

dedicated to finding a cure

JDRF Northwest Ohio serving the counties of Defiance, Fulton, Hancock, Henry, Lucas, Ottawa, Putnam, Sandusky, Seneca, Williams, Wood, Wyandot and Southern Michigan.

Islet Cell Transplant

By Kathy White

I received an islet cell transplant in July of 2008. I have not needed insulin since September of 2008. I feel better than I have in many years, better than I would have believed possible. I feel like I am cured. The clinical trial in which I am so fortunate to be a part of is in collaboration with the JDRF. Here is my story.

I remember well the first time I heard about the patients in Edmonton, Canada who had received islet cell transplants. The year was 2000. It was at a point in my life when my blood sugars were becoming increasingly difficult to manage, and I was contemplating trying a pump to deliver my insulin. I believed that this could be a biological answer to my illness instead of a chemical or mechanical adjustment. Could this be the cure? I read everything I could find about the Edmonton project and became very excited. The procedure is basically removing the pancreas from a donor, separating the insulin producing islet cells, and inserting them into the liver of the diabetic recipient. The cells survive in the liver and make insulin. The recipient must take immunosuppressive drugs so that their immune system will not destroy the donor islet cells.

Meanwhile, I was managing as well as I could. I had an endocrinologist, Dr. Gerstenmaier, who was good at keeping me at the cutting edge of advancements in treating my diabetes. I went on the pump. It helped. I tried a new drug, Sym-lin, which works like insulin in that it helps to lower blood sugar. It helped. I even tried a continuous glucose monitor, which I really liked. But it was expensive, and sometimes I

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National News

From JDRF International

The JDRF FY09 Annual Report is now available in electronic format at www.jdrf.org/annualreport2009.

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Walk Dates Announced!

The Ottawa Park Walk is set for Saturday, October 2, 2010. The North Coast Walk is scheduled for Sunday, September 19, 2010 at East Harbor State Park.

Board members Jane Marie Rahe and Mary Brown Grieger have again agreed to lead our Ottawa Park and North Coast walk efforts, respectively. Visit www.JDRF.org/walkcentral today to join our great group of Northwest Ohio supporters.

Government Relations

Promise to Remember Me...

Dawn T. Christen, Government Relations VP

JDRF will fund \$100 million in research this year due to your hard work and support. But our families and friends cannot do it alone! A huge part of diabetes research is funded by federal support through the Special Diabetes Program, which provides \$150 million a year. The current diabetes program is due to expire in 2011, and we need Congress to support the renewal of this program. Without securing their support and the passage of the renewal bill, federal support for type 1 diabetes research will be reduced by 35%!

How can you help? Become an advocate and join Northwest Ohio's Government Relations team in a meeting with your representatives. The Northwest Ohio Government Relations team is in process of securing dates to meet with Rep. Bob Latta, Ohio's 5th Congressional District; Marcy Kaptur, Ohio's 9th Congressional District; and Jim Jordan, Ohio's 4th Congressional District. Meeting with your respective Representative gives you the chance to tell your story about living with diabetes, highlighting the personal toll and the economic impact of diabetes, and the opportunity to ask your Representative to **'promise to remember you'** when making decisions about diabetes. Sign up today to participate at <http://promise.jdrf.org/>. Once a meeting is confirmed, a JDRF Government Relations representative will contact you to confirm your availability. Thank you for your support of JDRF!

Outreach

Helping Today...Hope for the Future

Although the mission of JDRF has been to find a cure for diabetes and its complications since inception in 1970, we have found there is a need to connect with families who are struggling in the daily life of coping with diabetes. The purpose of JDRF's service programs is to provide emotional, social and practical support, along with information about diabetes management to persons affected by insulin dependent diabetes and their families. Connecting newly diagnosed families with our mentoring network, for example, addresses the fear and anxiety of the disease making it easier to cope with; and just having someone to talk with who "has been there and done that" often becomes a lifesaver.

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JDRF Networking Coffee

Please Join us in a casual and relaxed setting
NETWORKING~SHARING~LEARNING

Monday, February 1, 2010

9:00-10:30AM

Vintage Coffee Bistro

4570 W. Sterns Rd., Ottawa Lake MI 49267

(Located in Jacob's Garden)

To RSVP or for more information contact:

Dawn at dawnwoolford@msn.com or

Denise at dpentescu@jdrf.org

Children Welcome ~ light refreshments served



JDRF staff contact: Denise Pentescu 248.355.1133 x14

Diabetes Scholars Foundation

The Diabetes Scholars Foundation will be awarding college scholarships to students with Type 1 diabetes. At least fifteen \$5,000 college scholarships will be awarded to incoming freshmen. The college scholarship is not based on need but rather looks at several criteria including grades, community involvement, school activities, leadership, advocacy, and essay and letters of recommendation from both an endocrinologist and a high school counselor/teacher.

The application will be available online on the website at www.diabetesscholars.org beginning in January. In addition one \$1,000 college scholarship will be awarded to a student with Type 1 diabetes residing in the State of Michigan with plans on attending the University of Michigan (University of Michigan D.R.E.A.M. Scholarship), and one \$1,000 college scholarship will be offered to a student residing in the State of Ohio (Josh Smith Memorial Scholarship). Those students applying to the \$5,000 college scholarship program will automatically be considered for the other two if they qualify.

In the past two years almost \$200,000 in college scholarships have been awarded to students with Type 1 diabetes. Some of the schools recipients are attending include Harvard, Yale, Dartmouth, Columbia, Stanford, Vanderbilt, Duke, Northwestern and University of Chicago.

HOW TO REACH US

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Article Submission

All information must be sent via email to:

northwestohio@jdrf.org.

Articles must be received no later than the 30th of each month.

Pictures must be sent in jpeg format.

Article selection and printing of pictures is subject to the discretion of the e-news editors.

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juvenation
a type 1 diabetes community
created by JDRF

Join Juvenation, the largest social network for people with type 1 diabetes, their families and friends. Now with over 5,000 members.

- Network with others living with diabetes.
- Share your story.
- Create a group or blog.
- Educate others.
- Get support!

join today

we are one.

juvenation.org

2010 Happenings

Monday, February 1
9:00a.m.—10:30a.m.

Networking Coffee

Vintage Coffee Bistro
(inside Jacob's Garden)
4570 Stearns Rd
Ottawa Lake, MI 49267
Hosted by Dawn Woolford

Wednesday, February 3
4:00 p.m.—5:00p.m.

Walk Committee Meeting

JDRF Office

June 5

Diabetes Today and Tomorrow Conference

Burton Manor-Livonia-Michigan

Corporate Breakfast (TBA)

Family Team Rally (TBA)

Team Captain Kick-off luncheon
(TBA)

September 19

Walk to Cure Diabetes
East Harbor State Park

October 2

Walk to Cure Diabetes
Ottawa Park

December 2

Walk Awards Dinner

Holiday Schedule

Our offices will be closed:

Monday, January 18, 2010 in
honor of Martin Luther King.

Monday, February 15, 2010
President's Day

Help Wanted

JDRF's Kids for a Cure program is looking for volunteers to help make phone calls to schools in Northwest Ohio. Please contact Shelley at 419-873-1377 or scrossley@jdrf.org if you are interested in helping.



Have You Heard About JDRF's Kids for a Cure?

Kids for a Cure is a K-12 community service program designed to raise funds to help find a cure for type 1 diabetes while educating students, school staff and the community about the disease. Plus, it's a terrific way to boost your 2010 "Walk to Cure Diabetes" Family Team total! All funds raised by your child's school will be applied towards

next year's final team total. It's not uncommon for a school to collect over \$1,000 during a **Kids for a Cure** fundraiser through a variety of fundraising events, including:

- **Spare Change Fundraiser:** It's quick, it's easy and JDRF will provide your child's school with everything needed! JDRF will send each classroom a collection container and stickers for students to decorate their container. JDRF will also provide each classroom with a fundraising packet full of fundraising tips and fun classroom activities to educate students about type 1 diabetes. Plus, JDRF will provide a certificate of appreciation and pizza lunch to the classroom that collects the most funds!
- **JDRF Kids Walk:** JDRF will provide your child's school with collection envelopes and a fundraising packet full of tips, tools and ideas to guide your child's school to fundraising success! Plus, each student is eligible to earn prizes based on the funds they raise.
- **Your Own Creative Idea:** Schools are welcome to design their own school fundraiser such as a bake sale, dance-a-thon, paper sneaker sales, can collection, etc.

All schools collecting \$1,000 will receive a 3' x 5' banner personalized with their school name!

For pointers on recruiting schools in your area, to register, or for more information, contact: Sally Ruterbusch 248-355-1133 ext. 18 or sruterbusch@jdrf.org

Islet Transplant

From JDRF International

The following information is available at www.jdrf.org under Research/Replacement Replacement: Recent Key Advances, Spring 2009

Clinical Studies Show Benefits of Islet Transplantation

University of Minnesota researchers found that by modifying elements of the standard islet transplantation regimen, they achieved a 66% rate of insulin independence three years after the initial procedure. Moreover, although all of the study participants had severe hypoglycemia before the procedure, none of them experienced a recurrence. The study is one of several recent reports with similar results, showing that certain modified procedures can greatly improve the success of islet transplantation. In a separate study conducted at the University of Miami, researchers found that islet transplantation was associated with long-term

improvement in patients' quality of life. As the researchers noted, assessing effect on health-related quality of life is particularly important in the case of islet transplantation because recipients must take powerful immune-suppressing drugs for the rest of their lives, which can have serious side effects.

What this may mean for people with type 1 diabetes: These studies highlight the benefits of islet transplantation as a treatment option for some people with type 1 diabetes. They underscore the importance of addressing the issues that hinder its wider use.

Additional information can be found in the April 2009 addition of JDRF's Research Frontline E-Newsletter.

HOPE cont from page 1

The following is a “snapshot” of the exciting support programs areas JDRF offers in Northwest Ohio.

Bag of Hope – courtesy of JDRF and Roche Diagnostics, the Bag of Hope is designed to provide support and information to families with a child recently diagnosed with type 1 diabetes. This JDRF-branded backpack for kids contains Rufus, a cuddly stuffed bear who also has diabetes, an Accu-Chek blood glucose meter, a support DVD, and a variety of books for children and their caregivers. This Bag of Hope is free of charge and available only from the Juvenile Diabetes Research Foundation.

Peer-to-Peer Mentor Group - JDRF matches newly diagnosed families with trained volunteers who are ready to listen and eager to share their experiences living day-to-day with diabetes. JDRF mentors are available not only for the newly diagnosed, but to anyone with insulin dependant diabetes who might be have a need to talk with a friendly listener for support and guidance.

School Advisory Toolkit – developed by JDRF to help families and school staff answer questions concerning student safety and school issues. Request an electronic copy by going to www.jdrf.org/satrequest or contact the JDRF Northwest Ohio chapter for a hardcopy.

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felt like all I could really do is watch as my blood sugars swung up and down all day and all night. It was frustrating and sometimes discouraging. Despite these efforts, diabetes was continuing to have a negative effect on my daily life and I was concerned for my future.

As my computer savvy increased, I began reading blogs and online magazines to see how other diabetics were coping with the problems of diabetes. I discovered an article about islet cell transplantation. I went to the website that was mentioned and discovered that there were clinical trials occurring in several cities in the U.S for islet cell transplants. I filled out the online application, and to my surprise, they contacted me a few days later.

When I read all of the inclusion and exclusion criteria, I realized that I might just be a good fit. To increase my odds, I applied at four different centers. They were all interested in my case. I began researching as much as I could about all of the transplant centers and the doctors who were pioneering this procedure. I decided that Dr. Hering at the University of Minnesota seemed to have both the experience and a high success rate and chose that site to complete the application procedure.

After completing a variety of medical history forms, I traveled to Minneapolis for some extensive testing. I had blood sugar related tests, kidney and liver function tests, and cardiac testing to insure that I was diabetic enough to warrant the

Networking Coffees – JDRF Networking Coffees provide social interaction with others in your community to share experiences and information about diabetes. These groups are hosted by a trained volunteer, held in a casual and relaxed setting for sharing and learning.

Online support programs and newsletters – JDRF's Online Diabetes Support Team provides rapid responses to your questions and concern via the privacy of your personal computer. Utilize this resource and more by visiting our website at www.jdrf.org

“Diabetes Today and Tomorrow” Conference – this full-day conference held in the spring in Livonia, Michigan is quickly becoming the Nation's leading educational event of its type. It is intended for persons with insulin dependant diabetes, their families and the medical care community. The latest in research and treatment advances, diabetes management and care information are provided by nationally recognized speakers. Held concurrently with the conference, the JDRF Kids Camp offers a day of fun and education for kids with type 1 diabetes aged 5-12, while their parents attend the conference and view the many exhibits from noted pharmaceutical and diabetes supply companies.

risk, and otherwise healthy enough to handle the stress of the transplant and the immunosuppressive drugs. The tests confirmed that I was a good candidate and I signed the consent form. I then went home and waited for “the call”.

While I waited, I continued to read all that I could on islet cell transplants. I hoped to find a patient who was blogging about the experience, but never did. I decided that if I ever had the opportunity for a transplant that I would write a blog for others like me. The address of my blog is <http://Kathy-mynewislets.blogspot.com>

Part 2 of Kathy's story will be featured in next months newsletter.