

Testimony of

Mr. Ray Allen

Guard for the National Basketball Association's Miami HEAT

Accompanied by

Walker Allen

Age 6, JDRF Children's Congress Delegate from Florida

At the Hearing Entitled

**"Diabetes Research: Reducing the Burden of Diabetes
at All Ages and Stages"**

Wednesday, July 10, 2013

Before the

Senate Special Committee on Aging

Good afternoon.

It's an honor to be invited to appear before you here today to give you an understanding of what it's like for a family to live with type one diabetes, or T1D. As you listen to our story, please know there is nothing "special" about our family, my wife Shannon, our son Walker, or me. Hundreds of thousands of other families across the United States and the world could tell you a story similar to ours. So I am here as a voice for those families and for everyone else touched by this disease. Some of these families are NBA fans, some may even be Miami Heat fans and others are certainly fans of different teams...but, today we are all united on one team with one goal in rooting on Congress to run a fast break toward curing this disease!

Here's our story.

In 2008, I was a member of the historic Boston Celtics; we had a great run that year and found ourselves playing in the NBA Finals against the Los Angeles Lakers — the moment I had dreamed of since I was a little boy. There I was, competing for an NBA championship, it was surreal.

There were a lot of special things about that series; it was the first time since 1986 that the Celtics won the NBA title; it was the most watched NBA telecast in NBA history and personally, it was my first NBA Championship. All of those things are memorable; but, I may remember it more for another reason — while our family was in LA for Game 5, our son Walker, who was 17 months old at the time, became very ill. My wife, Shannon, rushed him to the hospital where he was diagnosed with T1D. It was as if the rug was pulled out from underneath us. Life as we knew it was over; you see, even though just a few days later we finished one journey, winning Game 6 and being crowned as NBA Champions, another journey began that we are still on today.

Walker is six now.

But, he is still too young to manage his diabetes on his own. No disease is easy but managing T1D may be one of the most complicated and complex responsibilities facing any caregiver or person living with a disease.

From the moment Walker wakes up to the moment he goes to sleep we have to monitor everything he eats and drinks. We have to test his blood sugar with finger pricks 10 times a day; we have to count the amount of carbohydrates he consumes, then do the mathematical calculation required to decide how much insulin to inject — this can be as many as 7 shots a day just so his blood glucose levels remain in a safe range. Any miscalculation on our part could be life threatening for Walker.

You might think we finally can catch our breath when Walker goes to bed? Not so. T1D can be at its most dangerous at night. Blood sugars that seem fine at bedtime could suddenly come crashing down in the middle of the night. Without juice or food to restore the right balance, Walker could drift into a coma and we'd never know it until we tried to wake him in the morning when it might be too late. So, we wake up every

two hours throughout the night to check Walker's blood sugars. Shannon and I often joke that we are vampires, neither one of us has slept the night through in five years since Walker's diagnosis and that is the reality for all families, not just ours.

The Miami Heat played 106 games this past season. We had game days, practice days, travel days even a few off days; days to rest, to heal, to rejuvenate and recharge. But, for our son Walker and any family living with T1D there are no off days.

As he gets older Walker will gradually take more charge of his T1D. But it won't get any easier because more and more factors will impact his blood sugar levels. Exercise, stress, even normal changes in adolescent hormonal activity; changes utterly beyond Walker's control, will cause blood sugars to gyrate wildly. Shannon and I know from talking to other parents that children and young adults with T1D show tremendous courage, resolve, and a steadfast determination not to let this disease define them. But we also know that no matter how old Walker is, no matter where he is or what he's doing, every day with T1D is a new day, what works one day may not work the next day, and risks are ever-present. I doubt Shannon and I will ever go a day without just a little bit of fear and worry in the back of our minds. Fear for our son's safety, his overall health, that he reaches his potential, is able to live his dreams.

It isn't Walker's fault that he has T1D. There's nothing he or we did to cause it. It isn't diet or lifestyle related, as is the case with type two diabetes. Genetics are part of it but there is no history of T1D in our family. We do know this: T1D is an autoimmune disease. The body launches an attack on the cells that produce insulin eventually destroying them and leaving people with T1D dependent on synthetic insulin to survive.

But insulin is not a cure.

It is a lifeline and there is a big difference. That's why Shannon and I got involved with JDRF. Shannon now serves on their Board of Directors. We know that JDRF is working on therapies that may reduce the tremendous daily burden of living with T1D, and that it is working towards a cure. And we know JDRF is working with Congress to make sure the government does its share and funds important programs like the Special Diabetes Program.

On the basketball court, a lot of your success comes from experience, hard work, repetition, practice, instinct, and of course a little luck. A rebound careens off the rim, a teammate grabs it and passes the ball to you in the corner — without thinking you catch it, step back, and hit a 3 pointer to tie the game and keep your championship hopes alive.

We will need more than hard work, repetition, instinct, luck, practice and experience, though, to beat T1D.

I know T1D will never hold Walker back. But we dream of a day when Walker can leave this disease behind. With the continued support of Congress for the Special Diabetes Program, with the investment of JDRF and the private sector, and with the dedication and

commitment of the families surrounding us today, and hundreds of thousands of others around the country, we will create a world without T1D. We have to. Together, we are a winning team.

Thank you.