Danielle Leach
Director of Government Relations
St. Baldrick's Foundation

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Education and Related Services

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Good morning. Thank you for the opportunity to share my story with you today. My name is Danielle Leach. I am the Director of Government Relations for the St Baldrick's Foundation, based in California. St. Baldrick's donors and volunteers have enabled the foundation to fund over $154 million in grants, making St. Baldrick's the largest private funder of childhood cancer research other than the U.S. government. I am pleased to join with the united cancer community in formally requesting that in the coming year, Congress provide **$33 billion for the National Institutes of Health (NIH)** and **$5.4 billion for the National Cancer Institute (NCI).**

I am also the Co-Chair for the Alliance for Childhood Cancer. The Alliance represents 29 national patient advocacy groups, healthcare professional and scientific organizations, committed to representing over 10 million Americans who care deeply about childhood cancer.

Most importantly, I come to you today as an advocate. My sister, Noel, survived childhood cancer and my middle son, Mason, died from brain cancer.

I was only 9 when my sister, Noel, was diagnosed with aggressive rhadomyosarcoma . The doctors told my parents she might survive two months. Luckily, she qualified for a clinical trial and I am happy to report she is still with us, 35 years later. My son Mason wasn't so lucky.

What can I tell you about our little boy? Our Mason was a fighter, a superhero, an artist, a soccer player, a baseball player and a cancer survivor. Our three-year old Mason was diagnosed with a brain tumor — medulloblastoma, in 2006. His only symptoms? Four days of vomiting.

I was shocked to discover that the recommended treatment had really not changed for 30 years. The doctors offered surgery, radiation, and chemotherapy. We also learned that the treatment would probably leave him disabled for life if he survived. Within days of diagnosis, we had a little boy with a surgery scar who could no longer talk or walk and we did not know if we would ever get him back.

Mason, lived his life as a force of nature. He was sweet and loved to give hugs and kisses but he was also stubborn as an ox and very vocal about what he wanted. We truly believe it was that stubbornness and his determination that helped him regain his speech and mobility after his surgery.

All our little boy wanted to do was to play with his brother, wear his soccer jerseys and be with his family. Mason, despite his age, was curious about what was happening with his body. Even at his young age, he demanded to be heard. He wanted to know why we were giving him this test or this medicine and what it would do to him.

How do you tell a child that you need to take him to the brink of death to save his life? As we navigated the childhood cancer journey, I learned that most of the arsenal of drugs being used on children were not made specifically for them. We bombarded Mason's body with adult drugs, some so old that they had been part of my sister's arsenal thirty years before.

They were also incredibly toxic. Imagine the terror of watching a nurse don protective gloves and gear to hang IV bags that say “poison” on them and knowing those drugs were going into your child. You know full well that it could kill him before it cured him. But you do it because you have no other choice.

There is no worse feeling than not being able to take away your child’s suffering and pain. These children suffer. The treatment decisions we parents have to make have lifelong consequences for our kids with cancer. We have to fund the research to find a better way to save these kid’s lives.

Mason continued to live his life despite what was happening to his body. He taught us that despite all the horrible things, the hospitalizations, the medicines, the shots, etc., that life was meant to be lived. We have had to remind ourselves of his fortitude and his example as we mourn his loss. He died on October 13, 2007. He did not get the miracle.

In many ways, childhood cancer represents one of the great successes of our investment in medical research. In the 1950s, almost all kids diagnosed with cancer died. Because of **government investment** in research, today about 90% of kids with the <u>most common type</u> of cancer will live. But this statistic does not tell the whole story. For many other types, progress is limited, and for some kids there is no hope for a cure. Our job is not done and to be satisfied with the status quo is not acceptable. I repeat, **our job is not done,** and we have so much more to do to find better, less damaging treatments for our children. I work every day so no mother will have to tell their son like I did that he will go to heaven because we can’t help him with another medicine. **Only funding for more research can change that.**

Even for kids who survive, the battle is not over when treatment ends. My sister Noel has endured multiple plastic surgeries to repair her face – every time she looks in the mirror she sees what childhood cancer did to her. Most survivors will have a chronic health problem or severe life-threatening conditions. I know a child wheelchair-bound for life after a radiation-induced stroke and another who has the heart of a 50 year old in his 8-year-old body. For our children, survival comes at a price that is too high to pay. We can and have the capacity to do better by making cancer research a priority.

Here lies our challenge. We have come far – but not far enough. Clearly, there is a great deal that needs to be done better for our pediatric cancer patients.

I have been encouraged by recent meetings we have had with the NCI about childhood cancer. We all agree more needs to be done. But that promise and hope for childhood cancer will not happen if NIH as a whole does not get the money it needs to accomplish its work.

Speaking as a mother, and as an advocate representing tens of millions of other parents and citizens, we stand ready to work with Congress and the NIH to make childhood cancer a top priority so we can give hope to all children and families.

I would ask that you address this problem much like Mason approached life.

Be creative. Mason loved to make a mess and then create something beautiful. We need to find ways we can support cancer research and childhood cancer in particular. It may be a messy process but we need to be creative in our thinking to save our nation’s children.

Mason was persistent. The tenacity of his spirit is something I aspire to everyday as I fight for children with cancer and their families. We need to be persistent in this difficult political environment and fund research to save children’s lives with less toxic treatments.

Mason liked being a part of a team. He loved projects and constructing things and being a part of a team on the soccer field. "A coordinated effort" should be our mantra. We need everyone in the fight - Congress, government agencies, non-profits, companies & the public to conquer childhood cancer. But we need Congress to give us the funding to launch those efforts to create solutions.

Lastly, Mason was a superhero- he loved to dress as Batman and other superheroes. He fought the bad guys and saved the world. We need more superheroes for research and the funding needed that will change these kids’ lives. In honor, in memory and in defense of all children with cancer, I ask you to become superheroes for kids with cancer. Our nation’s children deserve nothing less.