

Speech at the First Showing of the CWD Quilt for Life on the National Mall
Washington, DC
June 8, 2006

I remember well the day in late August 1987 when my daughter Marissa was born. I remember well her first steps, her first words, her first day of school, when she learned to ride a bicycle, her first boyfriend, when she drove off on her own for the first time, when she graduated with honors from high school, when she moved into a dorm in college. These are the memories that all parents share and cherish.

I also remember that day in September 1989, 6,122 days ago, at the Children's National Medical Center just five miles from where we are now standing, when, at the age of 24-months, Marissa was diagnosed with type 1 diabetes.

I also remember when, as a child barely out of diapers, she stuck her finger with a razor sharp needle to draw blood to measure her blood glucose level on her own for the first time.

I also remember when, at the age of 4 and a half, she gave herself an insulin injection on her own for the first time at a diabetes summer camp.

I also remember three severe insulin reactions, during which I fed her sugar as fast as I could to ward off a seizure.

I also remember Marissa's first insulin pump, when she was eleven, and her realization a couple weeks later of the freedom that the pump represented when she could sleep late again on the weekends, something she had not done in over nine years.

I also remember the shadow of worry as she drove off for the first time – worry about Marissa having a low blood sugar on the road.

I also remember the thousands of middle-of-the-night glucose checks that my wife Brenda did to ensure that Marissa slept soundly and safely.

I also remember wondering if boys would like her, or if they would stay away because of her diabetes. Those of you who know me have seen the photos of Marissa in her prom dresses, insulin pump safely hidden away and invisible.

I also remember worrying about how she would make it through the night in her college dorm without her mother there to be sure her blood sugar levels were safe throughout the night.

These are the memories that we parents of children with diabetes share.

To help other parents like me and my wife Brenda, and to help other kids with diabetes like Marissa, I created Children with Diabetes in the summer of 1995. I realized that the Internet was the perfect tool for the support that we needed – always on, always accessible.

Over the years, Children with Diabetes grew to become one of the world's largest web sites about diabetes, and the largest support site for families who have kids with diabetes.

In the summer of 2000, at the urging of one mom – Laura Billetdeaux – 110 families from CWD met in Orlando, Florida for the first CWD event. From that not-so-humble beginning, CWD's summer conferences have grown enormously, and last July we hosted 2,200 people at Disney World for our annual Friends for Life conference. CWD conferences are simply magical, as any family who has attended will tell you.

So why a quilt?

I remember well how, in October 1987, the display of the AIDS memorial quilt helped to change the nature of the debate about HIV in our country, how it personalized AIDS, put real faces in place of abstract numbers. The AIDS memorial quilt helped us all realize that the illness was the enemy, not the people affected it. It helped us move beyond discrimination and blame and shame to understanding and compassion and caring.

People living with diabetes today are often confronted with their own kind of misunderstandings. Kids with type 1 diabetes are told they will be fine if they stop eating sugar, or that their bad eating habits gave them their diabetes. They are told that they cannot do the things they used to do, that they have to put their dreams aside. They are singled out at school and turned away by our military. None of this is right.

And so, in the spring of 2002, I decided that our children with type 1 diabetes needed a quilt, a quilt to celebrate their lives, to recognize their accomplishments, to share their challenges, and to affirm their futures. Thus began the Children with Diabetes Quilt for Life.

Our quilt is about our kids. It's about what living with type 1 diabetes means to us. For some it's about sports or family or friends. For some it's about blood checks and insulin injections or insulin pumps. For some it's about praying for a cure. But for everyone the Quilt for Life is about living life well even with diabetes. It's about savoring each and every day, and to paraphrase Thoreau, to suck the marrow out of life. This is what CWD is all about. This is the message of our Quilt for Life.

I hope that the Children with Diabetes Quilt for Life will help us all to see that the tears of sadness we shed when our children were diagnosed are in fact the water of life that will nourish and sustain us all during our life's journey.

Thank you for coming.