

**Testimony By
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and Government Affairs Committee
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Thank you, Senator Collins, for your tireless efforts to bring health to the children in this room, and to so many more across the country. When we came to the Children's Congress four years ago, and entered the lobby of the Marriott hotel, we saw a strange but familiar sight. It was all families with diabetes. Every kid or parent held some kind of bag with a blood tester and a few boxes of juice. There weren't so many pumps back then. People were sitting on the chairs in the lobby—pricking fingers, filling syringes, giving injections, and trying to take care of the siblings who never get enough attention. Everywhere I looked, it was like a strange mirror. I saw myself in every father. I was part of a new tribe, a new identity, and it was more defining than my race, religion, or economic status. I was a father of a child with an incurable disease... But let me go back to the beginning.

Six years ago, in the weeks before our daughter, Tessa, was diagnosed, I was a guy with a great sense of possibility. I was preparing a movie about 2nd Century Rome, and I was traveling around the world trying to figure out where we could recreate the ancient Coliseum. We chose the island of Malta and began construction. We brought in an army of artisans from around Europe to start building weapons and wardrobe. We hired animal trainers to train lions and tigers, and a rhinoceros that never made it into the movie.

We had just returned home from Christmas in Hawaii, where the kids loved playing in the warm ocean and sipping those fruit drinks that come in a pineapple. But Tessa, our youngest, had been gulping down whole bottles of Evian in one swoop—and my wife thought something was wrong. “I think she has diabetes,” she said.

I thought my wife was insane, but we went to the doctor nevertheless. Tessa took a urine test and the nurse came into the waiting room a few minutes later and gave us our sentence. “You know what you were looking for,” she said. “Well...you got it.” But that wasn't yet the moment when it really sunk in. That came later that afternoon, when I went to pick up Tessa at school to take her to UCLA hospital.

We loved her elementary school... It was an oasis. It was where we started off as a young, innocent family with our three girls. It was a place where I had learned about being a father; where every teacher was loving; and together, we had watched our children bloom. I had to go to the office to sign Tessa out. And on the form, it asked for the reason for leaving early. I hesitated, and then wrote “medical”.

It was the first time I cried.

That night, I sat on Tessa's bed and tried to answer questions about her future. She was eight years old. We used to call her "frat girl" because she was always in a good mood. But not that night.

She asked if she would have to have any more shots.

"Yes," I answered.

"How many?"

"A few a day."

She asked for how long.

"For a while," I said.

"But how long?" she asked again.

And I had to answer, "As of right now, forever."

She asked about pricking her finger. (That hurt more than the shots.)

"How many more times?"

What could I say? "5, 6, 8 times a day...for the rest of your life."

She said she hated God, because he was mean, and she hated her life.

I have never felt like more of a failure. I was her Dad, I was supposed to make things ok. I was supposed to keep her safe. But now, all I could offer her was to live needle to needle. Can you imagine as a father telling your child that her life as they know it is over, and that that the best future you can offer is one of pain and uncertainty? That wasn't going to be her life, and I promised her that somehow, some way...we would find a way to make it better.

That was 6 years ago.

The next week, I had to go back to Malta. My wife was overwhelmed with the new burden of being the doctor, nurse, mother, and father to a sick child. She was terrified that if she made the tiniest mistake in filling the syringe, she might put Tessa into a coma. She got up frequently every night to check her little girl and make sure she was still breathing. Then she got up first thing in the morning to act like everything was normal for Tessa and her two sisters, get them off to school, and then race off to her own job of running a studio.

Our family was at a crossroads. My wife and I felt alone and afraid. Tessa was shy and self-conscious about her disease. She did not want to be different, and made us promise to keep her diabetes a secret. But a few days later, Tessa's 9-year-old sister, in a noble attempt to cheer things up, got her entire class to sign a giant get-well card for Tessa. One girl even wrote, "Tessa, I will never forget you...!" So much for keeping it a secret. But "coming out" turned out to be a blessing in disguise.

The next day at school, Tessa's friends surrounded her as she pricked her finger and tested her blood sugar at lunch—and from then on, they never left her side.

They have walked mile after mile for diabetes, with her two sisters leading the way, they have sold hundreds of glasses of lemonade, squeezed money from their parents, squeezed more money from their parents' friends, their parents' workplaces, and pounded on every neighbor's door with the simple plea, "Our friend has diabetes and we want to cure her." The parents of those friends have not just opened their purses, opened their hearts, but they studied diabetes. They learned more about carbohydrates and dosing, so Tessa would feel safe and always welcome in their homes. And if Tessa ever needed proof of God, she saw it in the shining faces of these fine people.

So our family was managing. We became active in JDRF, and when Tessa was 10, she testified before this committee as a delegate to the Children's Congress. She was feeling very hopeful. Her walk team, Tessa's Troopers, had raised hundreds of thousands of dollars, and she felt proud she could be part of the cure. But as she waited for her turn to testify, she heard details about her disease that we had never mentioned.

She heard about horrible complications that could start to occur to her body after five years with the disease. She heard about kidney failure, amputation...blindness. I sat beside her as she listened. Once again, I could only wonder... What future was I offering my child?

I was still commuting to Malta when a human tragedy occurred on the movie. A great English actor, Oliver Reed, who played a character named "Proximo" who owned and trained the gladiators had dropped dead in the middle of the shoot. He was a great man and it was a terrible loss. And we had a practical problem. We had spent almost \$100 million shooting the movie all over the world and now we couldn't finish the movie without him. He couldn't just disappear from the story.

But Hollywood has a history of making the impossible possible—and with the magic of modern technology, we were able to take close-ups from other parts of the movie, bring Oliver back to life, and complete his performance. I was working in a field where, if you can imagine it, you can make it happen. Surely, with that spirit, there was something more we could do for Tessa.

I spoke to the scientists at JDRF, and I spoke to friends who were struggling with other diseases. And they all talked about embryonic stem cell. We started to meet with scientists, and I was amazed at the consensus. I learned that the vast majority of Nobel Prize-winners believed that we were at the dawn of a new age of medicine.

I reached out to my friend Nancy Reagan. My father, Charles Wick, served in the Reagan administration for 8 years. When the Reagans came home to Los Angeles, I had watched as Mrs. Reagan suffered through her husband's decline. I watched her robbed of her Golden Years—the years when she had planned to sit on her California ranch and reminisce with her husband about the likes of all of you.

Mrs. Reagan and I both listened to more scientists who told us about a new kind of Morning in America. It might not happen today or tomorrow, but it was going to come—

a new era of medicine where mankind would shine its light on the shadows that surrounded so many families in the darkened rooms of sick loved ones. And like so many other families, we turned to Washington D.C.

Surely, if the might of the federal government, the power of the NIH (the greatest funder of medical research in the history of the world) put their minds on making embryonic stem cell a reality, the same spirit that put a man on the moon could cure our children's diabetes, and rid the world of so many other dreadful diseases. And we were so grateful as Senators started to speak out about his new science...

Senators Hatch and Specter, Kennedy and Feinstein, Harkin and Smith, and you, Chairman Collins, had done their own interviews with the best scientists in our country, and saw the same opportunity for 120 million Americans with diseases that might someday be cured by this research. We were optimistic.

The night President Bush was to announce his compromise on federal funding for stem cell research our whole family sat around the TV and watched. And as the President announced his new policy and his words sunk in, my wife, who always kept her chin up, started to cry.

We had a sick kid. What could we do?

We co founded Cures Now, and tried desperately to get the message of scientists out to the people. And when we failed in Washington, we co-chaired Proposition 71 in California. And the people spoke, and California will move forward with embryonic stem cell. But no one can make a real dent without the full might of the federal government.

Our five year mark, which once seemed so far away, has come and gone... and Tessa knows enough to be afraid. Now, every time she goes to the doctor, she has to have an eye test and a kidney test. And when she has a stomachache, or tired eyes—every time she goes in for her checkup—she fears there might be scary news.

That is her life.

I am here today to beg you for my daughter's future, and for the future of so many brave children like her. On behalf of all the fathers who have had to watch their children suffer, helpless to protect them, I ask for your help.

Please let me tell my daughter that the Congress of the United States will use its might and heart to pursue the science that can restore her health.

Please let me tell my child that the Congress of this great country will allow the stem cell lines to move the research forward—that you will explore any and all avenues.

We can make movies about men like Maximus who rise up, sword in hand, to fight for good. But Maximus, as good as he is at fighting tigers and emperors, can't do a thing for

Tessa's future. She needs a different kind of hero, one wearing not a toga, but a suit or dress. And one who will fight—not in the coliseum—but on the floor of the Senate...for her health and her future.