the first place. If NIH funding is reduced, it will stifle progress for some of the most vulnerable people in our country who face devastating diseases like DIPG.

I ask that when you consider the proposed cuts to the NIH budget you think about my son Chad and all of the other children who were not given a fighting chance. You picture his face and you think about what might have been. Our family and others like ours will continue to work tirelessly in this fight, but we cannot do it alone. Without additional funding for research, children facing diseases such as DIPG will continue to have no hope for long term survival. That is not a future we can accept; for these children, it is no future at all. Our children deserve more. We must do better.

Thank you, again, for the opportunity to speak to you today. I would be happy to answer any of the Committee's questions.

Tammi Carr

Mother of Chad Carr

The ChadTough Foundation

Tammi Carr is the Co-Founder of The ChadTough Foundation, formed in 2015 after the passing of her son, Chad, of Diffuse Intrinsic Pontine Glioma (DIPG). Tammi spent more than a decade (2002-13) fundraising for Mott Children's Hospital, which opened the doors of their new children's hospital in 2011 and is among the nation's top children's hospitals. Prior to fundraising, she worked at Turner Sports and CMU Public Broadcasting in television production. Tammi earned a double major in communications and psychology from the University of Michigan.