Testimony
By
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On Behalf of
Juvenile Diabetes Research Foundation International
Regarding Federal Support of Juvenile Diabetes Research
Before the
Senate Permanent Subcommittee on Investigations

Once again, it is my privilege to Chair the Juvenile Diabetes Research Foundation's Children's Congress. This year we brought twice as many delegates – 200 children with Type 1 diabetes – because we have twice as much to do. First, we must thank you for keeping your promise, and second we must challenge you, just as each of us here has challenged ourselves, to do more.

First things first: Thank you. We are grateful you remembered us, last year, by approving legislation that provides a historic increase for juvenile diabetes research funding at the NIH -- $240 million new dollars over three years. We should also acknowledge, with thanks, the provision in that legislation of similar new dollars to expand the special Native Americans diabetes programs. We are grateful too, that Congress and the Bush Administration, even with other program growth being constrained, have re-committed themselves to the bi-partisan effort to double funding for the NIH -- an action that surely will result in more research to find a cure for diabetes and its complications. So, again, for all you've done to keep your promise these last two years, we thank you.

Of course, you have not been alone in these important efforts. We never ask others to do something we have not asked ourselves to do, first. So we have and will remain your partner in this purpose. As evidence of our dedication to finding a cure, since the last Children's Congress, JDRF has more than doubled our own funding of diabetes research – from $55

million in 1999 to $120 million in 2001. We too made a promise, to ourselves, these children, our loved ones. The stakes for us are very real, very personal.

Many of you know that I have had juvenile diabetes for more than thirty years. And like each of these children, I struggle, everyday, to do what happens naturally for people who don't have diabetes: achieve a balance between what I eat, what I do, and how I feel. Though to most of you, metabolic balance is as automatic as breathing, to people with juvenile diabetes, like me, it requires 24/7/365 vigilance, constant factoring and adjusting, frequent finger sticks to check blood sugars, and multiple daily insulin injections just to stay alive. Even with the greatest of care and closest of personal scrutiny, I find I am often unable to achieve good balance, my sugars dangerously low, or frighteningly high. Yes, dangerous and frightening – because, frankly, serious lows can lead to seizures, coma and death, and highs, over time, result in life-limiting and life shortening complications like blindness, amputation, kidney failure, heart disease and stroke. Diabetes is an all too personal time-bomb which can go off today, tomorrow, next year, or ten years from now – a time bomb affecting millions, like me and the children here today, one which must be defused.

This reality is made all too clear by the recent sudden death of Danielle Alberti. Danielle was 31. She was an aspiring artist and daughter of one of JDRF's most active and generous volunteer leaders. Though rapidly losing her vision due to diabetic retinopathy, Danielle stuck to her dream of being a painter, and was pursuing her career when she recently, like too many young adults with Type 1 diabetes, developed kidney failure. People with diabetes related kidney failure don't do well on dialysis, so kidney transplant was her only real option. With her doctor's guidance, she and her mother, decided to return home, together, to Australia, where her chances for a near-term transplant were greater. But Danielle didn't survive the flight. She died at 30,000 feet, seeking comfort in her mother's arms -- her last words, "Mum, hold me."

Chairman Levin, Senator Collins, members, we're here again because our children, our loved ones with diabetes, look to us for comfort, for a way to stop their suffering, and we are determined to find it. This is the quest you have joined us on and it remains our greatest challenge. The good news, today, is we have reason to be encouraged. Since the last Children's Congress, we have achieved a critical research milestone

necessary for us to make progress along our path to a cure.

In May of 2000 at the University of Alberta in Edmonton, Canada, and subsequently elsewhere, researchers have successfully transplanted insulin producing islet cells into men and women with juvenile diabetes – restoring normal blood sugars. This reproducible clinical success is the first significant proof of a scientific principle JDRF has long led in promoting: That insulin-producing cells can be harvested from cadaver pancreases and transplanted into patients with even the most severe cases of juvenile diabetes. Further, that these islet transplant patients could be treated with a less toxic regimen of immuno-suppressant drugs than whole organ transplant recipients require. And finally, that as a result of the transplant they could achieve normal blood sugars while no longer needing to take insulin injections. Quite simply, these findings are the first real, clinical evidence that a cure is within our grasp.

But there is a "however" to this positive news: as encouraging as these results are (and they are), the cure will remain out of reach unless we can overcome two very important obstacles:

First: This first group of islet transplant patients still must take potentially toxic immuno-supressant drugs for the rest of their lives. This makes islet transplant, at its current state of development, too risky for children and all but those people with diabetes whose lives are immediately threatened. To overcome this obstacle, JDRF has joined the NIH in a major research partnership – called the "Immune Tolerance Network." One of the focuses of the ITN is to support the development and testing of new non-toxic approaches to establishing immune tolerance. As progress is made in this area, new resources will undoubtedly be needed to expand opportunities for success and we will need your help.

The other major obstacle is the lack of supply of islets for transplant. The only current source for islets suitable for human transplant, are cadaver pancreases. And in the US less than 2000 such pancreases become available for transplant each year. If tomorrow we had the perfect solution to immune tolerance, we would still only be able to offer islet transplantation to a tiny fraction of the millions of people with diabetes who might benefit. There is hope, though, that an alternative, inexhaustible supply of islet cells can be created. Hope that very much depends on actions you, your colleagues,

and the Administration choose to take. The hope I refer to resides in the potential of embryonic stem cells to be coaxed to develop into any cell in the body, including islet cells. This would solve the islet cell supply problem. Of course the promise of stem cell research is not exclusive to islet transplantation, or to patients with diabetes. Stem cells could, potentially, help restore vision for those with macular degeneration, prevent Alzheimers, or reverse Parkinson's disease eventually helping as many as 100 million Americans who suffer from chronic illnesses. Stem cells could improve heart muscle function after heart attack, allow spinal injury patients to walk again, or replace bone marrow in cancer patients. As a greater authority than I, Dr. Harold Varmus, former director of NIH, has stated: "it is not unrealistic to say that [stem cell] research has the potential to revolutionize the practice of medicine and improve the quality and length of life." To make our hope a reality, embryonic stem cell research requires federal support. So, I am here, today, to urge each of you, your colleagues, and the Bush Administration to support stem cell research within the framework of the ethical guidelines approved by the NIH in August of 2000.

I understand that support for this research raises concerns among people of good will, each trying to do what's right based on their very personal religious and moral beliefs. I have not shied from that personal soul searching, nor has JDRF in its policy making, nor should anyone. I have found comfort in my heartfelt view that embryonic stem cell research is truly life affirming. It is a direct outcome of a young family making a choice, without coercion or compensation, to donate a fertilized egg not used for in vitro fertilization, for research. An egg that otherwise would have been discarded or frozen forever. Because of the great potential of stem cell research, donating un-used fertilized eggs is much like the life-giving choice a mother whose child has died tragically in an automobile accident makes when donating his organs to save another mothers child. It is the true pinnacle of charity to give so totally, so freely, of ones self, to give life to another. Federal support for stem cell research is, therefore, an extension of this affirmation of life and is the best way to insure it is undertaken with the highest of ethical standards.

Chairman Levin, Senator Collins, Members, to borrow a phrase, "diabetes ain't bean bag." My 30 plus years of diabetes has led to visual impairment, painful neuropathy, the threat of

limb loss from poorly healing foot wounds, and peripheral vascular disease which has started to limit how far I can walk. I push through all this, just like each of the children here, today, push through the burdens imposed by diabetes, because we are a determined lot, none of us willing to be deterred by adversity. We all share the firm conviction that through our efforts, and the help of friends --like the members of this Committee -- we will find a way to stop the suffering, end the pain, restore the balance.

Please listen to the stories of the children here today and promise to remember all of us who suffer from juvenile diabetes when you make decisions that will impact research.

The cure is truly within our grasp—together we will find it. Thank you.

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