The Inherited Metabolic Disorders News

Children's Hospital
London Health Sciences Centre

Summer 2015 Volume 12 Issue 2

In this Issue

From the Editor

It's hard to believe that we held our 11th Metabolic Family Workshop and Low Protein Cooking Demonstration in May. Once again they were a huge success. See the section "What's New" for a full report of the events, as well as pictures.

Thank you to many of you who have shared your emails so that we don't have to send printed copies of newsletters. Please send me your email address if you haven't already done so.

As always, your suggestions and stories are welcome. You may contact me anytime by email - **janice.little@lhsc.on.ca**

I hope everyone has a safe and happy summer!

Janice Little

From Dr Chitra Prasad

Dear Friends,

I hope you all are enjoying the beautiful weather. Our 11th metabolic family workshop went off very well. My sincere thanks to the metabolic family workshop planning committee, speakers, volunteers, sponsors, service groups, Children's Health Foundation and many other individuals who make this event a grand success. The visiting speakers from Children's Hospital of Eastern Ontario Ottawa Dr. Pranesh Chakraborty and Dr. Beth Potter shared their insights with us about different aspects of metabolic disorders. Families and children enjoyed the different workshops, art therapy and child life therapy which were new additions to this year's Metabolic Family Workshop.

This newsletter brings a journey of hope for many patients and families. A few years ago we brought you a story of our young friend Stefan who has Morquio disorder, a condition that causes dwarfism (short stature) and many other medical issues. Stefan has remained active and he has done well in his school and extracurricular activities despite his challenges. We are also very privileged to have the story of two young men (brothers) with Morquio disorder Lucas and Zane. They were initially diagnosed in London and have since been receiving treatment in Toronto. All three of them were participants in the research trial of VIMZIM ® (elosulfase alfa) enzyme replacement therapy. That required lot of commitment and travel back and forth to Toronto for a couple of years for both the families. Enzyme replacement therapy is now available to all three of them at their own respective homes. Verica (Stefan's mom) and Debbie (Lucas and Zane's mom) share lot of courage and commitment. You can read their inspiring stories in the newsletter.

From Dr Chitra Prasad - continued

I attended the Garrod association meeting in Vancouver, one of my favorite places to visit. Dr. Sylvia Stockler is now the president of Garrod association. Our metabolic community of physicians and professionals interested in inborn error of metabolism is growing. Newer therapies are on the horizon which will bring new hopes for healing and may be even cure for some of the metabolic conditions. Parent and family support groups such as ours are in the forefront to guide the funding agencies, physicians and government.

With hopes for ongoing collaborations!

With best wishes
Your friend
Chitra Prasad

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence." Helen Keller

Personal Stories

Reprinted from Winter 2008 newsletter

In January 1995, my husband, my son Boris, and myself arrived in Canada. We were fortunate to escape the civil war in the former Yugoslavia. We decided to settle in London and start a new life. We were so thrilled to be in Canada and when our second son Stefan was born in January of 2000 life seemed perfect. He was a healthy baby until the age of two. Around his second birthday, Stefan started to get sick more frequently and his growth slowed down. My husband and I were worried about our baby's declining health and embarked on an odyssey of hospital visits. In 2003, Stefan was diagnosed with Morquio Type A at the London Children's Hospital. At first we did not understand the significance of the diagnosis. We had never come into contact with Morquio before and the consequences of the diagnosis took a while to sink in. Once we understood what having Morquio meant for our baby's future, we were devastated. What kind of life would Stefan lead?

Stefan will be turning 8 in a few weeks. He is an energetic and rambunctious child in spite of the limitations that his condition imposes upon him. This summer, he had cervical fusion surgery to stabilize his neck and he was required to wear a halo for 3 months. A few weeks after the surgery and with the halo supporting his neck, he was trying to play soccer in the backyard! He is aware that he is different from his classmates at Kensal Park Public School but he does not allow that to affect his

Stefan - 8 years old

Personal Stories - continued

confidence or influence his quality of life. Due to his sunny disposition, Stefan has plenty of friends and is always involved in school activities. The students and staff at Kensal Park are tremendously supportive of Stefan and his needs. Like many boys his age, Stefan loves to watch baseball, soccer, and hockey. He is doing well in school and his teachers continuously praise his intelligence and wit. Although our life has changed in many ways since Stefan was diagnosed with Morquio, it has not been the negative experience we expected it to be. Thanks to the dedicated scientists who are working on enzyme replacement therapy to counteract the effects of Morquio, we believe that Stefan will have a bright and exciting future! We are grateful that we are in place where Stefan can get the care and support he needs to lead a fulfilled life.

Fast Forward to 2015 ...

Health Canada Approves Drug for Rare Disorder but will Ontario?

By Jennifer Palisoc
Reporter, Global News

TORONTO - Stefan Gacic, 14, was diagnosed with Morquio A Syndrome and said it was hard for him to get out of bed.

But a few years ago he began taking part in clinical trials for a drug called Vimizim which breaks down the complex sugars, helps reverse some changes to his body, and stops the disease from progressing.

"Overall patients have reported improved endurance, energy levels, well-being, maybe less symptoms of pain or stiffness and generally feeling better," said Dr. Raiman.

Watch the video and read the full story here:
http://globalnews.ca/news/1518597/health-canada-approves-drug-for-rare-disorder-but-will-ontario/

Stefan receiving Vimizim

Personal Stories - continued

Hi there my name is Debbie Braun and I am the mother of two of the most incredible little men. My sons Mitchell "Lucas" Braun and Zane Murray Braun. Both my sons were born with MPS IVA or Morquio Syndrome. After the boys diagnosis almost 16 years ago our lives have been an incredible rollercoaster of ups and downs and twists and turns. But our lives are full of love and lots of laughter and we are very blessed to have great doctors and people in our lives. Both boys have had many corrective surgeries over the years and between the two of them have had 11 orthopedic surgeries to help keep them walking and mobile. We see a series of 9 different specialists at the Hospital for Sick Children in Toronto and currently since Lucas turned 18 we are being followed by a new series of doctors in the greater Toronto area. When the boys were diagnosed there was very little information or even talk of treatments or a cure for their disease we were told to take them home and enjoy the time we would have with them. I can tell you from a mother's point of view my heart was broken but we picked ourselves up and enjoyed every day for each day. Almost 4 years ago we received a phone call from our metabolic genetic specialist at SickKids Dr. Julian Raiman. We were asked to join a new trial for an enzyme replacement therapy drug to help treat the boy's condition. We were nervous and excited to be a part of such a ground breaking trial. The trial involved driving to Toronto weekly to stay over for treatments of an experimental drug now called Vimizim. The boys were on a double blind study which meant they were either on drug weekly or bi weekly or on placebo. We have since found out the Lucas was on placebo for the first six months and then a biweekly dose for the next six months and Zane was on the biweekly dose for the first year. Since January 2012 they have both been on weekly doses of the new drug. We have certainly noticed a marked improvement in the boys mobility and endurance and the progression of the disease has certainly slowed down. It of course will not reverse any of the affects that have already occurred with the boys but as their mom I have noticed great changes in the boys abilities and we have a new found sense of hope with this new drug. Both boys are typical teenage boys playing lots of playstation and video games but they enjoy riding their bikes, playing ball, and going to the beach. We are an active Easter Seals family helping kids with physical disabilities get much needed equipment and the ability to go to fully accessible camps. Lucas was the ambassador for the year 2010 in which we travelled all across the province helping raise funds and awareness and since 2011 I now sit on the board of directors as a parent representative. We are also involved in our local community by sitting on the accessibility committee to help get awareness for an accessible province. Lucas will be finishing up his grade 12 in the next year and a bit as he missed a lot of school while part of the trial and Zane is entering grade 11 this fall. I could never be more proud of my two little men and the way they have impacted my life and the many others around them. They always smile and are full of life; they take nothing for granted and live each day to the fullest.

Featured This Issue

Morquio Syndrome

Summarized by
Dr. Chitra Prasad

Morquio A is a rare inherited disease that affects major organ systems in the body. The disease is a form of mucopolysaccharidosis (MPS). The MPS are a group of inherited lysosomal storage disorders. Lysosomes function as the primary digestive units within cells. People born with Morquio A can't break down glycosaminoglycans (GAGs) molecules because their bodies don't make enough of an enzyme, or protein, called N-acetylgalactosamine-6 sulfatase (GALNS). This enzyme breaks down or recycles materials the body can't use. When the body doesn't produce enough of the enzyme, GAGs build up in tissues, bones, and major organs. GAGs cause serious problems, including heart disease, skeletal abnormalities, vision and hearing loss, difficulty breathing, and in some cases early death. Children with Morquio syndrome show marked growth retardation from early in life. The elbows, wrists, hips, knees and other large joints are abnormally flexible, causing overall instability. Early development and intelligence are typically normal. High frequency hearing impairment is common.

Morquio syndrome is an autosomal recessive genetic disorder. The risk for two carrier parents to both pass the altered gene and, therefore, have an affected child is 25% with each pregnancy. Diagnosis is suspected by excessive amounts of keratan sulfate in the urine. The diagnosis is confirmed with the finding of a deficiency of N-acetylgalactosamine-6-sulfatase (type A) in blood or skin cells and also by DNA based testing.

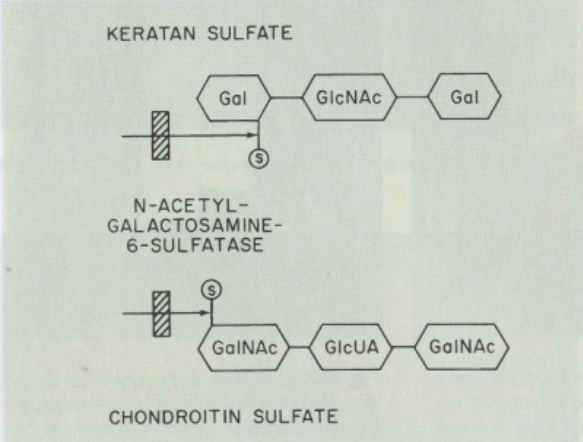


Fig. 76.1 *N*-Acetylgalactosamine-6-sulfatase and the degradation of keratan sulfate. This is the site of the defect in type A Morquio syndrome. The enzyme also hydrolyzes the sulfate from the *N*-acetylgalactosamine-6-sulfate moieties that occur in chondroitin-6-sulfate.

Atlas of Metabolic Diseases by Nyhan, WL & Ozand, PT

The management in the past has mostly been supportive. In 2014, The U.S. Food and Drug Administration (FDA) approved Vimizim (elosulfase alfa), as the first FDA-approved treatment for Morquio A syndrome. Vimizim, marketed by BioMarin Pharmaceutical Inc., is an enzyme replacement therapy for the missing GALNS enzyme.

References:

http://www.morquiosity.com/

https://rarediseases.org/rare-diseases/morquio-syndrome/

Suzanne's Corner

BuPHElo Wings

Serves 6

Cauliflower is used as a chicken substitute for a Low Phe version of the ever-favorite Buffalo Wing. The same sauce is used to coat the florets, which are then further coated with Low Protein Bread crumbs and baked, not fried.

Ingredients:

- 1 small head cauliflower, separated into bite-sized florets (about 5 cups)
- 4 tablespoons butter, melted
- 5 tablespoons Tabasco Buffalo Sauce (or similar hot sauce of your choice)
- 1 tablespoon cider vinegar
- ½ teaspoon garlic powder
- ½ teaspoon smoked paprika
- salt and ground black pepper, to taste
- 2 cups Low Protein Bread crumbs
- ½ cup chopped green onion
- ½ cup Low Protein Mozzarella Shreds

Directions:

- Preheat the oven to 375° F.
- Prepare a baking sheet lined with parchment paper.
- In a small bowl, add the melted butter, hot sauce, cider vinegar, smoked paprika, garlic powder, salt and pepper. Stir to combine.
- Place the Lo Pro Bread crumbs in a small, shallow bowl.
- Make an assembly line with the cauliflower florets, the sauce and the bread crumbs.
- Use one hand to dip the florets into the sauce then drop it into the crumbs.
- Using the other hand, coat the floret well with the crumbs and place it on the baking sheet.
- Once all of the florets are coated, use a very light spray of cooking oil to coat the tops. This will help hold the crumbs in place, as well as aid in their browning. (I use a cooking spray atomizer instead of the aerosol cans.)
- Place the baking sheet into the preheated oven and bake for 20-25 minutes, or until the crumbs are golden brown.
- Remove the baking sheet from the oven. If you have any remaining sauce, it can be lightly brushed onto the tops of the florets.
- Serve hot with Ranch or French, carrot and celery sticks.
- Garnish by sprinkling chopped green onion and mozzarella shreds on top.

Serving Size: 5 pieces Protein (gm): 2.3 Phe (mg): 83

Recipe by Chef Kevin Brown: kbrown@nicoletcollege.edu

By Olivia Faust

Accomplishments

Cameron

Medway's Camaron Jabbar hugs Lee Janzen as they celebrate Jabbar's first-place finish in a powered wheelchair race at the Thames Valley District School Board's Special Olympics at TD Waterhouse Stadium in London.

Craig Glover – The London Free Press

Bon Travail Annabella!!

Annabella is very proud to show off her achievements from this past school year. Annabella was awarded a recognition certificate for French at the end of year assembly.

Though she is enjoying her summer, Annabella is looking forward to many more awards in grade three.

What's New

thePage
LHSC Online Staff Newsletter

Metabolic Family Workshop 2015

The 11th Metabolic Family Workshop was held on May 8 at the Best Western Lamplighter Conference Centre, bringing together families from across Ontario all facing similar challenges related to metabolic disorders for a day of learning and sharing.

Metabolic disorders, also referred to as inborn errors of metabolism, are multi-systemic in nature, and children and adults living with them can have problems with growth, developmental delays, and issues with organs such as the heart and kidneys, brain and others. These disorders can require special restrictive diets, as well as enzyme replacement therapies, medications and organ transplant. The metabolic section at LHSC currently treats close to 500 patients with metabolic disorders. Families in attendance were invited to interact with speakers, learn about various metabolic formulas and foods, see what is new with treatment and research, visit displays of metabolic food products and learn about the resources available in their community. The day also provided an excellent opportunity for families to talk with each other, share their experiences and make a few friends along the way. The day opened with greetings from Dr. Chitra Prasad, Director of Metabolic Clinic and Bob Giorgini, Director, and Partner Liaison for the Children's Health Foundation. The foundation's sponsorship as well as sponsorship from several other companies ensures that families do not need to pay to attend.

Guest speakers throughout the day covered topics such as therapies and their impact on metabolic disorders, coping strategies and adult resiliency. Dr. Pranesh Chakraborty, Director of Newborn Screening Program at the Children's Hospital of Eastern Ontario and Dr. Beth Potter, Associate Professor School of Epidemiology, Public Health and Preventive Medicine University of Ottawa were the invited speakers. Dr. Julie Richard, a psychiatrist at LHSC, led the discussion on adult resiliency.

What's New - continued

The following day a low protein workshop was conducted under the leadership of Suzanne Ratko (dietitian). Chef Kevin Brown gave hands on demonstration to families with PKU (Phenylketonuria) and other diet related disorders.

Staff from LHSC's Art Therapy and Child Life programs were on hand to work on activities and projects with the children and teens in attendance.

The family presentations included Lama Kadri, a young woman with PKU, who shared with the group her success story of how she managed her health and dietary control, and now helps others as an RPN. Justin Massicotte, a young boy with mucopolysaccharidosis 1 who has had cord cell transplant, corneal transplant shared a video of him performing his new hobby - breakdancing.

Young Jasper More became the star of the workshop without even setting foot on stage. Jasper's parents, Darren and Pam, shared a 'Day in the Life' video to demonstrate that despite Jasper's diagnosis of MPS VI, a rare lysosomal storage disease, their family is just like any other.

"Jasper is a little boy who happens to have MPS VI," says dad Darren. "But he is still Jasper. His illness doesn't define him." Jasper's video showed the realities of living with a metabolic disorder – I.V. enzyme replacement therapy every week with visits from Child Life specialists to help pass the time in hospital while waiting for lengthy treatments to finish. But more importantly than that, the video showed an active boy who loves the outside, playing sports, dancing and singing. There were few dry eyes as Jasper broke out into song at the end of the video, singing a favourite John Denver song "I Want to Live" that summed up perfectly the theme of the day.

"I want to live, I want to grow, I want to see, I want to know, I want to share what I can give, I want to be, I want to live."
Dr. Prasad expressed her sincere gratitude to Dr. Tony Rupar (Biochemical Laboratory Director), event sponsors, Children's Health Foundation, parents, families, the entire metabolic teamand volunteers - in particular Jennifer Culp - mother of a PKU child who for 11 years has run the day care for children at metabolic family workshop. In Dr. Prasad's words "the success of this workshop for last 11 years is due to the belief, the hard work and dedication of many. We have established a unique model of metabolic family workshop here in London that is now being emulated by others in the country."

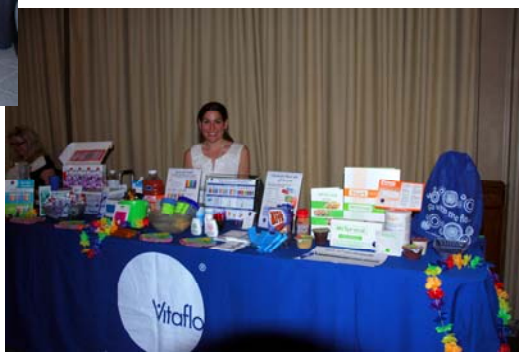
Justin

Jasper

The organizing committee and special guests of the Metabolic Family Workshop.
This years attendance was 144 family members, speaks and guests.

A special thank you to Kathy Lucas for being the workshops official photographer, all of our Volunteers and Sponsors, to Justin Massicotte for his "Dancing Wizard" video and Jasper More for his"A Day in the Life" video.

Metabolic Family Workshop 2015



Lama Kadri - Speech given at the 2015 Metabolic Family Workshop

Hello, my name is Lama Kadri; I've been living with PKU for 24 years, and today I'm going to tell you a little bit about my journey from my diagnosis to where I am now. Here it goes, this is the story of my journey into independence while living with PKU. I was diagnosed with classical PKU when I was about 10 days old. I'm sure at first my parents, like all parents would have been, were devastated that the doctors were telling them that their perfect child was not so perfect after all. PKU was new to them, they had no clue what this meant for my future, nor did they have any clue how to care for a child with PKU. Luckily they had the support of the metabolic team here in London, helping them along the way, but the challenges they faced were something more than just PKU, they also had the added challenge of a stubborn child (that would be me) who always wanted things her way. My parents went into research mode, trying to learn everything they could about PKU, and also getting our entire family on board (my siblings included). They say it takes a village to raise a child, well it took a village and then some to make sure that I stuck to my diet.

As a toddler, I was very dependent on my mother and family members to keep track of my diet, understandably so, but my parents knowing that the first 10 years of life are so crucial to brain development really tried very hard to ensure that I adhered to it. This is where that village and then some I was telling you about comes into play. Not only were my parents constantly monitoring my diet, but they had my siblings, my aunts, my cousins, even close friends and their parents watching me like a hawk. My mother would always make my formula for me and would prepare all of my food. Growing up my biggest struggle was drinking my formula, I didn't like the taste of my formula and really didn't understand why I had to drink it. My mother would sometimes have to spoon feed it to me, and on some occasions my siblings would join in trying to encourage me to drink my formula. But I also struggled with keeping my diet at a young age, I sometimes didn't quite understand why I wasn't able to eat all of the same things that my siblings, cousins, and friends would eat. And me being that stubborn child, made everyone have to work twice as hard at keeping me on track. Needless to say, my mom had a full-time job just making sure that I was following my diet. I remember a time when I was little, my sister saw me eating peanut butter, and just as she was trained to do she saw me and immediately went to tell my mom. The moment my sister told my mom, my mom put me in the car and rushed me to London hospital just to make sure that I was okay.

My mom always went out of her way to make sure I did not feel different from everyone else. She would always make sure that the meals she made for me were the same as what the family was eating, just made with my own low protein ingredients. For example if she made pasta for everyone she would make me some pasta with my own special noodles, this

helped me feel like I was eating the same food as everyone else. I didn't really understand my diet restrictions fully. Until about the age of 10, I was very aware of what I should and should not be eating. The foods I would eat would be low protein, but that didn't mean that I was keeping track of my phe intake. My mother would constantly be on me, checking what I was eating and telling me how much of each thing I should be eating, but again, I would often overdo it. As I started to better understand what I can eat and why I can't eat it, I finally took charge and started to make my own formula. I still needed reminders and was not very good at always drinking it but I was trying. I even started being proactive in helping make my meals.

Keeping my diet perfectly and drinking my formula has honestly been a difficult thing and something that I struggled with up until quite recently. Up to about year ago I was still struggling with my diet. One day it just hit me I am going to be a Registered Practical Nurse. My job is going to be telling people how to take care of themselves and I was not doing a good job of keeping myself on track with my diet. So I called Suzanne my dietician and told her I need to know what I can do to lower my blood levels and how much Phe I should be having per day. She was very helpful and gave me some good tips. Now, I drink my formula regularly, count my foods and eat a lot of fruits and vegetables. I started to be healthier in all aspects of my life, I work out daily and I am significantly more active. I keep a food journal where I count my Phe intake for the day and even my calories. I started to examine the food labels closely, and cut out a lot of things that I used to eat daily like potatoes and chips, which for me were a really big thing. Now when I go to a restaurant with friends I look for healthier options and usually they are very accommodating in substituting things I can't have for things that I can. I am now making a lot of low protein healthy choices like cauliflower pizza, cauliflower shepherd's pie and zucchini pasta. They taste pretty good to my surprise!

To leave you with a few words, keeping your diet is tough but it is not impossible. The important part is being ready, willing, and asking for help when you need it. If you are struggling talk to someone who can help you, there are so many resources available to us from our supportive families, to the supportive team here at LHSC-metabolic disorder team. Though my success was self-driven, there are so many individuals that make up that village that helped me get to this point. These individuals never stopped getting on my case, they kept at it and remained motivated to get me on track even when I was most resistant.

If anyone has any questions, please feel free to ask.

Save the Date 2016!

Metabolic Family Workshop
Friday, May 13th

Low Protein Cooking Demonstration
Saturday, May 14th

In Memorandum

Jennie Belinda Verbeek, a long time member of the metabolic community, passed away unexpectedly on Thursday, June 11, 2015 at the age of 41. Jennie will be missed by the entire metabolic group for her ever smiling face, her creativity and her enthusiasm for participating in the Metabolic Family Workshops. The Verbeek family has kindly donated to the Children's Health Foundation and Metabolic program in memory of Jennie.

Goodbye to Kara, Welcome to Rana

Kara Bigelow, medical secretary for the last year in metabolics, has re-joined the pediatric neurology department. Good luck to Kara in her new role!

Hello! My Name is Rana Elshourafa and I'm the new medical secretary working with the Metabolic Team. I started working with Genetics April 2011 with the prenatal genetics team. I am very excited and looking forward in joining the Metabolic team.

Inspirational Quotes

1. *Life isn't fair, but it's still good.*
2. *When in doubt, just take the next small step.*
3. *Life is too short to waste time hating anyone. Change the way you think.*
4. *Your job won't take care of you when you are sick. Your friends and family will. Stay in touch.*
5. *Pay off your credit cards every month..*

From Melanie - Learning About Mitochondrial Disorders

Hello Everyone,

I recently attended “Mitochondrial Medicine: 2015” in Herndon, Virginia. This conference is hosted by the United Mitochondrial Disease Foundation (UMDF) and allowed me an opportunity to learn about new and ongoing research as well as patient advocacy groups and their available resources. There were many great talks given by leaders in the field of mitochondrial medicine. Here are a few highlights of the meeting that I hope interest you.

Dr. John Christodoulou’s group in Australia is working to validate a new test and determine how useful it is in diagnosing mitochondrial disease. At the current time there are very few non-invasive blood tests a doctor can order that are helpful when they suspect a patient has mitochondrial disease. The proportion of individuals with mitochondrial disease who are correctly identified by the current screening ranges from approximately 15-70% based on which test and how the sample is collected. Preliminary results indicate that there may be an 85-90% chance of correctly identifying a patient with mitochondrial disease with these new tests, which would hopefully result in a person being referred to a mitochondrial/ metabolic disease clinic sooner.

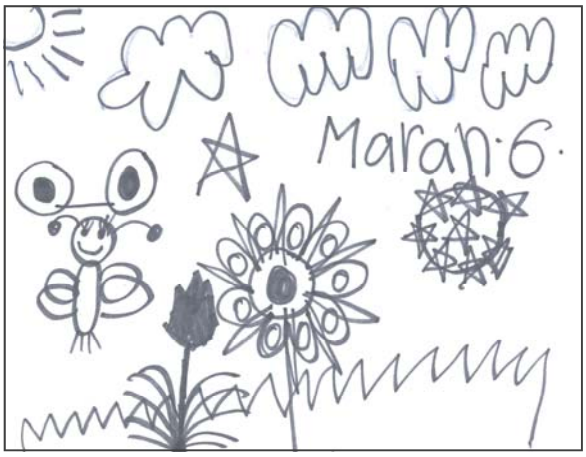
Dr. Carlos Moraes’ group in Florida is developing a process to remove disease-causing mitochondrial DNA mutations from affected mitochondria in cells. Initial laboratory studies using a common MELAS mutation have shown that the mutation can be removed and complex I activity returns to normal. This research needs more work to determine if there can be applications for future gene therapy for patients. Dr. Peter Stacpoole’s group in Florida has developed an innovative, survey -based computer tool for parents to track how their children with Pyruvate Dehydrogenase Deficiency feel and function in their home environment. This tool will be used in an upcoming clinical trial to help identify changes that a parent may notice in their child that cannot necessarily be measured by a medical test. Parents were involved in the making of this survey so it is user-friendly and uses words that families use to describe symptoms, rather than medical terms. This tool is the first to be developed for mitochondrial disease and is hoped it can be used in the future when more clinical trials for mitochondrial disease become available.

The North American Mitochondrial Disease Consortium (NAMDC) is recruiting individuals with mitochondrial disease for the purpose of establishing a registry to learn about the spectrum of mitochondrial disorders, their prevalence and how these diseases progress, which is not well understood. There are also options for individuals to enroll into a registry to be contacted when clinical studies become available and receive information from awareness groups. There are currently 790 patients who have self-enrolled. If you are interested in learning more, the websites are below:

http://www.rarediseasesnetwork.org/namdc/studies/7401.htm
http://www.rarediseasesnetwork.org/namdc/register/index.htm

I recommend that you check out the UMDF website (www.umdf.org), as well as MitoCanada (www.mitocanada.org). These websites have great information about mitochondrial disease, advocacy and support resources. Feel free to contact me if you have any questions, or speak with me at your next clinic visit.

Sincerely,
Melanie Napier, MSc, CGC, CCGC
Genetic Counsellor



Maran - age 6

How to Make a Donation

Donated funds are used for future Metabolic Family Workshop Days as well as further research, teaching and education. If you wish to make a donation, please do so through Children's Health Foundation at; www.childhealth.ca, and simply "click" on the Donate Now button at the top of the page.

There are many ways to make a donation, from a single donation, to a donation in honour of someone special, to becoming a Caring Hearts monthly donor. Whatever you chose, simply follow the prompts and you will taken through the steps which will include a comment box, where you can instruct your donation to go to the Inherited Metabolic Disorders program. Alternatively, if you would like to donate by phone with your credit card, please call 519.432.8564 or toll-free at 1.888.834-2496, Monday to Friday, 9 am to 5 pm. An tax receipt will issued with donations.

Thank you for your support.

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: http://www.lhsc.on.ca/Patients_Families_Visitors/Genetics/Inherited_Metabolic/index.htm

Parent Support Contact: Jennifer Culp

Tel: 1.519.632.9924

Email: jennc2011@hotmail.ca