The Inherited Metabolic Disorders News

Spring/ Summer 2006 Volume 3 Issue 2

## In this Issue



## From the Editor

Summer is finally here, and the weather has been beautiful!

Our 3rd annual Metabolic Family Day on May 5th and the Low Protein Cooking Demonstration on May 6th were a huge success. See the section "Announcements" for a full report of the events, as well as pictures.

As always, your suggestions and stories are welcome. Please contact me by email or telephone (see page 11 for contact details) if you wish to contribute to the newsletter.

I hope everyone has a safe and happy summer!

Janice Little

## From Dr. Chitra Prasad

This issue brings a new era of friendship and working together as a team of professionals and families. The article by Joanne Miller is a wonderful tribute to persistence, love and caring. I would urge all of you to read this article.

Our Metabolic Family continues to grow. The Metabolic Family Day's success reminds me of a quote I often use:

*"A Journey of a thousand miles begins with a single step"*

Clearly there are a number of things we have to still work for, but the journey continues to get easier when we all have a common goal of seeing our young and older patients achieve their best potential and good health. May you all have a wonderful summer.

With best wishes, your friend Chitra Prasad

*"It is amazing how much you can accomplish when it doesn't matter who gets the credit"*

**Spring/ Summer 2006** **Volume 3 Issue 2**

# Personal Stories

Rediscovering the PKU Diet for Life As presented at The Metabolic Conference in London, Ontario May 5, 2006

by Joanne Miller

My story is about Tracey a young girl born almost 40 years ago in Goderich, diagnosed with PKU in London and grew up in Kirkland Lake, or as some call it "The Great White North;" she was taken off her diet at a young age and got lost in the system. I hope my story will convince parents and children the importance of PKU diet for life. It is my hope that I can show you all how much damage not following the diet can do to an individual with PKU, how important it is to research and understand every aspect of the disease.

I met Tracey March 27, 1975. She was an adorable tiny 9-year-old girl with curly blond hair and blue eyes. My boyfriend explained to me that his sister was a "PKU" child that she was born without the enzyme to enable her to break down proteins. He went on to explain that if she ate food with protein the protein would build up on the brain and cause brain damage. So for the first 5 years of her life Tracey had to be on a special formula and could not eat any regular foods but once she turned 5 her brain was fully developed and she could eat what ever she wanted to.

For the next 30 years life went on quite normally; I married my high school sweetheart and Tracey became my sister in law. During that time I didn't give much thought to PKU. Tracey went to special Ed classes through out her school years. She was a great swimmer and competed in the Special Olympics both Provincially and Internationally. She won gold medals in all the Provincial meets she went into and also won gold in New York and Baton Rouge. She had a beautiful voice and would sing solos in church but the choir director would not allow Tracey to join the choir, as she could not read.

The problems started around 2000 when Tracey began having severe anxiety attacks. She went from a fairly independent girl to a young woman who wouldn't stay home alone and even taking a shower became an ordeal, as she wanted someone near by at all times. Both my husband and I thought it was just behavioral and that my in-laws simply needed to be stricter with her. The problem, in our minds seemed to have started after Tracey spent a lot of time with her grandmother who was afraid of everything. It seemed to us that Tracey was merely trying to be like Grandma and that my in laws were being too tolerant of bad behaviour.

It wasn't until October 2003 that I realized how severe and real Tracey's anxiety was. My mother-in-law was in the hospital in Sudbury at this point in time, so Tracey and her dad traveled to Sudbury, and were staying at our home there. One night I told Tracey that we were going to walk to the hospital to visit her Mom. Tracey and I had gone on many walks together in the past, so this should have been quite a pleasant experience, and I expected it would be; however, shortly after we left the house, Tracey's anxiety started. I could see true fear in her eyes. I tried to talk to her about things she loved, but all I got were one-word answers. Her eyes seemed to have glazed over, she had her head down, and her arms were flying. Tracey was in total concentration to get where we were going as fast as she possibly could. We managed to make it to the hospital but the experience left me extremely unsettled. What was happening to my darling sister-in-law? That night I sat with my husband and told him about my concern, and how I felt. It was at this point I decided to find out as much as I could about PKU. I didn't realize how much this decision would change all our lives.

The first article I read was written by Virginia Schuett, director and Editor of the National PKU news. She explained PKU to an extent that I had never really understood. In the section Diet Maintenance she explained that at one time it was common for children to be taken off the diet between the ages of 6-10 but that it was now known that stopping the diet could result in a variety of serious problems. She went on to list the different problems, such as a drop in IQ, behavior problems, and personality problems, which included panic attacks and schizophrenia. She also went on to explain that if young adults did not return to their PKU special diets these symptoms would only increase. The next article I found was called Off-Diet Young Adults with PKU: Lives in Danger! I have done enough research to understand that in order to get the whole story one must look in a variety of places and to make sure the information comes from reliable sources. So I continued on the Internet, going to different hospital sites, university sites and in general PKU sites. The story was the same wherever I went. I read Andrew's story, Jason's story, Doug's story and on and on. Every one had the same theme: kids Tracey's age who had learning disabilities due to PKU but had been happy individuals, off their diets at a young age, suddenly started to have severe anxiety attacks; kids who had been able to live normal lives, all of a sudden wouldn't leave their homes, refused to be alone.

The story that hit home the most was Kevin's story. The whole plot of the story was the same as Tracey's: a young boy who stopped his PKU diet at 8, rode his bike, swam, cross-country skied, played the piano, walked to the mailbox to get the mail, took long walks on the beach. Then all of a sudden at 38 Kevin began to have problems with anxiety.

**Spring/ Summer 2006** **Volume 3 Issue 2**

He wouldn't walk up stairs, wouldn't get out of the car without help, wouldn't leave his bed room, stopped walking on the beach. The mother explained the nightmare that followed. She didn't know where to turn, wasn't getting help from the medical profession; meanwhile, Kevin was getting worse. He wouldn't even get up at night to go to the washroom since leaving his room scared him too much. Finally they found a neurologist who listened to their problems, suspected that Kevin's very high levels of PHE was the culprit and that getting him back on the PKU diet was the solution. Kevin's mother explained that once back on the diet his change in behavior was almost immediate. Within weeks of restarting the PKU diet he started walking on the beach again and was a happy and self-confident guy.

Reading these articles both terrified me, and yet gave me hope that finally we could get Tracey back to the happy young person I knew and loved. Did we finally have a solution to our problems? Could it really be as simple as restarting a PKU diet? I printed out quite a few articles and sat down once again with my husband to show him that there was a solution, there were answers to Tracey's problem and he could now tell his parents the good news.

Our joy however, was short lived. When we discussed my finding with my in laws we were confronted with skepticism and doubt. After all, Tracey was being followed by a "behavioral therapist in Kirkland Lake and really who were we to question her professional diagnosis? This Professional's approach to Tracey's problem was to tell Tracey that she didn't have to stay alone until she was ready. This had been going on for years and nothing had changed. We later found out that this behavioral therapist wasn't really a professional in the behavioral field, but a counselor and that none of the medical professionals working with Tracey in Kirkland Lake knew that Tracey had PKU. Part of me understood my in-laws reluctance; after all, the thought of taking Tracey off all protein and going back to a regimented diet, I am sure, was terrifying and overwhelming for them. It was also a point in Mrs. Miller's life when she was very sick with complications from type 2 diabetes and she was just not ready to add any further stress into her life. The next time we got together Tracey, in my mind was getting worse. I tried again to convince my in laws to at least consider the possibility that Tracey's problem could be PKU related. Again I was confronted with skepticism and this time anger. My mother-in-law told me that this was just an American belief, not substantiated in Canada. After all if it were in Canada, would London not have contacted them? She also was quite annoyed that I would question the therapist's work. After all she was the best. In her mind I was putting down Kirkland Lake and my in-laws' parental ability. This was not my intent at all. My concern was 100% Tracey. I kept thinking of Kevin and how much his anxiety had grown; I did not want this for Tracey.

My frustration took me back to the Internet, back to Virginia Schuett. I e-mailed Virginia and begged her for her help. Where could I go in Canada to get the information I needed? e How could I convince my in-laws to listen to me? Was I really so wrong for wanting Tracey to get help? Virginia Schutt quickly e-mailed me back and told me whom to contact at Sick Kids in Toronto. She also encouraged me to push for help, as she, too, was concerned for Tracey's well being. Once I got some Canadian information we again confronted my in- laws. When Tracey was back in Sudbury for an appointment with an allergist, my husband, son and myself decided to take the opportunity to have a form of intervention. After many tears and much discussion my mother-in-law finally realized that we were not questioning her intelligence, her parental ability or we were not trying to put down her beloved Kirkland Lake. She finally agreed to contact London Victoria Hospital where Tracey was initially diagnosed with PKU. This was in October of 2003. It had taken over a year to finally convince my in-laws that Tracey's problem may indeed be PKU related.

Once the phone call was made to London, Tracey was seen within a few weeks. We found out that Tracey PHE levels were over 1300 and her anxiety was most likely due to the high levels. We met with Suzanne Ratko, a registered dietitian at Children's Hospital of Western Ontario, and in my mind there is no one on this earth who is more caring. We were advised to take Tracey off all food high in protein: meat, dairy, legumes etc. Since at that point Tracey was not funded and there was really no funding available for adults who needed to go back on the diet; we could not put her on the formula or any of the low PHE foods. For the next year Tracey ate mostly fruit and vegetables. Suzanne was a real blessing during this time. I must have driven her crazy with all my questions, e-mails and concerns, but every time I called she was always eager to help. I don't know what I would have done without her. In September 2005 Tracey's levels had dropped to 1095; lower, but still quite high. The concern at this time was that her Tyrosine levels were also quite low due to inadequate protein. Suzanne was able to get samples of the formula in order for Tracey to get the nutrition she needed and decided it was time to press the government for funding for Tracey. We had applied in 2004 for funding and Tracey had been turned down but Suzanne was not willing to give up. She asked me to call Michele Sanborne from the Ministry of Health, to explain our situation and to try to get funding.

In early December 2005 I got a call at 6am from Suzanne. She was so excited she could hardly speak. Tracey had been approved.

**Spring/ Summer 2006** **Volume 3 Issue 2**

Since that time Tracey has been on a very strict, no protein diet. She takes her formula 5 times a day. She is really quite amazing. She will not eat any foods she is unsure of without checking with someone and will never eat anything after she has been told it is not good for her. Her anxiety is virtually gone. She is a happier, brighter girl and her levels have dropped to well within a very normal range. We bought Tracey a blender and she makes her own formula; she measures the water into a blender and then measures the powder, adds fruit and blends.

At Christmas she came to the gym with me and we went to a step class. The first day Tracey refused to go to the dressing room without me, but the next day while I was chatting with a classmate, Tracey informed me that I was taking too long and she was going to shower and would meet me in the lobby. Another time Tracey was sitting in the dining room coloring when I casually mentioned how beautiful it was out and that maybe she and Trevor, my son, could go for a walk when he came home. Before I knew it Tracey had her coat on and was out the door going for a walk on her own. What a change! When she comes for a visit she sets herself up in what she calls her "Secret Room". It is a room in our basement where she goes to watch movies. She sits there in complete darkness by herself with her videos on. A year ago she would not have gone into our basement alone with all the lights on. Until very recently she was on high doses of anti-anxiety medication. Since Christmas she has been cut back to just one tablet a day. Hopefully before long she will be off all these narcotics completely. She still tends to use the excuse "I don't have to do it until I'm ready" but at this point it is just a normal human way of not doing what she doesn't want to do.

One day, a few months ago, we were sitting in a Chinese food restaurant. After the meal Tracey took out her fortune from the cookie and read it. I said, "Let me see that." I couldn't believe what I was hearing. She had read the fortune word for word. Then I passed her my fortune, and she read it too. Tracey had not been able to read before. There is such a difference in her since her PHE levels have dropped.

Mrs. Miller died in November, a few weeks before Tracey's funding went through. She would be so proud of her daughter and the difference the diet has made in so many aspects of Tracey's life. Since her Mom's death, Tracey continues to live with her Dad, who will soon be turning 80. He has been amazing and has also taken Tracey's diet extremely seriously. He is her primary caregiver and cooks all her meals. He is quite receptive to new ideas and always asks me for recipes that he can try. He was telling me a few weeks ago that he can't believe the change in Tracey, how happy she is, how easy-going she now is, how she would once give him a hard time about a lot of different things but instead goes along with whatever she's asked to do.

There are many conditions people have which limit either what we can eat or things we must do to stay healthy. I grew up with a sister who was diagnosed at 11 with juvenile diabetes. I really credit my mother for pointing Sue in the right direction. My mom took the condition seriously, and made sure my sister did also. My mom ensured that Sue understood the danger of high blood sugar levels, and the importance of exercise. I look at my sister today; she is extremely healthy. As a child her health was in my parents' hands. As she grew older, it changed to her own hands, and I am very proud of the way she handles her diet. It is the same with PKU children. Initially it's the parents' responsibility, but in the long run it's up to the individual to want to stay healthy and it is very important to understand the disease as much as possible. I have a rare lung disease; my health does not depend on a diet, but in order to stay alive I must exercise to keep my lungs functioning. Believe me, there are days I would much rather just give up. But I had such a great role model in my sister that I know that's just not a possibility. There are many people whose lives are challenging.

PKU is like any other disease that when we, through ignorance or error, don't take diet or exercise seriously, it can be quite terrifying and in some cases deadly but when understood and controlled, can lead to quite normal lives.

***Teams share the burden and divide the grief.***

***Doug Smith***

Spring/ Summer 2006 Volume 3 Issue 2

# Kids Korner

**Birthdays: April, May, June, July August, September**

| Child's Name | Metabolic Disorder | Birthday | Age |
|---|---|---|---|
| Rozlin | PKU | August 7, 1990 | 16 |
| Daniel | PKU | April 25, 2003 | 3 |
| Zacharia | PKU | June 6, 2004 | 2 |
| Olivia | PKU | September 6, 1991 | 15 |
| Hailey | PKU | August 19, 2003 | 3 |
| Lama | PKU | September 1, 1990 | 16 |
| Patrick | PKU | July 2, 1991 | 15 |
| Julia | PKU | July 29, 2001 | 5 |
| Abilene | PKU | June 12, 2005 | 1 |
| Stathie | PKU | May 7, 1992 | 14 |
| Dusan | PKU | July 21, 2003 | 3 |
| Carter | PKU | September 5, 2001 | 5 |
| Elijah | PKU | June 18, 2003 | 3 |
| Samantha | PKU | July 31, 2000 | 6 |
| Brock | ALD | April 6, 1991 | 15 |
| Royce | ALD | April 6, 1991 | 15 |
| Joan | Glycogen Storage Disease | June 20, 2003 | 3 |
| Michelle | HMG coA lyase Deficiency | September 1, 1999 | 7 |
| Emma | Hurler | September 9, 2004 | 2 |
| Austin | MCADD | July 17, 1996 | 10 |
| Kelly | MELAS | July 10, 1995 | 11 |
| Aaron | ML4 | Aug 30, 1993 | 13 |
| Jordynn | 5-MTHFR | May 30, 2000 | 6 |
| Jared | OTC | September 22, 1993 | 13 |
| Jack | OTC | August 8, 2005 | 1 |
| Sarah | Sanfilippo | April 12, 1997 | 9 |
| Paisley | Metabolic Disorder | September 24, 1999 | 7 |
| Zachary | Metabolic Disorder | September 4, 2005 | 1 |
| Wyatt | Metabolic Disorder | July 18, 2002 | 4 |
| Alexa | Metabolic Disorder | September 29, 1993 | 13 |
| Jeff | Metabolic Disorder | June 24, 2001 | 5 |
| Madison | Metabolic Disorder | June 23, 2000 | 6 |
| Marlo | Metabolic Disorder | August 15, 2005 | 1 |
| Nicholas | Metabolic Disorder | September 1, 2002 | 4 |

PKU Phenylketonuria
MCADD Medium chain acyl-coA dehydrogenase deficiency
MELAS Mitochondrial myopathy, encephalopathy, lactacidosis, stroke
5-MTHFR Methylenetetrahydrofolate reductase deficiency
OTC Ornithine transcarbamylase deficiency
ML4 Mucolipidosis type IV (4)

**Happy Birthday Everyone!**

**Spring/ Summer 2006** **Volume 3 Issue 2**

## How to Make a Donation

Donated funds are used for future Metabolic Family Workshop Days as well as further teaching and education. If you wish to make a donation, you may send a cheque to:
The Children's Health Foundation C/O Medical Genetics Program of Southwestern Ontario
Attention: Janice Little
800 Commissioners Road East
London, Ontario, N6A 5W9
Charity # 118852482 RR0001
Your donation is tax deductible, and an income tax receipt will be mailed to you.
***Thank you!***

## Laughter is the Best Medicine


Parkhurst Exchange May 2006

***The path to greatness is along with others.***

***Baltasar Gracian, Spanish priest***

Spring/ Summer 2006 Volume 3 Issue 2

## Suzanne's Corner

# Quick and Easy Cheddar Wafers

Cambrooke Foods


## Ingredients

3/4 cup butter
3 tbsp Cambrooke Foods (CBF) *Cream Cheese Wizard*
1 3/4 cups CBF *All Purpose Baking Mix*
1/2 cup CBF *Porridge*
4 tsp CBF *Shake "N' Cheeze*
1 tsp salt

## Directions

**Preheat oven to 350 degrees Fahrenheit**

1. Cream butter and CBF *Cream Cheese Wizard* together
2. Add all the rest of the ingredients and mix to blend well
3. Place dough on a long piece of wax paper and roll into a 2 to 3 inch log shaped roll. Refrigerate approximately 1/2 hour until firm.
4. Slice 1/2 inch rounds and place on ungreased cookie sheet and bake for 7 to 9 minutes until the wafers spread out and edges begin to brown.
5. Cool completely before serving.

**Servings: Makes 30 wafers**
**Total Protein: 0.08 g per wafer**
**Phe per serving: 4 mg per wafer**

**Recipe Source: www.cambrookefoods.com**

**Spring/ Summer 2006** **Volume 3 Issue 2**

# What's New

**From Suzanne Ratko, Dietitian**

Greetings!

Few things to tell you about:
In the next couple of months, a new low protein cereal called **Crackels** made by Applied Nutrition should be available for purchase from the Specialty Food Shop (Toronto) or National Food Distribution Centre (Montreal).
Visit www.dietforlife.com for launch information.

Applied Nutrition will be sponsoring **Network PKU Conference: An Interactive Low Protein Culinary Experience** in Denver, Colorado for families on October 27-29th, 2006. This is an excellent opportunity for you to interact in workshops with Master Chefs from Johnson & Wales University - College of Culinary Arts who plan to "expand & excite your low protein diet plan". For more information check www.medicalfood.com.

Another source for low protein foods is **PKU Perspectives.** There are some really delicious products available for purchase from this Utah-based company.
Visit www.PKUperspectives.com.

Please contact me if you have any questions @ 519 685 8484, ext 52469.

**From Dr. Chitra Prasad**

Garrod meeting:

Drs. Rupar, Prasad and Kathy Corley attended this meeting in May 2006 in Halifax. It was an excellent forum for Canadian metabolic specialists and other professionals to get together. There were number of exceptional talks by renowned speakers from Canada and USA particularly Dr. Harvey Levy, Dr. Charles Roe and Dr . Steve Goodman. Information was exchanged at various levels about the newer therapies, reimbursement issues and also issues related to newborn screening. It was also an opportunity to meet old friends and colleagues (Dr. Jon Kronick) who has conveyed best wishes to all.

Fabry Meeting:

A number of ancillary meetings took place such as the first inaugural meeting for Canadian Fabry Association with help of the Fabry community and professionals. Both Enzyme companies (Genzyme and Shire) sponsored this event.

Acetelion Meeting:

Acetelion (Zavesca) meeting was held to discuss new substrate reduction therapy in Gaucher disease.

**Newborn Screening Update**

On April 3, 2006, Ontario increased the current newborn screening from 2 tests (PKU and Congenital Adrenal hypothyroidism) to 3 with the addition of MCADD (Medium Chain Acyl-CoA Dehydrogenase Deficiency). Ontario will screen newborn babies for up to a total of 27 disorders by the end of 2006.

For more information, visit:

The Ontario Newborn Screening Program : www.health.gov.on.ca/newbornscreening

# Resources

- **Fabry Society of Canada**
  www.fabrysociety.org Youth area: www.fabrysociety.org/youth.html
- **Maple Syrup Urine Disease**
  www.msud-support.org

**Spring/ Summer 2006** **Volume 3 Issue 2**

# Announcements

## Metabolic Family Day 2006

The 3rd annual Metabolic Family Day was held on Friday May 5th 2006 at the Lamplighter Inn on Wellington Road, London. The purpose of this special day was to bring families together that have a child or relative with a rare metabolic disorder. Metabolic disorders (also called inborn errors of metabolism) include many disorders that are usually the result of a lack of or dysfunctional enzyme required for cell metabolism. This day provided an excellent opportunity to share information among families and professionals. Families also had the chance to make connections with other families who have the same or a similar disorder, as well as interact with speakers, learn about different metabolic formulas and foods, see what's new with treatment and research, visit displays of metabolic food products and learn about the resources available in their community. Attendance has doubled in the last three years to over 150 family and guest participants.

This year there were 3 group sessions:

1) Diet group which included disorders such as PKU (phenylketonuria), OTC deficiency (ornithine transcarbamylase deficiency) among others.
2) Neurological aspects of metabolic disorders
3) Lysosomal storage disorders

Keynote speaker, Professor Joe Clarke, Director of Metabolism, Hospital for Sick Children Toronto, spoke to the entire group about the treatment of metabolic disorders. It was a great opportunity for the families to meet with Dr Clarke as he has provided clinical care to a number of our patients. The attendees then split into the three groups for concurrent sessions. Dr. Simon Levin, Children's Hospital of Western Ontario, spoke to the neurology group about seizures, epilepsy & metabolic disorders

The wrap up session was led by Dr. Tony Rupar, CPRI Laboratory Director. He and Dr Clarke gave the group latest information on newborn screening.

On Saturday May 6th 2006, 35 family members and professionals watched a low protein cooking demonstration from Erica Lesperance, Registered Dietitian from Cambrooke Foods (Boston). She prepared many delicious low protein products using medical foods, fresh fruit and vegetables, which the families were able to try. This event has become an integral part of our metabolic family day under the leadership of Suzanne Ratko (Dietitian). We were very pleased to see families from Hamilton join this year as well.

Sarah Foster (Applied Nutrition, has PKU) left, Laura Ridout (has PKU), centre, Suzanne Ratko (Dietitian) right

**Spring/ Summer 2006** **Volume 3 Issue 2**

## A Parents Perspective – Sarah Faulds

On May 5th, the Lamplighter Inn in London was the perfect setting for the 3rd annual Metabolic Family Workshop. Over 150 participants enjoyed displays, food samples, a recipe exchange and speakers.

Dr. Joe Clarke from the Hospital for Sick Children in Toronto began the afternoon with a detailed overview of some of the most common metabolic disorders. Following this, concurrent sessions were provided for three groups – diet management, neurological issues and lysosomal storage disorders. In the diet group, we heard about a G-tube success story. We also heard from two families about their individual challenges with PKU and the diet for life principle. Erica Lesperance a dietitian from Cambrooke Foods provided some very practical tips on handling special diets for school age children. Joanne Weir from CPRI and Suzanne Ratko dispelled some myths about the route that blood samples take. The session was concluded by Dr. Tony Rupar who reviewed the revised newborn screening protocols.

Having played a very small part in the planning of this day, I know how hard the Metabolic Team worked to organize this event. Many thanks also to parent volunteers Jennifer Culp and Samantha Smith for organizing the kids entertainment room and helping to obtain speakers and displays.

This event served as a reminder to our family as to how fortunate we are to be under the care of the Metabolic Team at Children's Hospital of Western Ontario.

Low protein cooking demonstration

All successful events require the time and energy of a number of dedicated individuals. Our grateful acknowledgements are extended to Children's Health Foundation, Garrod Association of Canada, Genzyme, Ross Metabolics, Cambrooke Foods, Mead Johnson Nutritionals, Applied Nutrition, Vitaflo, Nutricia North America (SHS), PKU Perspecitves, BARD and National Food Distribution Centre as well as the Metabolic Team at LHSC, administrative staff, genetics support staff, speakers, members of planning committee (which also included four mothers of children with inborn errors of metabolism), patients, families and many volunteers. Jennifer Culp's (one of our PKU moms) organized the room for children's care and was very much appreciated by all the families.

***"SANDRA DAY O'CONNOR***

***We don't accomplish anything in this world alone ... and whatever happens is the result of the whole tapestry of one's life and all the weavings of individual threads from one to another that creates something."***

Spring/ Summer 2006 Volume 3 Issue 2


Samantha (age 5, artist of the picture) and Vanessa, sisters with hyperPhe

## Contact Information

**Editor:** Janice Little
**LHSC -** Medical Genetics Program of Southwestern Ontario
**Tel:** 1.800.243.8416
1.519.685.8453

**Email:** janice.little@lhsc.on.ca
**Website:** www.lhsc.on.ca/ programs/rmgc/met/metaboli.htm

**Yahoo Online Chat:** health.groups.yahoo.com/group/metabolic_disorders
**Post Message:** metabolic_disorders@yahoogroups.com

**Parent Support Contact:** Jennifer Culp

**Tel:** 1.519.632.9924

**Email:** donjen2000@hotmail.com