

Nancy Cook – Fund A Cure Speech, 2007

The year was 1956; I was 4 years old and had just had the best weekend of my life. My Grandma Fanny had taken me to Minneapolis to go shopping at Dayton's, dinner at her favorite restaurant and a night at the Ice Follies but when we got home grandma told Mom that something was wrong with Nancy. Grandma noticed that I was drinking large quantities of water and going to the bathroom all the time. I just shake my head now thinking about what a smart lady my Grandma was. Diabetes was not talked about in 1956 and only mentioned in medical books. Mom and Dad called my uncle DeWitt Burnham who was an internist in San Francisco specializing in diabetes. He told Mom to get me out to SF and Mom said she would see about getting seats on the train. My uncle said "You need to get that child out here **now**...you need to fly!" My Dad even got on the plane, asked the pilots if they could guarantee that they would get his little girl, who was very sick, to SF safely, the pilots called my uncle and the plane was delayed until everyone agreed. Here begins my life with diabetes. We had a town doctor who told my parents that he would not take care of me because he didn't know enough about diabetes. I am so thankful every single day that my

Mom's sister, Aunt Betty, married a doctor who specialized in diabetes. Uncle DeWitt took care of me for the next 25 years which, back in 1956, was my life expectancy. His last words to his family before he died were "Take care of our Nancy." And, boy, have they! Thanks Aunt Betty and Duke.

In 1956 the only way to test for glucose in your body was to take a sample of urine, mix it with Benedict's solution and boil it on the stove. That result was a reading that was over 4 hours old. Insulin was given in large glass syringes and thick metal needles. Back then the insulin was given deep into the muscle so the needle was 3 inches long. To a four year old girl it was terrifying. The insulin wasn't pure so the injections were painful and abscesses were common. My Mom would boil my syringes every day and my Dad would sharpen my needles on a stone every night. I would get one shot in the morning and my Mom would send me out the door to school. I don't know how you did it Mom. I love you so much.

In my first 15 years with diabetes I had so many things go wrong, I seemed to be the poster child for complications. I had strange insulin reactions where I would be paralyzed on one side of my body, like I'd had a stroke.

Tests and more tests were done on my brain, I was put on anti-seizure medication and had lab work drawn every day and yet the doctors could not figure out what was going on. Eventually those types of reactions just stopped.

In the summer of 1962 I was diagnosed with a very rare condition called renal glycosuria. My kidneys were literally filtering all the glucose out of my body even when my blood sugar was normal or low. So at age 10 I had to take insulin and eat sugar throughout the day and try to balance everything. It was a nightmare.

When I was twelve I was using test tape to check my urine for sugar. One morning I was home sick, my urine was negative for sugar so Uncle DeWitt told Mom to withhold my insulin because I had been throwing up all morning and couldn't eat. She kept rechecking and it continued to read negative on the test strip. We discovered later that the test tape was reading false negative. I actually had a lot of sugar in my urine. Finally my uncle told Mom to take me to the neighboring town to the hospital as I was getting sicker. I vividly remember being in the back of the car wrapped in my grandma's arms while Mom raced to the hospital. Grandma had to keep slapping me awake and telling me to breathe but every time I tried to it was

like someone was stabbing me in the lungs with knives; I just wanted to go to sleep. By the time we got to the emergency room I was in full blown ketoacidosis and shortly thereafter I slipped into a diabetic coma for 3 weeks. If it weren't for the doctors in this tiny hospital talking on the phone every day to my uncle I have no doubt I would have died; diabetes just wasn't something most doctors knew how to treat.

In the 80's I started having eye problems. Diabetes is the #1 cause of blindness among Americans between the ages of 25 and 75. I had just been to see a retinal specialist and he was so amazed that my eyes were in such great shape. Three months to the day I was back in his office with a full blown bleed in both eyes and ended up having laser treatments for the next 10 years to stop the bleeding and save my vision. I even had to have this done on my wedding day 3 hours before the ceremony. Turns out my diabetes complications lasted longer than the marriage and for once IT was easier to control than the marriage was.

Three years ago it was discovered that, although I don't have kidney disease my kidneys no longer make a hormone called erythropoietin that tells the bone marrow to make new red blood cells. If it weren't for the discovery of

a synthetic hormone that I can inject, I would have to have blood transfusions every 2 months. These injections are very costly though...one shot costs about \$2500. I have to take them every other month and this will only increase with time. I will now have my blood checked every two weeks for the rest of my life.

Even having diabetes for over 50 years, being a nurse for 20 years, working at JDRF for the past 9 years and being pretty smart for a girl. I have had a few episodes in the past couple years that have scared me and I don't scare easily. One had to do with Bear, an 8 year old retriever that I had adopted from Golden Retriever rescue. I had only had Bear for three months. One night I was awakened at 3 in the morning to this big 90# dog lying next to me pawing my face. I tried to push him away but he wouldn't stop. I finally sat at the side of the bed ,did my blood sugar and the meter just said low...meaning my blood sugar was somewhere below 20. I don't know what happened in my sleep to cause Bear to do what he did but he saved my life that night.

Then there was the day the war broke out in Iraq. I left work and there were no buses or cabs downtown due to the rioting. I started walking home and

my blood sugar started to drop. I ate sugar tablets and granola bars until I ran out of both. I got to the corner of Polk and Sutter, I saw a corner market and knew I should go inside but I didn't know why or what I was supposed to do once I got in there. I happened to turn to my left and saw a cop car pull up to the light. Something made me go over to their car, knock on the window and start crying. They asked me what was wrong and I didn't know what to say, I just stared at them. I finally pointed to my medic alert bracelet, they read it, realized I was a diabetic and rushed me home.

The last scary situation was when I was on the #3 Jackson bus coming home from work. I had already corrected for a low blood sugar by eating 4 glucose tablets and two granola bars. The next thing I remember is the bus driver telling me it was his last stop and I needed to get off. I had no idea where I was, what state or city I was in...my brain had shut down. People don't understand that when your blood sugar gets too low you DO NOT think right. You don't know to reach out for help and sometimes you may even start to hallucinate. Whatever part of the brain is suffering the most from lack of glucose will manifest itself in very bizarre, extreme ways sometimes and every time you have a reaction your body deals with it differently. Honestly, you can never be truly prepared. What works one time won't

necessarily work the next time. That day it took me one hour to walk the 5 blocks to my house and even when I walked in the front door and saw my dog I had not a clue who he was or where I was. I walked into the kitchen, started eating any food within reach and all of a sudden, BOOM, I was back...I knew my dog , I recognized my kitchen , I knew I was home safe. It wasn't until the next morning when I was taking a shower that it hit me how much danger my life had been in the day before and the tears started rolling down my cheeks and I cried for 20 minutes, got out of the shower, said to myself "Well, that felt good, and got ready for work.

OK...why am I telling you all of this. It is certainly not to have you feel sorry for me. Good grief what good would that do! And, honestly, despite all my health problems I've had a wonderful life thanks to my family and friend's incredible love and support. But I do want you to know that it is a struggle every day. This disease is relentless and no matter how tight of control you are in and how well you take care of yourself you may be dealt a devastating complication. My brother Jerry, who's here with me tonight, got diabetes when he was 17 and he was taking good care of himself. He was on an insulin pump and checking his blood sugars 8-10 times a day BUT at the age of 38 he had a silent heart attack and a quadruple bypass. The doctor's told

us his arteries looked like the vessels of an eighty year old man. He is now 54 years old but without a cure for diabetes and the toll it takes on his body, the next thing my brother will be looking at is a heart transplant. I live in fear of that every single day. I love my brother so much and I will not stop raising money and asking everyone and anyone to help us find a cure for this disease. That's why I come to work every day at JDRF. The people at JDRF are my family. I am inspired every day by our volunteers...those who have a direct connection, those who don't have a direct connection and the founders of this chapter, Susan and Jon Bloom and Pammy and Stephen Mittel who all give their time, talent and endless energy to raise money for JDRF. All of you in this room tonight give me so much hope that we can wipe diabetes right off the map! We have made incredible progress since 1956 but we need a cure! So please Fund-A-Cure to find a cure and raise your paddles now!