

Building Connections: The Maestro Project



Participant Newsletter Issue 43 Spring 2010



Upcoming Project Events

Bean Bags Next Meeting:

Tuesday, June 22nd 7-9PM

Second Cup River and Osborne

TEAM MAESTRO – JDRF Walk for Diabetes

**Sunday, June 13th at Assiniboine Park – Locomotive Drive
Registration starts at 9:00am, the WALK begins at 10:30am**

Please join or pledge our team!!

DER-CA 25th Anniversary Celebrations

June 10, 2010 - See page 5 for more details!

Maestro Project Facebook Group – Launched April 2010

Exclusively for young adult participants!

Please contact the project office for your invitation!



TEAM MAESTRO Needs YOU!!

IN THE



2010 WALK TO CURE DIABETES

Sunday, June 13th

This year, our goal is to be the **BIGGEST WALK TEAM** in our city and show the rest of Canada that **young adults in Manitoba are ready for a cure and want it now and that they are willing to stand up and make that happen by raising funds for cure research!!**

Register at www.jdrf.ca – Register with **TEAM MAESTRO!!!**

Research News

April 2010 Researchers from the Scripps Research Institute in the US have uncovered a piece of the puzzle answering the 40-year old mystery of how certain tiny genetic mutations can lead to autoimmune conditions like type 1 diabetes. Three genetic variations located in the region of the HLA genome (HLA-DQ2, HLA-DQ8 and HLA-DR0405) within human DNA are known predictors for type 1 diabetes. Scientists involved in this study looked on a molecular level at these regions to determine why a single residue at position 57 on the beta chain of HLA molecules seemed to be linked to type 1 diabetes. They found that diabetes causing mutations changed the charge at one end of the peptide binding groove. Generally in individuals not predisposed to type 1 diabetes, molecules have a negatively charged residue at position 57, in contrast, disease causing molecules have a neutral residue and consequently positively charge the surrounding region. The result in this charge was that the mutated molecules would then select a unique subset of T cells that would bind to it strongly. These T cells would then misidentify “self” peptides as dangerous rather than harmless. Sounds familiar right!! The big discovery with this research is that we now finally have an understanding of WHY the body breaks its immune tolerance – an understanding of why the T cells start attacking healthy “self” cells. This new understanding can potentially be used to develop new therapies for type 1 and other autoimmune disorders such as celiac disease. This study was published in advance in the online issue of the *Journal of Clinical Investigation*, April 19, 2010, and will appear in full in the May print edition of the journal.

April 2010 The first clinical trial of an artificial pancreas system using two hormones (insulin and glucagon) to mimic the body’s control of blood sugar and maintaining near normal levels of glucose in a small group of 11 patients with type 1 diabetes was conducted successfully at Massachusetts General Hospital in Boston. You can read about the trial in the April 14th online issue of *Science Translational Medicine*. The trial was designed primarily to test the software that controls the artificial pancreas. To get the most accurate BG readings they used a sensor placed directly into a vein instead of taking finger pokes. During initial testing, six of the eleven participants were able to keep their glucose in close to target levels for the 27 hours they were being tested. (Time for 3 meals and a hospital sleep over). 5 patients went low and were treated with orange juice. This was explained by differences in insulin absorption rates among patients, the fastest being four times faster than the slowest. The software controlling the system was initially designed to dispense insulin at an expected absorption rate. This explains the patients who absorb at a slower rate getting too much insulin and developing hypoglycemia. When adjustments were made for individual absorption rates, the tests were repeated and none of the participants went so low as to need to be treated for hypoglycemia. (They should have read Bethany’s blog first and then they would have known everyone is unique hey!!!) Researchers are now planning to follow up this study with another set of experiments that run for more than 48 hours involving both adults and children. This time they will use the revised individualized settings!! The long term goal for this system is to have a wearable device that incorporates a glucose sensor that fits under the skin and communicates wirelessly with a pump. The pump would administer both insulin and glucose to help control glucose levels and could contain a microchip that would run and control the software, eliminating the need for patients to continually have to check their blood glucose levels and make treatment decisions every few hours. While not a cure for type 1, it would be more like a functioning pancreas, taking much of the drudgery out of daily diabetes management.

Feeling a Little D-Stressed? Is your life (and your A1C) out of control?? Could you use a Diabetes Boot Camp to get your diabetes mojo back??

If you answered YES to the above, we want to hear from you!

“We” are thinking about hosting a Diabetes Boot Camp in late August for people with A1C’s >10% who are willing and ready to re-commit to getting back on the ole d-wagon!

What we need to know is: Are you up for an URBAN or a RURAL camp experience?

Urban: *tentatively*: 1-day wellness retreat with a fitness component, guest speakers, cooking class etc.

Rural: *tentatively*: overnight camping experience with outdoor fitness activities, guest speakers etc.

Please let me know if you are interested. We are polling your votes and as usual, will be planning our next event based on your feedback! Call the project office at 204-789-3719 or email cmacdonald@mich.ca



Stir Fried Scallops with Strawberries

1 ½ lbs bay scallops
½ tsp salt
¼ tsp white pepper
1 tsp sugar
1 Tbsp rice vinegar
1 tsp sesame oil
2 tsp minced fresh ginger
2 tsp cornstarch
1 egg white
1 pint strawberries
2 Tbsp oil
½ lb sugar snap peas
3 Tbsp lemon juice



Wash and pat dry the scallops. In medium bowl, combine salt, pepper, sugar, rice vinegar, sesame oil, ginger, cornstarch and egg white. Beat until foamy and then add scallops and stir gently to coat well. Cover and chill for 1 hour.

Hull strawberries and cut into quarters.

In a wok or large skillet, heat oil and add scallop mixture. Stir fry over medium heat for 3-5 minutes or until just opaque. Add sugar snap peas and stir fry for 1 minute more. Add strawberries and lemon juice and stir-fry gently for 1-2 minutes longer. Serve immediately over the grain of your choice. (You might want to try this on the BBQ!!!)

Serves 4

Web Watchers

<http://www.chefbarrae.blogspot.com> Unrestricted tastes on restricted diets! Distinctive diabetic recipes! Thanks for sharing this site Bethany!!

<http://www.myabetic.com/home.php>
Stylish and functional testing cases!!



Upcoming Community Events

DER-CA is turning 25!! Come celebrate with us on June 10, 2010 See page 5 for more details!

Half-day scientific symposium: Theatre A UofM Faculty of Medicine (Downtown) Bannatyne Campus. Guest speaker: Dr. Lois Jovanovic from Santa Barbara, CA. **Evening Social Event: dinner, speaker, entertainment, bday cake!!**

Please RSVP by calling Pat Bobko at the DER-CA at 787-1021 or email her at pbobko@hsc.mb.ca

**CDA – Run for Diabetes!
Monday, September 6th**

10K run, 3K family walk, kids fun run at Assiniboine Park.

Register at www.runningroom.com or at Running Room Kenaston Village Mall at 1875 Grant Avenue.

Finisher medals, overall winner and age group winner medals for 10K run. Technical shirts to pre-registered 10K runners, T-shirts for all pre-registered walkers, draw prizes, refreshments and fun!! Help make a change in the lives of more than 3 million Canadians living with diabetes!

Visit <http://www.teamdiabetes.ca> or contact Kelvin at 204-925-3800 ext236 Kelvin.hollender@diabetes.ca for more information.

Get Better Together

A program for living better with chronic disease is continuing in centers across the city. If you are looking to participate in one this spring, there is one being held Wednesday afternoons May 5-June 9th from 1-3:30 PM at the North End Wellness Center, 363 McGregor St. Please call 632-3927 to register or for more information.

***What do you want to do
for WDD 2010?!***



Introducing a NEW section in the Newsletter... LET THEM EAT CAKE!!!

This is a spot where you can share ideas, writings, musings, musing of others that you find amusing...or inspiring, or pretty much anything!! Feel free to send in things you'd like to share. Our inaugural musing, is shared by Bethany and is from sixuntilme.com's blog. Enjoy!!

Diabetes Can be a Five Letter Word. ... and that five letter word is "guilt."

At the ePatient conference <http://sixuntilme.com/blog2/2009/10/epatient2009_voice_of_the_pati.html> last week, Sue Rago was talking about diabetes and the complications that can arise. "But the complications of well-managed diabetes? None." And despite the fact that I met and enjoyed hanging out with Sue, this statement cut right through me. Well-managed diabetes produces no complications? So diabetes-related complications are just the result of an inattentive "host," or "slacking off?" It's not the fault of diabetes itself?

The direct relationship between diabetes and guilt has always made me feel ... well, guilty. I'm not familiar with what it's like to live with any other disease than type 1 diabetes, so I do feel lucky that I have never experienced something like cancer, but since my scope is limited, I know this diabetes/guilt dance all too well. And diabetes - as a disease state including both type 1, type 2, and gestational - always seems to come with some added bonus of "You did this to yourself." It sounds harsh, but I hear it all the time.

It makes me feel so frustrated, this assumption that diabetes only does what we tell it do to. "The pump does it all for you, right? So diabetes is like, simple to manage?" Or "Just follow the rules and you'll be fine, right? Bad stuff only happens to people who are lazy and don't take care of themselves." I've never, ever heard someone ask a person living with a different disease - "Oh, what did you do to make this happen?" - but I've heard someone ask me about my diabetic retinopathy and respond, "Well, you must not be controlling your diabetes very well."

I work damn hard to manage my diabetes, and before I took the reins on my disease, my parents worked hard to manage it. I take my insulin, I test my blood sugar, and I see the doctor as often (maybe more often) than I should. Efforts are made to best manage my health, but the fact remains that I have a disease. I don't classify myself as "sick" and I don't view my life as compromised, but the reality is that type 1 diabetes is an autoimmune disease that causes my pancreas to stop its production of insulin. As a result of this, the blood sugar homeostasis of my body has been forever disrupted. And while the medical advances of the last few decades have been tremendous, giving rise to things like improved meter accuracy, insulin pumps, faster-acting insulin, and continuous glucose monitoring devices, there still isn't a cure. My pancreas remains busted, so I will never be in "perfect diabetes control."

Yet so many people think that a pump or a medication is the answer, robbing fault from diabetes for any complications that may arise and instead making complications the result of "something I did." I will fight that assertion tooth and nail for the rest of my life, because I care too much about my health and work too hard to let the perception of complications be that of fault.

Back in March of last year, I found this piece of paper wedged into an old diary of mine from middle school: *Diabetes and guilt - nasty combination.*

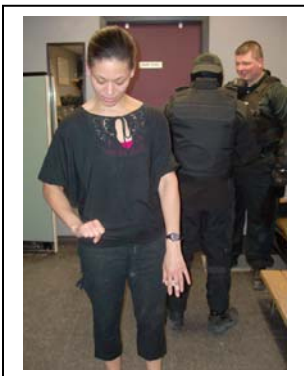
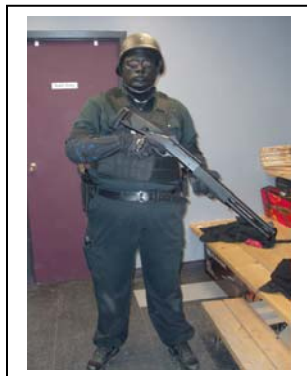
Even then, as a kid, I was taught to feel solely responsible for my diabetes, as though diabetes itself didn't play a role in any of the outcomes. "If I want to live:" is how that piece of paper starts off. What a heavy burden for a child with diabetes. High blood sugars? My fault. Spilling protein into my urine? My fault. Any threat of complication? My fault? Diabetes wasn't the cause - I was, apparently. (Granted, many times highs and lows were a result of being a rebellious teenager or eating a 'forbidden food,' but were it not for the diabetes in the first place, it wouldn't be an issue.)

I don't agree with this mentality, and I refuse to subscribe to it. Type 1 diabetes requires daily maintenance and diligence, but even if I follow "all the rules," there can still be complications. My genetic make-up plays a role. My family history plays a role. And of course, my actions play a role. This isn't a diatribe to give me a free pass to slack off and not care about my health. I need to take care of myself and work hard for my health. I have always tried to remember my role in this relationship with diabetes, but I can't fool myself into thinking that if I just work hard enough, my body won't ever exhibit diabetes complications. If my eyes start to bleed, it's not because I didn't care enough. Things happen, and I need to be able to roll with whatever life dishes out. I live with diabetes every day - I don't need the guilt.

Because at the end of the day, diabetes complications are the result of diabetes.

April 18th – Air Soft Event: War Against Diabetes at X-Treme Tactics!

It's hard to take photos when you are strapped into kevlar, wearing a face mask, a helmet that is three sizes too big and holding an MP5 – but we do have evidence that heros were born and tough women rule!! Despite the need for a couple of band-aides and minor flesh wounds (those pellets really DO sting!!) – it was a turbo-charged, adrenalin pumping afternoon!! Thanks to Lawrence and Tracy, brave, brave diabetes educators at HSC DEC and to Bradley, Cole, Conor, Joseph and Scott for making it a super fun (if not a little nerve-wracking at times) afternoon! Tip of the day...wear gloves and something a little thicker than a t-shirt!! Important life lesson...it's better to be the hunter than the hunted!! (And for those wanting to improve your d-control, there IS something a little euphoric about aiming for and hitting your target!!!!)



2010 marks the 25th birthday of the Diabetes Education Resource for Children and Adolescents, also known as the DER-CA!

Since the DER-CA opened in June 1985 in the Community Services Building on William Avenue, it has evolved into a regional comprehensive program providing care, education, advocacy, support and research opportunities currently for over 750 children with diabetes from Manitoba, northwestern Ontario, southeastern Saskatchewan and Nunavut. The team has grown from four to 12 full-time staff. The complexity of diabetes management has increased and the classification of diabetes has changed from exclusively type 1 diabetes in the early years to now include type 2 diabetes, drug-induced diabetes, diabetes secondary to cystic fibrosis and genetic diabetes.

In recognition of this 25 year milestone and the pride we have for the past, present and future of DER-CA, we are planning a celebration on June 10, 2010 to include an educational event and a social event. We will share this celebration with the children and their families, staff, community partners and volunteers who are currently involved with DER-CA. We will also welcome our alumnae roster of 1600 families, 900 participants in the young adult transition program and 30 previous professional staff of the DER-CA from Manitoba and across Canada.

Our special guest for the event will be Dr. Lois Jovanovic, an adult endocrinologist at the Sansum Diabetes Institute in Santa Barbara, California. Dr. Jovanovic is known internationally for her seminal research on improving the outcome of pregnancy for women with type 1 diabetes during pregnancy and their newborns. She will present Pediatric Grand Rounds at 0800 on Thursday, June 10, 2010 in the Frederic Gaspard Theatre (formerly Theatre A) in the Basic Medical Sciences Building. She will also contribute to the half day morning educational scientific symposium on current hot topics in diabetes research with a focus on past, present and future diabetes research in Winnipeg. Our families and the public are welcome.

Dr. Jovanovic has a special connection to Winnipeg and will share her personal story during the evening social event. In the **spring of 1922**, a very sick eight year old child survived the long train trip with her family from Winnipeg to Toronto to receive insulin from Dr. Banting. She wrote a thank-you letter to Dr. Banting in December 1922 to tell him how well she was doing with her insulin injections. That child was Dr. Jovanovic's paternal grandmother. Imagine the thrill we will share in hearing about her family treasures and memories of Winnipeg in the 1920s and about Dr. Banting's magic treatment that saved her grandmother's life. For more information on this incredible story, please go to <http://www.ourdiabetes.com/dr.-lois-jovanovics-story>.

We would like offer you a special invitation to join us for the evening social event to be held from 1800-2100 in the Brodie Atrium at the University of Manitoba Medical School. Please RSVP to Pat Bobko at 787-1021 before May 31, 2010 if you are able to join us.

Sincerely,
Heather Dean, MD, FRCPC

Results of April 2010 Maestro Project Young Adult On-line Survey

Thank you to everyone who completed our recent on-line survey! We had 50 participants of the Maestro Project complete the survey, thus providing us with an abundance of useful information that we will be able to use to make the services better for you.

Of those that completed the survey, the majority (66%) were older than age 23 years (28% were actually older than 27 years of age), and 74% were female. Many had graduated from the DER-CA a long time ago; 42% of respondents reported graduating before 2002, 16% between 2002-2004, 20% between 2005-2007 and 20% between 2008-2010.

Participants are definitely using the Maestro Project services: 90% read the newsletters, 44% have called or emailed, 42% have accessed the website, 36% have attended the evening events and 34% have attended the Bean Bags coffee group. Only 10% of respondents had never used any services.

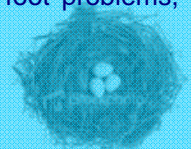
We were interested to learn where Maestro Project participants go for diabetes-related information. The vast majority talk to their adult endocrinologist or family doctor (84%), 50% talk to adult diabetes educators, 30% to pharmacists and 28% to CDA or JDRF. An overwhelming 48% use the internet/social networking sites (did you hear that the Maestro Project is on Facebook)! 32% reported reading newspapers or magazines and 26% talk to friends for information.

Here's some good news; in the past 12 months, 92% of respondents had seen an adult endocrinologist, and 68% had seen an adult diabetes educator for medical follow-up at least once. In fact, 38% had seen their doctor at least 3 times!

More good news: over 60% of respondents report having an HbA1c either <7% or between 7-8%. However, 10% did report having an HbA1c >11%, and 8% have not had an HbA1c "in a long time" – better call your doctor!

We were also interested in finding out if anyone had any medical emergencies or had developed complications of diabetes since graduating from the DER-CA. Although 62% reported no concerns, 28% of respondents had to go to the Emergency Department at their hospital (6% had to call 911), 14% had been admitted to hospital, 12% were told that they were in DKA, and 12% had severe low blood sugar (were unconscious or had a seizure). 68% of respondents reported no chronic complications; 4% reported heart problems, 6% nerve or foot problems, 10% kidney problems, 16% eye problems and 18% "other" health problems.

Norma Van Wallegem, MSc, RD, CDE



Please send your feedback to:

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