

From the Editor

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Welcome to the latest edition of the Inherited Metabolic Disorders News! Please feel free to contact me with story ideas and comments! We continue to take emails for electronic communication. Please email janice.little@lhsc.on.ca to provide your email address.

Janice Little

From Dr Chitra Prasad

Dear Friends,

Greetings! Hope you all are enjoying the beautiful summer. I thank you all for your contributions and messages. Thank you also for providing your emails so that we are saving paper and trees. Janice has been sending newsletter on email for many families now. Those of you who are still receiving on paper and would like to get these newsletters on emails kindly let Janice know at Janice.Little@lhsc.on.ca.

We plan to hold the next metabolic family workshop on Friday May 12th 2017 and low protein cooking demonstration on Saturday May 13th 2017. Please mark these dates in your calendar. We will be having the metabolic family workshop every two years. This will help us plan and organize better. We would love to see you there! There have been many accomplishments and achievements. Dr. Tony Rupar PhD FCCMG our Metabolic Laboratory Director is now a full Professor at the Western university. Congratulations Dr. Rupar!! Our group continues to collaborate with other specialties and physicians. You will read about this in the story in our newsletter. Teaghan's family has described their journey of diagnosis of acid lipase deficiency by Dr. Ashok Dhandapani Paediatric gastroenterologist and how the new enzyme replacement therapy Sebelipase alfa is being organized. These therapies are new and expensive and require collaboration of the professionals, hospital administration, government and industry and patient support groups. On another note I had to say good bye to my friend and colleague Dr. Sharan Goobie. Many of you know her as a very compassionate and brilliant physician. She has moved to Halifax and will be missed here! We recently had our Garrod meeting in Halifax. I met many of my old friends and colleagues. Some of you might remember Dr. Mark Korson who had come here a few years ago to our workshop. He was my mentor in Boston. He is now educating many physicians in USA and other countries about metabolic disorders. Dr. Korson also firmly believes in educating the families. I hope you will enjoy the newsletter. Please share your suggestions, your accomplishments and your ideas.

With best wishes - Be well (as Dr. Korson says)
Have a safe summer
Your friend
Chitra Prasad



Dr. Chitra Prasad & Dr. Mark Korson

"Finish each day and be done with it. You have done what you could. Some blunders and absurdities no doubt crept in; forget them as soon as you can. Tomorrow is a new day. You shall begin it serenely".

— Ralph Waldo Emerson

The Inherited Metabolic Disorders News



Halifax Waterfront



Peggy's cove

Personal Stories



Teaghan's story

Teaghan suffers from a very rare inherited metabolic liver disease called Lysosomal Acid Lipase Deficiency (LAL D). Teaghan's body does not produce enough active lysosomal acid lipase (LAL or LIPA) enzyme. This enzyme plays an important role in breaking down fatty material (cholesteryl esters and triglycerides) in the body.

Teaghan has endured numerous blood tests, ultrasounds, specialist appointments and a liver biopsy. On June 3, 2015 our lives were changed forever! It was the day that Teaghan was diagnosed with LAL D. No words can describe the rage and despair that we felt when the doctor gave us the results. Our world came crashing down before us.... a parent's worst nightmare is finding out that you may outlive your child. The worst feeling in the world is knowing that we can't make it all better! There is currently not a cure for this life threatening disease in Canada, however there is an enzyme replacement called Kanuma (Sebelipase alfa) that has recently been approved in Europe, the United States, and most recently in Japan.

Personal Stories - continued

We filled out paperwork with Health Canada to have Special Access to Kanuma, and we were granted up to 6 months access; however since Kanuma is an orphan drug, it is very expensive. We are working with the Government and the drug manufacturer to try to get approval and funding for the enzyme replacement drug. We promised Teaghan that we would get Kanuma approved AND funded in Canada, so that her life and the handful of others Canadians that suffer with LAL D can be saved. Not to mention the numerous others who have not yet been diagnosed, or that have been misdiagnosed as having fatty liver disease.

We started an online petition <https://www.change.org/p/health-canada-approve-sebelipase-alfa-so-that-my-daughters-life-can-be-saved> to try to bring awareness to this underdiagnosed disease. I have spent countless hours researching, finding contacts, other patients and resources to make our goal become a reality. I promised Teaghan that we would get this enzyme replacement for her, and we will not stop until we succeed!

Kind Regards,
Lisa Gearey



Featured This Issue

Acid Lipase Deficiency

Summarized by Dr. Chitra Prasad

Lysosomal acid lipase (LAL) deficiency is a rare disorder. The presentation ranges from the infantile-onset form (Wolman disease) to later-onset forms collectively known as cholesterol ester storage disease (CESD).

Unfortunately Wolman disease is very severe and presents with liver disease and adrenal gland calcification that results in adrenal cortical insufficiency in infancy. Unless successfully treated with hematopoietic stem cell transplantation (HSCT), infants with classic Wolman disease do not survive beyond age one year.

CESD may present in childhood in a manner similar to Wolman disease or later in life with such findings as serum lipid abnormalities, hepatosplenomegaly, and/or elevated liver enzymes long before a diagnosis is made. Main problems can arise with atherosclerosis (coronary artery disease, stroke), liver disease (e.g., altered liver function \pm jaundice, fatty liver, fibrosis, cirrhosis and related complications of esophageal varices, and/or liver failure), complications of secondary hypersplenism (i.e., anemia and/or thrombocytopenia), and/or malabsorption. Individuals with CESD may have a normal life span depending on the severity of disease manifestations.

Diagnosis of LAL deficiency is suspected in individuals with characteristic clinical findings such as hepatomegaly, elevated transaminases, and a typical serum lipid profile: high total serum concentrations of cholesterol, low-density lipoprotein, and triglycerides; and low serum concentration of high-density lipoprotein. The diagnosis is confirmed by identify cation of either biallelic pathogenic variants in *LIPA* or deficient LAL enzyme activity in peripheral blood leukocytes, fibroblasts, or dried blood spots.

Treatment of CESD includes reducing cholesterol through the use of statins, cholestyramine, and a diet low in cholesterol and triglycerides. Aggressive reduction of a dditional cardiovascular risk factors and lipophilic vitamins may also be beneficial. Consulting with a nutrition team for children with failure to thrive or adults with weight loss may be considered. Liver transplantation may be indicated when liver disease progresses to cirrhosis and liver failure.

Prevention of primary manifestations: Successful hematopoietic stem cell transplantation can correct the metabolic defect. Management includes reevaluating every 6-12 months depending on disease severity. Monitoring of nutritional status is important. Regular evaluating with fasting lipid levels, platelet count, and liver enzymes routinely should be done. For children and adults: monitor hepatosplenic volume and screen for hepatocellular carcinoma with serial liver and spleen imaging.

LAL deficiency is inherited in an autosomal recessive manner. Each sibling of an affected individual has a 25% chance of being affected, a 50% chance of being an asymptomatic carrier, and a 25% chance of being unaffected and not a carrier.

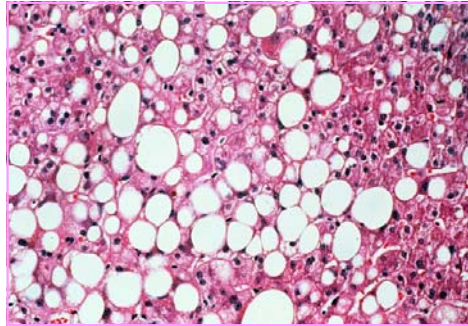
Carrier testing for at-risk family members and prenatal diagnosis of pregnancies at increased risk are possible if the *LIPA* pathogenic variants in the family have been identified.

Featured This Issue - continued

Recently enzyme therapy Sebelipase alfa has become available for acid lipase deficiency. Long term studies and follow up is essential. Preliminary data appears to be promising. Dr. Ashok Dhandapani (paediatric gastroenterologist) has been instrumental in trying to initiate enzyme replacement therapy for Teaghan. We are hopeful that Teaghan will be able to start the enzyme replacement therapy soon.

Ref: Gene reviews: <http://www.ncbi.nlm.nih.gov/books/NBK305870/>

Paton DM. Sebelipase alfa: enzymatic replacement treatment for lysosomal acid lipase deficiency. *Drugs Today (Barc)*. 2016 May;52(5):287-93.



Infants with LAL deficiency accumulate cholesterol esters and triglycerides in the lysosomes of liver cells
Mark Ratner. *Nature Biotechnology* 33,679(2015)



Dr. Dhandapani Ashok, MBBS, MD, FRCPCH (UK) joined the Department of Pediatrics at the Children's Hospital, London Health Sciences in October 2012.

Dr. Ashok graduated from Madras University and completed postgraduate training in Pediatrics in Dr. MGR Medical University, Chennai, India. In 1999, he moved to United Kingdom and trained in various university teaching hospitals during his pediatric residency programme. He developed a keen interest in childhood bowel and liver diseases and completed pediatric gastroenterology fellowship training programme in 2008. He gained specialist knowledge & breadth of experience at prestigious hospitals: Birmingham Children's Hospital, a major centre for intestinal rehabilitation, Liver & Small Bowel transplantation, Sheffield Children's Hospital, a busy diagnostic & interventional endoscopy centre and Great North Children's Hospital, a centre for intestinal failure and rare immune gut disorders.

Dr. Ashok's specific clinical interests are pediatric liver disease and inflammatory bowel disease. He also maintains a broad interest in all aspects of pediatric gastroenterology & nutrition. Following two years of practice as a consultant pediatric gastroenterologist in Hull & East Yorkshire University Hospital, UK, he was appointed to London Children's Hospital & Western University.

Dr. Ashok is an active member of the Canadian Pediatric Hepatology Research Group.

Suzanne's Corner



LowProRecipes.com

Party mix

Yield

Number of servings: 20
Serving size: 1/2 cup (125 ml)

Ingredients

66 Glutino stick pretzels (60 g)
4 cups (1000 ml) Rice Chex
5 focaccia bread from Cambrooke foods (2112) thinly sliced
¼ cup (60 ml) margarine

Seasonings (choose one of the 4 combinations)

1 Tbsp (15 ml) honey
1 Tbsp (15 ml) Dijon mustard
OR
1 Tbsp (15 ml) taco seasoning
OR
1 Tbsp (15 ml) Alfredo seasonings from Cambrooke foods (2802)
OR
2 tsp (10 ml) Red Hot Sauce
1 tps (5 ml) garlic powder
1 tsp (5 ml) onion powder

Preparation

- Slice the focaccia bread into thin slices. Place on a baking sheet and bake the oven at 350 F for about 15 minutes. Turn halfway through cooking.
- In a large microwavable bowl, mix cereals, pretzels and bread slices.
- In a small bowl, place the margarine and selected seasonings. Melt in microwave for about 40 seconds.
- Pour melted margarine over cereal mix. Mix well.
- Cook for 5-6 minutes in the microwave at high intensity. Stir every 2 minutes.
- Cool and store in an airtight container.

Nutritional facts

Serving	Recipe
Energy 86 kcal	1710 kcal
Protein 0.5 g	10.1 g
PHE 18 mg	370 mg
TYR 20 mg	403 mg
LEU 34 mg	683 mg
VAL 27 mg	535 mg
ILE 22 mg	431 mg
MET 10 mg	209 mg
LYS 20 mg	405 mg



Metabolic Family Workshop

Friday, May 12, 2017

Best Western Lamplighter

591 Wellington Road London, ON



Low Protein Cooking Demonstration

Saturday, May 13, 2017

Real Canadian Superstore

825 Oxford Street E London, ON

What's New



Farewell to Dr. Sharan Goobie

Dr. Goobie joined the Children's Hospital Medical Genetics and Metabolics Team in 2008. For the past 8 years she has been an outstanding physician who is dedicated to the care of her patients.

We wish her all the best in her new position at Dalhousie as she joins her family and friends in Nova Scotia.

Paediatric Family Resource Centre



Darren Connolly is the new Family Advisor in the Paediatric Family Resource Centre (PFRC). He started in the PFRC on Tuesday, September 8th last year.

The Resource Centre is open Monday to Friday 8:00 to 4:00 pm,

Darren has an extensive knowledge of community resources for children with special needs and case coordination. Darren has a great deal of experience mentoring families of children with health issues and has lead the development of peer support programs for families of children with special needs. Darren has expertise in advocating for resources for families

in collaboration with local community agencies and with provincial partners. Darren joins our team with a passion for bringing children, their families and communities together to create partnerships and inspire positive change for the advancement of patient and family centred care.

Welcome Darren!

- Mother Theresa -

"One kind act is better than a thousand kind thoughts."

What's New - continued



Children's Hospital Metabolic Program's dietitian Suzanne Ratko is now the nutrition consultant to provincial Inherited Metabolic Disease program in Ontario. Congratulations Suzanne!

Low Protein Cooking Demonstration 2016

The 12th annual low protein cooking demonstration was held in the Real Canadian Superstore on 14th May 2016 was a grand success with over 60 participants under the leadership of Suzanne Ratko and Sarah Denomme and many volunteers (Shari Beltran, Claire Bilik, Grace Lee, Lisa Talarowski).



Sponsored by Cambrooke Therapeutics and Metabolic program Children's hospital

MitoCanada prepares for Awareness Week

September 18-24 marks Global Mitochondrial Disease Awareness Week and MitoCanada is finalizing plans that include a national public service campaign (TV, radio, digital media) to increase awareness of mitochondrial disease. Follow us on <https://www.facebook.com/MitoCanada> to learn more.

For anyone within driving distance of Hamilton, we are hosting our 7th Annual Walk/Run on Saturday, September 24 at F.H. Sherman Recreation and Learning Centre. This is a free, family-friendly event to benefit mitochondrial disease awareness and research. Pre/post festivities include mini-golf, kid's fun zone, beach volleyball, a pop-up shop, silent auction, and ceremonial balloon release. Catering by Burger Priest. Everyone is welcome!

<http://raceroster.com/events/2016/9347/the-mitocanada-colour-walkrun>

Together we can beat mito – one step at a time.



Research & Publications

Congratulations to Dr. Tony Rugar who is now a Full Professor at Western University.



CIMDRN

We at LHSC have now joined the (Canadian Inherited Metabolic Research Network) CIMDRN. Dr. Beth Potter and Dr. Pranesh Chakraborty are the Principal investigators. (They were our speakers for the 2015 metabolic family workshop).

Canadian Inherited Metabolic Diseases Research Network

Has your child been diagnosed with a metabolic disease?

Research is needed to help us understand how to best provide care for children with metabolic diseases.

If you are interested in participating in research studies, tell your doctor!

For more information, visit our website: www.cimdrn.ca

Administered by:



CIMDRN
RCRMMH

Funded by:



Follow us on Twitter @CIMDRN

Research & Publications - continued

Publications

1. Keilland E, Rupal CA, Prasad AN, Tay KY, Downie A, **Prasad C**. The expanding phenotype of MELAS caused by the m.3291T >C mutation in the MT-TL1 gene. *Mol Genet Metab Rep*, 2016 Mar 1; 6: 64-9, DOI: 10.1016/j.ymgmr.2016.02.003.
2. Karaceper MD, Chakraborty P, Coyle D, Wilson K, Kronick JB, Hawken S, Davies C, Brownell M, Dodds L, Feigenbaum A, Fell DB, Grosse SD, Guttmann A, Laberge AM, Mhanni A, Miller FA, Mitchell JJ, Nakhla M, **Prasad C**, Rockman-Greenberg C, Sparkes R, Wilson BJ, Potter BK, Canadian Inherited Metabolic Diseases Research Network. The health system impact of false positive newborn screening results for medium-chain acyl-CoA dehydrogenase deficiency: a cohort study. *Orphanet J Rare Dis*, 2016 Feb 3; 11 (1): 12, **Coauthor**, DOI: 10.1186/s13023-016-0391-5.
3. Mirzaa G, Timms AE, Conti V, Boyle EA, Girisha Km, Martin B, Martin K, Olds C, Juusola J, Collins S, Park K, Carter M, Glass I, Krageloh-Mann I, Chitayat D, Parikh AS, Bradshaw R, Torti E, Braddock S, Burke L, Ghedia S, Stephan M, Steward F, **Prasad C**, Napier M, Saitta S, Straussberg R, Gabbett M, O'Connor B, Keegan C, Yin LJ, Lai AHM, Martin N, McKinnon M, Addor MC, Boccuto L, Schwartz CE, Lanoel A, Conway RL, Devriendt K, Taton-Brown K, Pierpont ME, Painter M, Worgan L, Reggin J, Hennekam R, Tsuchiya K, Pritchard CC, Aracena M, Gripp KW, O'Roak B, Cordisco M, Van Esch H, Garavelli L, Curry C, Goriely A, Hulya K, Shendure J, Graham J, Guerrini R, Dobyns WB PIK3CA-associated developmental disorders and mosaicism: classes, levels and tissue distribution of mutations. *Journal of Clinical Investigation*, 2016 insight.jci.org doi:10.1172/jci.insight.87623
4. Keilland E, **Rupal CA**, Prasad AN, Tay KY, Downie A, **Prasad C**. The expanding phenotype of MELAS caused by the m.3291T >C mutation in the MT-TL1 gene. Response to the letter to the editor from Josef Finsterer, MD, PhD. *Mol Genet Metab Rep*. 2016 Apr, 1 6. (6): p.64-9, **Responsible Author**, DOI: 10.1016/j.ymgmr.2016.02.003.
5. Beth K. Potter, Pranesh Chakraborty, Monica Lamoureux, Kylie Tingley, Doug Coyle, Jonathan B. Kronick, Kumanan Wilson, Valerie Austin, Catherine Brunel, Daniela Buhás, Maggie Chapman, Alicia K.J. Chan, Sarah Dyack, Annette Feigenbaum, Michael Geraghty, Alette Giezen, Jane Gillis, Shaaily Jain, Aneal Khan, Erica Langley, Julian Little, Jennifer MacKenzie, Bruno Maranda, Aizeddin Mhanni, Grant Mitchell, John J. Mitchell, Laura Nagy, Amy Pender, Murray Potter, **Chitra Prasad**, Komudi Siriwardena, Rebecca Sparkes, Sylvia Stockler, Yannis Trakadis, Lesley Turner, Clara Van Karnebeek, Hilary Vallance, Jagdeep Walia, Brenda Wilson, on behalf of the Canadian Inherited Metabolic Diseases Research Network (CIMDRN). The Canadian Inherited Metabolic Diseases Research Network: Initial findings from a pan-Canadian longitudinal study of affected children. *International Congress of Human Genetics*; Tokyo, Japan; 2016.
6. Beth K. Potter, Shabnaz Siddiq, Brenda J. Wilson, Ian D. Graham, Monica Lamoureux, Sara D. Khangura, Kylie Tingley, Laure Tessier, Sarah Wafa, NataliyaYuskiv, Pranesh Chakraborty, Anne-Marie Laberge, **Chitra Prasad**, Fiona A. Miller, John J. Mitchell, Kathy N. Speechley, Komudi Siriwardena, Scott Grosse, Yannis Trakadis, Rebecca Sparkes, Alette Giezen, Jagdeep Walia, Robin Hayeems, Shaaily Jain, Cheryl Greenberg. The little things that matter: A qualitative study of the disease management experiences of caregivers of children with inherited metabolic diseases. *International Congress of Human Genetics*; Tokyo, Japan; 2016.
7. Kylie Tingley, Monica Lamoureux, Doug Coyle, Jonathan B. Kronick, Kumanan Wilson, Valerie Austin, Catherine Brunel, Daniela Buhás, Maggie Chapman, Alicia K.J. Chan, Sarah Dyack, Annette Feigenbaum, Michael Geraghty, Alette Giezen, Jane Gillis, Shaaily Jain, Mariya Kozenko, Erica Langley, Julian Little, Jennifer MacKenzie, Bruno Maranda, Aizeddin Mhanni, Grant Mitchell, John J. Mitchell, Laura Nagy, Amy Pender, Murray Potter, **Chitra Prasad**, Suzanne Ratko, Ramona Salvari, Andreas Schulze, Komudi Siriwardena, Neal Sondheimer, Rebecca Sparkes, Sylvia Stockler, Yannis Trakadis, Lesley Turner, Keiko Ueda, Clara Van Karnebeek, Hilary Vallance, Jagdeep Walia, Brenda J. Wilson, Beth K. Potter, and Pranesh Chakraborty on behalf of the Canadian Inherited Metabolic Diseases Research Network (CIMDRN). The Canadian Inherited Metabolic Diseases Research Network: Initial findings from a pan-Canadian longitudinal study of affected children. *American College of Medical Genetics*, United States; 2016.
8. Kylie Tingley, Monica Lamoureux, Doug Coyle, Jonathan B Kronick, Kumanan Wilson, Valerie Austin, Catherine Brunel, Daniela Buhás, Maggie Chapman, Alicia KJ Chan, Sarah Dyack, Annette Feigenbaum, Michael Geraghty, Alette Giezen, Jane Gillis, Shaaily Jain, Mariya Kozenko, Erica Langley, Julian Little, Jennifer MacKenzie, Bruno Maranda, Aizeddin Mhanni, Grant Mitchell, John J Mitchell, Laura Nagy, Amy Pender, Murray Potter, **Chitra Prasad**, Suzanne Ratko, Ramona Salvarinova, Andreas Schulze, Komudi Siriwardena, Neal Sondheimer, Rebecca Sparkes, Sylvia Stockler, Yannis Trakadis, Lesley Turner, Keiko Ueda, Clara Van Karnebeek, Hilary Vallance, Jagdeep Walia, Brenda J Wilson, Beth K Potter, Pranesh Chakraborty on behalf of the Canadian Inherited Metabolic Diseases Research Network. The Canadian Inherited Metabolic Diseases Research Network: Initial Findings from a Pan-Canadian Longitudinal Study of Affected Children. *ACMG Annual Clinical Genetics Meeting*, Florida, United States; 2016.
9. **Melanie P Napier**, Charushree Prasad, **C Anthony Rupal**, **Chitra Prasad**. Two siblings and family with Fumarase deficiency: diagnostic odyssey solved and counselling dilemma begins. *Garrod Symposium 2016*. Halifax, Nova Scotia, Canada. 2016 May.
10. **Prasad C**, **Napier M**, Goobie S, Karp N, Mok Siu V, Ratko S, Chakraborty P, **Rupal CA**. Culturally sensitive provision of rapid biochemical and molecular diagnosis at birth in children at risk for metabolic disorders. *Garrod Symposium 2016*. Halifax, Nova Scotia, Canada. 2016 May.

Research - continued

11. Srinitya Gannavarapu, Cathy Regan, **Chitra Prasad**, **Melanie Napier**, Charles A. Rugar. Identifying the disease-causing gene variant in an unidentified white matter disease. 2016 Mar.
12. Ravi Datar, Asuri Prasad, Keng Yeow Taya, Charles **A. Rugar**, Pavlo Ohorodnyk, Michael Miller, and **Chitra Prasad**. The application of magnetic resonance imaging algorithms in the clinical diagnosis of white matter abnormalities at neurometabolic/neurogenetic/metabolic/neurology clinics (at London Health Sciences Centre) from 2004-2015. 2016 Mar. **Co-Author**

Conferences

Dr Rugar participated in conference on Krabbe's disease in NewYork (Sponsored by Hunter's Hope Foundation)- .

Melanie Napier (genetic counsellor) attended the Newborn screening conference in Ottawa Dr. Chitra Prasad, Dr. Nayayan Prasad, Dr. Rugar and Melanie attended the Garrod conference. Dr Rugar and Dr Narayan Prasad gave a talk on "Treatment Considerations for Neurodegenerative IEMs: Leukodystrophies and Epilepsies". Melanie Napier and Chitra Prasad attended Canadian Fabry Disease Initiative and presented on Cardiac variant for Fabry Disease.

Posters

Case report of two siblings with fumarase deficiency: diagnostic odyssey solved and counselling dilemma begins: Melanie Napier, Charushree Prasad, Tony Rugar and Chitra Prasad.

Culturally sensitive provision of rapid biochemical and molecular diagnosis at birth in children at risk for metabolic disorders Chitra Prasad, Melanie Napier, Natalya Karp, Sharan Goobie, Victoria Siu, Pranesh Chakraborty and Tony Rugar



Ravi Datar - Research Student

Under the supervising team of Dr. Chitra Prasad, Dr. Asuri Narayan Prasad, Dr. Keng Yeow Tay, Dr. Charles A. Rugar, Dr. Pavlo Ohorodnyk and Dr. Michael Miller, I had the wonderful opportunity to perform clinical research in the realm of cranial white matter abnormalities (WMAs). Under Dr. Chitra Prasad (as principal supervisor) I saw first-hand how seriously these WMAs can affect brain myelin in patients of all ages. Our research used magnetic resonance imaging (MRI) as a primary diagnostic tool for WMA diagnosis. Under Dr. Prasad's direction, I used a recently published MRI algorithm to consult two neuroradiologists on a cohort of patients with WMAs. We produced a set of preliminary statistics as to the usefulness of

this MRI algorithm and identified some important considerations when using MRI in the clinic. This experience was very rewarding. I also had the chance to step in on some of Dr. Prasad's clinics. I hope to carry these research and shadowing experiences with me while going forward with my own medical endeavours. Thank you again to Dr. Prasad, my supervising research team, and the entire administrative team at Medical Genetics!



Glycogen storage type IX

Contact Information / How to Make a Donation

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Patients_Families_Visitors/Genetics/
Inherited_Metabolic/index.htm](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

Donated funds are used for future Metabolic Family Workshop Days as well as further teaching and education. If you wish to make a donation, do so on the **The Children's Health Foundation website**: www.childhealth.ca

Ways to Give/ Under Giving Options: donate now/ Select: Make a Donation or Join Caring Heart Monthly Giving /Follow the prompts and it will give an online form with a comment box that you can type in and instruct the funds go to the *Inherited Metabolic Disorders program*.

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.

Your donation is tax deductible, and an income tax receipt will be mailed to you.

Thank you!

"Kind words can be short and easy to speak, but their echoes are truly endless."