Committee on
GOVERNMENTAL AFFAIRS
The United States Senate
COMMITTEE MEMBERS
SUBCOMMITTEES
HEARINGS
KEY LEGISLATION
JURISDICTION
PRESS STATEMENTS
SPECIAL REPORTS
VIDEO OF SELECTED HEARINGS
SITES OF INTEREST

**TESTIMONY**

**Testimony**
**By**
**New York**
**Los Angeles, CA**
**On Behalf of**
**Juvenile Diabetes Research Foundation International**
**Regarding Federal Support of Juvenile Diabetes Research**
**Before the**

# Senate Permanent Subcommittee on Investigations

**June 26, 2001**

Hi, I'm Katie Zucker. I'm 13 years old and I have juvenile diabetes. I'm proud to be here and to meet all of you, along with my friend Kevin Kline, who is also a good friend to all of us with diabetes. Kevin has been a great JDRF volunteer and today he's here to ask that you "promise to remember" us!

Thank you Katie. Mr. Chairman and Members of the Subcommittee, thank you for this opportunity to speak on behalf of the Juvenile Diabetes Research Foundation and all children with juvenile diabetes. I am honored to share a stage with these 200 extraordinary young people.

Before I begin, may I direct your attention to this large pile of mailbags. These bags are filled with approximately 55,000 letters that the children have collected from friends, family members and community members, from across the United States in support of juvenile diabetes research. I congratulate and thank the delegates for this tremendous effort. Thank you, kids.

Each year approximately 30,000 Americans are diagnosed with juvenile diabetes. Over 13,000 of them are children, stricken at random. No child is immune.

That's 35 children every day. More than one every hour, stricken suddenly, made insulin dependent for life, now facing the constant threat of devastating complications.

These are statistics, numbers that impress but not like the reality of being touched personally by this dreaded disease. If it hasn't happened yet, it is very likely to happen to all of us sooner or later … someone we know, we work with, or one of our own family.

Surprisingly, many people still have strange misconceptions about diabetes. They think that it comes from eating too much sugar, or that it can be transmitted, not inherited but given, to another person, or that insulin is a cure! All of you know that none of this is the case. And those who are touched by diabetes surely know this, too.

In July of 1999, I joined the Board of Directors of the New York Chapter of JDRF and in July of 2000, I was elected to the position of Vice President of Public Outreach and Education.

Through my work with JDRF, I have met countless children who have juvenile diabetes and have witnessed firsthand the devastating impact of this disease on them and their families —children like my friend Katie Zucker.

Katie lives with her parents in Los Angeles, California. She was diagnosed with juvenile diabetes in the summer of 1999. There is no history of the disease in her family, so Katie and her parents were entirely unprepared for the daily regimen of insulin injections and finger pricks and the endless balancing act that goes with them.

Now, Katie is at an age where she can help her parents manage her diabetes. But how about younger children? For them, parents are their lifeline, taking charge of everything that must be done to keep them alive and well, in addition to the love and reassurance that are so very important. It's a 24-hour vigil! Here's what a typical day is like in the life of a child with juvenile diabetes:

7:00AM – Give blood test by pricking the child's finger. Based on the blood sugar level, insulin is measured out and injected. The amount and type of insulin is carefully measured based on how much and what type of physical activity the child will engage in. Based on all this, breakfast is measured out with carefully counted carbohydrates, proteins and fat.

Another blood test at 10AM is followed by a snack, adjusted to blood sugar level and activity level. The same routine at lunch as at breakfast.

Snack at 3:00 – same again.

5:30PM - Another finger prick and injection. Snack at 8:30PM with yet another finger prick – always alternating fingers, which have become sore and callused.

Bedtime – Shot and blood test.

2:00AM –Test again, give shot if necessary, or awaken the child to give orange juice if blood sugar level is low.

7:00AM – Begin again.

As you can see, this is far from a normal lifestyle. Everyone must feel compassion for the parents, who are doing everything in their power to make the brightest possible future for their children while coping with the emotional roller coaster that is everyday life with diabetes. But it is these children we must admire. Their honesty and bravery are models for us all. Their stories and their role here today – advocating for their cure, their own future – must be heard.

Trust me, we at the Juvenile Diabetes Research Foundation are not confused about our dream – and neither, I hope, are you. My dream, our dream – the dream of 200 children in this room and millions of children and parents across the United States, is simple: a world without diabetes. We are passionate, we are committed. But we need your help to make this dream a reality.

Thank you.

Committee Members | Subcommittees | Hearings | Key Legislation | Jurisdiction
Press Statements | Current Issues | 1997 Special Investigation | Video of Select Hearings | Sites of Interest