## Testimony delivered by Lauren Stanford Plymouth, Massachusetts

Before the
Senate Health, Education, Labor and Pensions Committee
and the
Senate Labor, Health and Human Services and Education
Appropriations Subcommittee

Friday, January 19, 2007 9:30 a.m. 192 Dirksen Senate Office Building Thank you Senators Kennedy, Harkin, Specter and Enzi for inviting me to appear before your committees today. It's wonderful to live in a nation where the cares of a 15 year old girl from a small town are heard in the United States Senate, and that is because of leaders like you. I admire and respect all of you so much.

To see me sitting here, you'd think I'm just a normal American teenager, and in most ways I am. I play tennis and field hockey. I swim and ski. I'm pretty much addicted to instant messaging. I cannot survive without my cell phone nearby. Yes, on the surface, I'm just another *American girl*.

But inside me, a battle has been raging for ten years now. Because, just at my sixth birthday, I was diagnosed with Type 1 diabetes. Type 1 isn't something you do wrong to get; it isn't something you can change your habits to avoid. It's a terrible malfunction of the immune system that leaves the person forever dependent on insulin injections and forever suffering the consequences of this disease.

In the past 10 years, diabetes has sent me to the hospital 14 times, twice to intensive care. It has pricked my fingertips over 30,000 times. It has injected needles in me tens of thousands of times, and it has forced me to learn to change my own pump catheter every two days from the time I was seven. It has made my blood sugar soar to sickness and sink to shakiness... It has forced my mother to be a part of my life in a constant way every hour of every day. Now, imagine accepting that as a 15 year old girl? Diabetes has indeed ruled every minute of my life.

Every two months, doctors peer deep into my eyes, waiting the time when they tell me it's begun to break down my eyesight. They poke at my feet and hands to see if it's robbed me of circulation yet. They test my kidneys to see if how far its assault on them has gone. And through all this, I walk and talk and try to live in the world as just another *American girl*. But time is not on my side, and I know that my only hope for a cure lies in medical research.

My family has helped me learn about research over the years, and my friends and I have raised a lot of money to help fund it. My group, called "Got Islets: Lauren's League for a Cure," has raised hundreds of thousands of dollars for the Juvenile Diabetes Research Foundation since I was diagnosed, and we're just a bunch of kids. But we kids can't do it alone. We need the government to help by allowing scientists to fully unleash the potential of embryonic stem cell research. This research could hold the key to a change in not just my life, but in the life of so many Americans. Imagine if it can help get to the source of what causes diabetes and stop it before it starts? Imagine if it can find a way to create new islet cells so my destroyed ones can be replaced with working ones? I cannot imagine what it's like to have one day, *just one day*, when I was not sick. That's because I've had diabetes for longer than I can remember. Now is the time to expand the current stem cell research policy, not just because I want to know first hand what a healthy day feels like, but because scientists believe they can make real advances in the search for cures for diabetes, and for other diseases as well.

While I wait for scientific advances, I really am doing all I can to keep myself alive. Recently, I took a brave new step in fighting diabetes, and it has not been easy. I am now wearing what is called a Continuous Glucose Monitoring System and I'm one of the first kids in the nation to do it. This means I have a radio transmitter strapped to my side 24/7, in addition to my insulin pump. Attached to it is a wire probe that I insert under my skin every few days again, on my own, doing something most would need a medical staff for. It helps me see more often what my blood sugar is and helps to keep my blood sugar in better control, but it's not a cure. It's a step forward in helping me to take better care of myself until scientists find a cure. Because even though I have more information from it, it's not stopping diabetes from attacking my body. I still get high and low. I still need insulin. I still fear the future.

Because, you see, I have hopes and dreams for the future like most other kids. I want to go to a great college – but I have to worry about how to balance my constant care with a life in the dorms. I want to get married and have children – but I have to worry about how I will make that happen. Women with diabetes can have children now, but only with constant and very invasive care. I want to be a Senator like you, but I have to worry if my body will hold up long enough for me to get the experience I need to even try for that.

I have to admit I am lucky in some ways: Living in Massachusetts and near Boston means I am close to some of the best care in the world. At my diabetes camp and through my advocacy, I've met kids who are not that lucky. They don't have a good team to help them take care of themselves and try new treatments. They don't get to meet with great researchers like we have at Harvard. I worry for them too: how will they achieve their dreams if I'm worried about mine? I am also lucky that my parents are willing and able to work very hard to pay for all the things that diabetes demands. Because even with good insurance, it's expensive. Pump supplies, needles, insulin, test strips, and more; it all adds up to tens of thousands of dollars a year my parents spend. What of the kids who are not lucky enough to afford that?

Embryonic stem cell research could be a key to the answer in all of this. As I try my hardest to take the best care of myself I can, and those thousands of kids out there who are not as lucky as me do the best in their situations, I hope that the government will do its part by giving our best scientists the best tools to get to a cure as soon as possible. One of the best tools out there is embryonic stem cell research.

With it, with our great nation and with brilliant scientists, I can go on and live that life I dream of. Will I go to a good college? Maybe. Will I get married and have kids? Hopefully. Will I be a Senator? We shall see. But one thing is for sure, once stem cell research helps us cure diabetes, I'll be that one thing I truly do dream of: just another *American girl*.