

Testimony of Dana Lewis
U.S. Senate Committee on Health, Labor, Education, and Pension
“The Broken Pipeline: Losing Opportunities in the Life Sciences”
March 11, 2008

Mr. Chairman and Senators of the Committee:

Good morning. Thank you for the opportunity to speak today. My name is Dana Lewis and I am from Huntsville, Alabama. I am sophomore at the University of Alabama pursuing degrees in Public Relations and Political Science, with a minor in Computer-Based Honors. I have an interest in working in public health. I appreciate you holding this hearing on the importance of research funding opportunities. My interest in this field and reason for speaking with you today stems from my battle of living with type 1 diabetes.

Tired, achy, always hungry, always thirsty – these symptoms, combined with losing around 15 pounds, preceded my diagnosis of diabetes during my freshman year in high school. Being diagnosed seemed like it should be the end of my problem – my doctor should have said the magic phrase, “I think you have diabetes,” hand me some medicine, and I’d be all healthy again. But that isn’t what happened. My diagnosis was not the end but rather the beginning of a love-hate relationship that has played a significant role in my life for the past 5 years, one that will remain with me until I die.

There are 20.8 million Americans living with diabetes, a condition in which the pancreas either does not create any insulin, which is type 1 diabetes, or the body doesn’t create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. Insulin is a hormone that allows glucose or sugar to move from the blood stream into the cells where it is used for energy. Since my pancreas no longer produces any insulin, I must administer it throughout the day in order to survive. After diagnosis, I quickly learned that diabetes is more than just daily injections. While a normal pancreas is able to secrete

just the right amount of insulin, I have to balance these doses of insulin with the number of carbohydrates I ingest. It is not a simple puzzle that can be solved by filling in the right formula, nor does diabetes pose as a sphinx, requiring a correct answer before letting you cross the road to good health. When this balance is off, I suffer from what is referred to as high blood sugar (hyperglycemia) or low blood sugar (Hypoglycemia).

It can be difficult to maintain blood glucose level in a safe range, yet it is essential. I strive for tight blood glucose control because research has established that this is the way to avoid the devastating long-term complications of diabetes. In order to manage my diabetes I need to carefully monitor my blood glucose levels and make adjustments about the amount of insulin I administer, taking into account the food I eat, and the exercise I get, while assessing factors such as emotions, stress and illness that are affecting my body.

One wrong step, one miscalculation, and the consequences can be life threatening. A severe low blood sugar could cause a seizure, unconsciousness, brain damage and even death. While a severe high blood sugar is also very dangerous, and could send me into a coma. In the long term, it is high blood sugars that lead to the many complications of diabetes – including blindness, heart disease, kidney disease, and amputation. Therefore, I constantly test my blood sugar. I test first thing when I wake up in the morning, between classes, walking across campus, before I snack or eat a meal and an hour or so afterwards. I test before I get in the car to run errands, every few hours while studying and each night before going to bed.

Experiences with highs and lows influence my every day routine. I am forced to remain diligent because diabetes affects my behavior. If I receive good news or get excited, adrenaline surges and my blood sugar will skyrocket and later plummet. If I read news of a tragedy or stress over an upcoming exam, my blood sugar slowly creeps upward. When I incorrectly calculate the number of carbohydrates I eat in the dining hall, my blood sugar spikes and I get dehydrated, my brain feels fuzzy, and my eyesight is very unclear. It affects my performance in the classroom because I can't concentrate. If I forget to

adjust my pump to give me less insulin before walking across campus, my blood sugar may drop. When this happens, I start weaving on and off of the sidewalk, I stumble, I mumble, and I cannot complete the simplest tasks such as opening a door and then walking through.

If my blood sugar is low or high during an exam, I may not clearly articulate my skills and abilities or may perform poorly. It could affect my grade in the class, my GPA, and possibly my career. I could pass out in the middle of class or worse, never wake up from nights sleep. In addition, if my body develops ketones (acids that build up in the body due to illness or high blood sugars), people can detect the fruity odor on my breath and think poorly of my hygiene or incorrectly assume that I have consumed alcohol. These may seem extreme, but are all part of the many consequences that those of us with diabetes face all of the time.

My life with diabetes is like this because there is no cure. I walk, talk, sleep, and dream for a cure but the truth is, one does not yet exist. Insulin is not a cure. In the meantime, I am thankful that there have been tremendous improvements in the technologies used to care for diabetes in the past five years since I have been diagnosed. These improvements have been life-altering.

When I was first diagnosed, I pricked my fingers to measure my blood glucose levels 12-15 times a day and self administered insulin shots 2-3 times a day, adjusting the amount of insulin as discussed above. Additionally, the glucose meter that I used was bigger and heavier than a Blackberry. I had to constantly use it to prick the side of my finger tips. It was cumbersome and left my fingertips looking like I sewed without a thimble. It was also embarrassing to have to test in front of people who didn't know I had diabetes because it looked like an obscure handheld computer monitor. Today, I have a very small glucose meter that weighs less than my cell phone. It fits easily into my pocket or an eyeglass case. It also provides quicker test results and allows for alternate site testing so that I do not always need to use my fingertips.

Eighteen months after I was diagnosed I went on an insulin pump. Insulin pumps deliver rapid –or short—acting insulin 24 hours a day through a catheter placed under the skin. Going on the pump allowed me to eliminate individual insulin injections and instead inject insulin directly into the pump once every two to three days. Rather than administering insulin injections and matching my life to how the insulin reacted, the pump has allowed me to more easily match insulin around my activities while stabilizing my blood glucose levels within my target ranges.

Last year, I went a step further and began using a continuous glucose monitoring system (CGMS), a device that provides continuous “real time” readings of glucose levels. The CGMS allows me to better manage my diabetes and decreases the frustration of high and low blood sugars. I now have a 24 hour view of my blood sugar activity, instead of 15 still photos that don’t tell the entire story. This allows me to not only to better understand the current level of glucose, but also see when my levels are rising or falling, and to intervene to prevent it from going too high or too low. The nights I sleep wearing my CGMS set, I do not have to fear not waking-up, because the system has safeguards and alarms that will wake me –even from a dead sleep—if my blood sugar plummets or skyrockets during the night. Because of the extensive research done in developing this device, we are now one step closer to a “closed loop” artificial pancreas system, which could someday regulate insulin delivery and bring us one step closer to a cure for diabetes.

The technology I rely on would not be available if not for the extensive research of dedicated scientists. Research is so important for people with diabetes because it provides hope for a cure. It is difficult to remain motivated day in and day out to keep control of my blood sugar and to keep myself healthy. When you are a young adult, it is frustrating to add diabetes and the thoughts of future health complications into a busy academic and social schedule. My peers without diabetes do not carry syringes, packages of glucose tabs, and spare test strips in every purse or backpack they use. They do not count every bite of food placed in their mouth and they do not need to know exactly how long it will take for different types of food to affect their blood sugar. All the wonderful

technologies only help fight the battle to stay healthy while I wait for a cure. For me, knowing that research for diabetes is ongoing is what keeps me fighting.

I am not alone in living with this disease. Many of your wives, children, siblings, parents, cousins, friends, coworkers, and peers are also affected. We are all fighting diabetes and we need the help and support of researchers and Congress to do so. Diabetes will not be cured by apathy and sitting back while more people are diagnosed and suffering complications of this disease. We need additional funding to maintain and increase research to create better technologies and to find a cure for diabetes.

Please help me fight diabetes. Increase funding for diabetes research. Help me get a cure “sooner” rather than “later.”

Again, thank you for the opportunity to speak here today.