

## The Journey

By Kathryn White

**On July 21, 2008, Kathryn White received 6,081 IE/kg islet cells and her journey as an islet cell recipient began. Kathy agreed to share her experiences with our readers to help educate the public about this life-changing procedure. Here is Kathy's story as told by her.**

In 2000, I read an article about the Edmonton Protocol and was fascinated by the procedure. At the time, my diabetes had become increasingly difficult to control. I have lived with diabetes for 25 years after being diagnosed at age 24. I thought the islet cell transplant procedure would be a biological fix, not just a mechanical or chemical fix. I followed whatever articles I could find on the topic, but they were few and far between.

I continued to strive toward good control and started using the insulin pump—adding Symlin to my regimen. I even used a continuous glucose monitor. Even with all of the new treatments I had incorporated into my diabetes care my blood glucose levels continued to fluctuate dramatically—I could jump from 35 to 500. Needless to say these fluctuations wreaked havoc on my life.

One day while on the Spring Point Project website I clicked onto a link to the University of Minnesota Schulze Diabetes Institute. There was a project underway to develop a herd of pigs suitable for harvesting pig islets that could be used for pig islet cell transplantation in humans... eliminating



*Dr. Bernard Hering and Kathryn White*

the need for insulin injections—thus curing diabetes.

I personally love pigs—they are a big part of my home decorations (ceramic, not live pigs), and to think that they could play a part in treating my diabetes fascinated me.

I continued my research and found that pig islet transplantation was not yet approved for human trials, but islet cell transplantation from a human cadaver—retrieving islet cells from the pancreas of a cadaver and implanting them into individuals with Type 1 diabetes—was being done.

There was a short online questionnaire that I completed, and sometime thereafter I received a phone call stating that I met the criteria for the program. The study was being offered at several different centers; so to increase my chances I applied to four different centers. I began to research the facilities—their successes and results. Although Dr. Hering at the University of Minnesota was not the closest, it appeared to have the best results

and most successes. I submitted an application with them.

I was asked to submit paperwork from each of my doctors to satisfy questions concerning my current health status. I had to be healthy to be eligible for the procedure as well as demonstrate that I had done what was required to try to get my diabetes under control. My endocrinologist was not in favor of the transplant; he and I had an excellent relationship so this was an uncomfortable situation. But I felt strongly that this was my decision to make and I felt I was making the right decision for me. Interestingly, I now have a new endocrinologist (my old one retired) and he is most excited about my transplant but acknowledges he was glad he did not have to participate in the initial decision to go ahead with the procedure.

While this was a decision only I could make, I had a great deal of support from family and friends—but no one pressured me in either direction. Today when I talk to potential recipients on my blog I am very careful not to tell

them they “should” do this. Everyone is different and needs to make his or her own decision.

I was required to make a trip to Minneapolis for extensive testing to be sure my diabetes warranted the risk of the procedure as well as to ensure that I was healthy enough to handle the stress of the transplant and immunosuppressive drugs. Once I passed the battery of tests, I was required to make another trip to Minneapolis to sign the consent forms. It is very important that the risks of the procedure and treatment are understood. From working in the medical field as a medical technologist, the language used was not foreign to me, but this brought forth the realization of the seriousness of my decision.

In March 2008, I was accepted into the clinical trial and the waiting began. I did what was necessary to prepare myself because when the call came I would have to leave quickly. I discovered that Northwest Airlines would provide a discounted ticket to someone traveling to have a transplant. My preference, however, was to drive the 10 hours if possible. Then the call came; my husband Gary and I began the drive to Minneapolis. Three hours into the trip we received another call... the doctors were not able to retrieve a sufficient number of beta cells from the pancreas to make a viable transplant. Gary and I returned home and began the wait again.

My husband and I were preparing to leave for a family vacation when the second call came. Once again Gary and I hit the road for Minneapolis. This time we took the trip a little slower; if it turned out there was another cancellation we would be able to reroute and join the family vacation.

Upon arriving at the hospital, the process began. Numerous tests were performed to ensure I was still in good health. Immunosuppressant therapy was started before the procedure to reduce the chance of rejection of the implanted islet cells. These medications

were administered intravenously and it was necessary for the doctors to insert a pic line (an IV that threaded into my heart) in order to administer the medications. On Monday July 21, I received my 6,081 IE/kg islet cells.

The protocol calls for continuing my insulin to allow the islet cells to settle in before placing strain on them. The intent is to gradually decrease the insulin I take. So upon discharge from the hospital I was back on my insulin pump taking 22 units of insulin. Fortunately my husband has

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a good friend who lives just outside of Minneapolis and we were able to stay there a few days until I could return home to Ohio.

I was required to return to Minneapolis 12 times over the course of the next year. I also had to have blood work done and sent back to the University. At first I was concerned about the frequent visits required back to the hospital, but I ended up looking forward to these trips. Dr. Hering and the staff were wonderful during my visits.

I cannot say that there have not been any complications... I had to change my immunosuppressant medication because the one I was using was removed from the market, and there have been some minor bumps in the road with the new regimen. But I can't say enough about the level of care I received and continue to receive from Dr. Hering and the medical staff. They monitor my health very closely and react to any problems that I might have. I have complete trust and confidence in them all. They really want this to be successful, not just for the sake of the study but for my sake as well. I feel like

I am an important part of this project. I also feel that by participating and being a part of this research, I am helping to bring us closer to the cure.

Presently my A1C is 5.4. Since my transplant I have so many freedoms that I didn't have before. I no longer have to worry about unexpected low blood sugars that prevent me from doing what I want, or that interrupt whatever I might be doing. I can get as much exercise as I want and not have to wonder if I might be putting myself in danger. I can go out to dinner and not become nervous about experiencing a reaction if I am not served in a timely manner. The work that I perform as a medical technologist has to be one hundred percent accurate. Before having the procedure I had to constantly stop what I was doing because my blood sugar was so unpredictable and I couldn't trust myself to report out results if I wasn't feeling adequate. Another big bonus is that now I am a MUCH safer person on the road.

Physically, I am no longer hooked up to a pump or a continuous glucose monitor. They both helped immensely but were labor intensive, and the monitor was very expensive.

Psychologically, I feel much more hopeful for the future. My kidneys, eyes, and other organs are getting a relief from the constant fluctuation of my blood sugar. Instead of feeling like I am losing my health, I feel like I have made a miraculous escape from a scary place.

I continue to eat a healthy diet and I routinely exercise. I am trying my best to keep my islet cells alive in honor of the young man who donated them. This is certainly a wonderful journey I am on. I am honored and pleased to have been given the opportunity to share my story with you. 🍏

*If you are interested in learning more about Kathy's journey check out her blog at: <http://kathy-mynewislets.blogspot.com>. If you have questions about islet cell transplants call the Diabetes Wellness News Helpline at 800-941-4635 or order our brochure: **Is Islet Cell Transplantation an Option for You?***