The Inherited Metabolic Disorders News

To receive the next issue of the newsletter by email, contact maria.bata@lhsc.on.ca

Children's Hospital
London Health Sciences Centre

Summer 2022 Volume 19 Issue 2

In this Issue

From the Editor

Hello everyone! I hope everyone's year has been going well since we last touched base. We are excited to deliver the Summer edition of our newsletter to you and your families. Stay safe always, and all the best!

Maria Bata

From Dr Chitra Prasad

Dear Friends,

Greetings! Hope you and your families are staying healthy. It has definitely been a challenging last couple of years with the pandemic. I'm happy that we are able to do some in person visits. I have learned that as human beings we adapt to the new situations. Virtual care helped us to connect even in these difficult times.

After nearly 2 years I attended the Garrod meeting in person. It was held in Calgary. This is the national metabolic meeting. I am very proud of our many students who presented at the Garrod meeting and also our consultant Dr. Mia Sethna and Post-doctoral fellow Dr. Stephanie Newman who presented at the Society of Inherited Metabolic Disorders (US). It was truly wonderful to meet our metabolic colleagues after so long. The scientific sessions were excellent. During my walk outside the hotel where I was staying, I found something amazing which I would like to share with you. They are building a bridge in Calgary and have called it "Jaipur Bridge". Jaipur and Calgary are sister cities. Jaipur is a beautiful city in India where I got part of my primary education. It is the capital of Rajasthan. I'm sharing some pictures from Jaipur and Jaipur Bridge.

On another note, Melanie Napier (our metabolic genetic counsellor) will be leaving us. Many of you have known her over the years. She has been with our metabolic team for last 10 years and has helped a lot in the area of newborn screening and care of all metabolic patients. We all wish her the very best in her new job as research genetic counsellor for Gene Dx. We will be announcing additions to our metabolic team in the very near future. I am hopeful that we can have our metabolic family workshop next year in person.

This newsletter has a patient story from Jennifer Boin, who is an amazing advocate for a metabolic condition called hypophosphatasia. While the enzyme replacement therapy for this condition was approved for the affected children, the adults are still not able to avail this treatment. Jennifer has been instrumental in forming the support group "soft bones". She is currently receiving the enzyme replacement therapy on compassionate basis. Metabolic disorders as you all know are seen in all age groups, from childhood to adult. At present we do not have an adult metabolic disorder clinic separately at London Health Sciences Centre. In this issue of our newsletter we are bringing some messages and stories from our adult patients who are doing their very best in spite of dealing with various challenges associated with metabolic disorders. Wishing you all the best of summer.

Your friend,
Chitra Prasad

"We cannot direct the wind, but we can adjust the sails." – Dolly Parton

Personal Story: Jennifer Boin

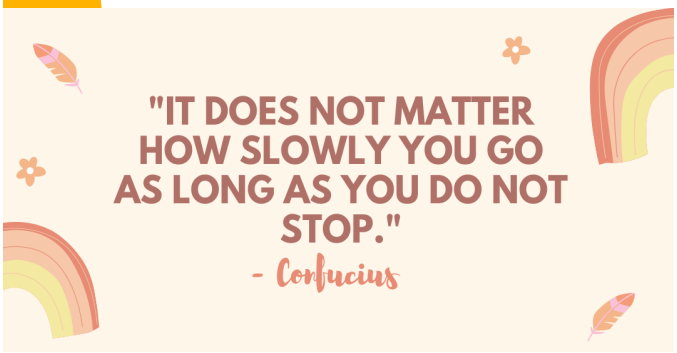
I read a book once called “If Life Is a Game, These Are the Rules: Ten Rules for Being Human as Introduced in Chicken Soup for the Soul”, by Cherie Carter-Scott. The first rule is that you will receive a body. It goes on to say that you may love it or hate it, but it will be yours for the duration of your life on Earth. I think of that idea a lot. You see, I was given a body that has never really felt like my own. It feels like I was given this shell by accident and that I have struggled to keep myself going because of its weight, shape, demands, etc. I watch people who are in synch with their bodies. They seem to be perfectly matched, working together in harmony. My body and I have had a strained relationship, a love – hate relationship really. I have cursed it for not doing what I want, for being weak and for hurting, but I have also applauded it because somehow in the face of so much, it continues to take me where I need to go.

From the beginning, my body was different. It had a secret that no one would discover for many years. You see, I have HPP. Luckily, I do not have the most severe form of the disease, so my childhood evolved pretty normally. I spent a lot more time in the dental chair than most people my age. I started losing my teeth, along with their gnarly, ugly roots early, just after my first birthday. My dentist did eventually send me for testing at the University of Western Ontario in London, ON, where they discovered that I had hypophosphatasia. I was about 3 years old. This name would literally be placed on a Post-It note in my dental file. Though we knew I had this disease, little was known about it, or about how it would manifest in me. So, the doctors sent my parents and I on our way with no real idea what we were dealing with.

Fast forward to my mid to late 20’s. I was having all kinds of aches and pains; everything from my jaw to my shoulders and legs. I was never given a diagnosis. It was stress, possible vitamin issue, hormones, lack of exercise, too much exercise, etc.

By the time I was in my 30’s, married with two children, it is safe to say that I had seen dozens of different doctors at different times to try to understand my pain. I was even told once by a rheumatologist that she was “the end of the line when it comes to weird things”, so I had come to the end of what medicine could tell me. That was a difficult time. I was angry with my body and with the medical profession, both kept letting me down.

Then one day, while I was Google-doctoring myself, I came across an article that explained that patients living with hypophosphatasia experience muscle and joint pain. It was the first hope that something could explain what was going on with my body. I reached out to Dr. Michael Whyte at the Shriner’s Hospital in St. Louis. That phone call changed my life! Dr. Whyte was gracious enough to speak with me and direct me what to tell my family doctor to confirm that HPP was in fact the reason for much of my pain.



As many of you know, that was just the beginning of the journey. Eventually, I helped to build Soft Bones Canada in an effort to ensure that others would have a place to find information about HPP and a community that could support each other. I am very proud of what we have accomplished.

Personal Story - continued

December of 2020, I received an amazing Christmas gift. I was able to access Strensiq (Asfotase Alfa) and it has had a positive effect. I no longer have stress fractures in my feet and legs. My endurance and gait have improved greatly, and my headaches have decreased. I don't love getting the needles, as they often burn and sting, but it has been a game changer. It has given me hope that my shell and I will get to continue doing the things I love to do without the constant threat of breaks and pain.

I mentioned that I felt like I was given the wrong body. I think it's true. I believe that I was meant to be a runner, or a mountaineer, or perhaps a superhero. That is the person I feel I should have been, but I didn't get to choose. While I may not always appreciate the body I have, I am fortunate to have been given some answers as well as some medication and therapy to help me move my shell about the world, for which I am eternally grateful. HPP is a rare disease and so it is rare to find people who truly understand the struggles. Being a part of Soft Bones Canada gave me a purpose and helped me meet extraordinary people who not only supported me, but who understood my situation in a way that no one else ever has. I am grateful in spite of my shell. In some ways, it has shaped who I have become. It has forced me to choose to be strong in body and spirit despite weaknesses in both.

METABOLIC FAMILY WORKSHOP: SAVE THE DATE!

WE ARE PLEASED TO ANNOUNCE A TENTATIVE RETURN DATE FOR THE METABOLIC FAMILY WORKSHOP:

MAY 5TH, 2023

SAVE THE DATE AND KEEP AN EYE OUT FOR DETAILS IN THE NEXT ISSUE OF THE INHERITED METABOLIC DISORDERS NEWS!

Featured This Issue

Hypophosphatasia

Compiled by Dr. Chitra Prasad

The first case report of hypophosphatasia was described by Dr. Bruce Chown from Manitoba, Canada. Since then many Canadian physicians and researchers have contributed to our understanding of hypophosphatasia, its clinical, biochemical, radiological and molecular basis such as Dr. Cheryl Greenberg, Dr. John Rathbun, Dr. Donald Fraser, Dr. Rod McPherson, Dr. Bernie Chodirker and their colleagues. Dr. Michael P Whyte has been instrumental in initiating the enzyme replacement therapy for this disorder.

Hypophosphatasia (HPP) is a rare genetic disorder characterized by impaired mineralization ("calcification") of bones and teeth. Problems occur because mineralization is the process by which bones and teeth take up calcium and phosphorus required for proper hardness and strength. Defective mineralization results in bones that are soft and prone to fracture and deformity. Defective mineralization of teeth can lead to tooth loss. The specific symptoms of HPP are broad-ranging in severity, and can vary greatly from one person to another, sometimes even among affected members of the same family. HPP is caused by changes (mutations) in the ALPL gene that produces an enzyme called tissue nonspecific alkaline phosphatase (TNSALP). Such mutations lead to low activity of this enzyme that should be breaking down a chemical called inorganic pyrophosphate that blocks mineralization. Depending on the specific form, HPP can be inherited in an autosomal recessive (among brothers and sisters) or autosomal dominant (multiple generations) manner. HPP has remarkably wide-ranging severity. The six major clinical forms are separated based primarily upon the age when symptoms occur and the diagnosis is made. By decreasing severity, these forms are called perinatal, infantile, childhood (severe or mild), adult, and odontohypophosphatasia (early loss of "baby" teeth in infancy or early childhood).

Childhood HPP is highly variable, and severe and mild forms should be considered. Affected children sometimes develop craniosynostosis with intracranial hypertension. Skeletal malformations may become apparent at 2 to 3 years of age. Bone and joint pain may occur. Typically, one or more baby teeth fall out earlier than the fifth birthday. Some patients are weak with delayed walking, and then with a distinct, waddling gait. Sometimes spontaneous improvements occur in young adult life, but complications can recur during middle-age or late adult life.

Adult HPP too has wide-ranging signs and symptoms. Affected men and women have "adult rickets" called "osteomalacia", a softening of the bones in adults. Bone pain is common. Affected adults may experience loss of teeth. Some have a history of rickets during childhood, or baby teeth lost early. Fractures can occur, especially "stress fractures" in the feet early on, or subsequently "pseudofractures" in the thigh. Repeated fracturing can cause chronic pain and weakness. Spine fractures are less common. Joint inflammation and pain near or around certain joints occur due to the accumulation of calcium phosphate crystals (calcific periarthritis). Generally, the reduction of TNSALP enzyme activity correlates with HPP severity (less enzyme activity causes more severe disease).

HPP affects males and females in equal numbers. In Canada, severe HPP is estimated to occur in approximately 1 in 100,000 live births. The overall incidence and prevalence of the various forms of HPP is poorly understood or unknown. Milder cases can go undiagnosed or misdiagnosed. HPP occurs with greatest frequency in the Mennonite population in Canada. HPP is sometimes first suspected from routine testing of blood that includes assay of alkaline phosphatase (ALP). Molecular genetic testing can support a diagnosis of HPP because it can detect mutations in the ALPL gene known to cause HPP.

In 2015, the U.S. Food and Drug Administration (FDA) approved asfotase alfa (Strensiq) as the first medical treatment for perinatal, infantile and juvenile-onset HPP. Supportive treatments for HPP are directed toward specific symptoms and complications. Treatment may require a team of specialists. Pediatricians, orthopedic surgeons, pedodontists, pain management specialists and other healthcare professionals may be needed for comprehensive treatment. Non-steroidal anti-inflammatory drugs (NSAIDs) may help bone and joint pain. Regular dental care beginning early on is recommended. Physical and occupational therapy may be helpful. Adults with recurring long bone fractures may need orthopedic management. Special medical devices (foot orthotics) may help foot (metatarsal) fractures.

Soft Bones™ Canada

Check out the Soft Bones Canada website:
https://softbonescanada.ca/

References:

- https://rarediseases.org/rare-diseases/hypophosphatasia/ (By Dr. Michael Whyte)
- Dr. Cheryl Rockman Greenberg. Pediatric Endocrinology reviews volume 10 supplement 2

Suzanne's Corner
Newsblast

New products

The inherited metabolic disease (IMD) program released a new list of covered drugs, supplements and specialty foods effective June 2022. This is exciting!

Newly covered formula

Coverage of these products is condition specific

Product	***Condition***
Homactin AA PLUS 15 Lemon Lime powder	Homocystinuria
HCU Easy Tablets	Homocystinuria
XMET XCYS Maxamaid	Molydenum Cofactor Deficiency
UCD Trio, unflavoured powder	Urea Cycle Disorders
UCD Trio, powder	Urea Cycle Disorders
Vilactin AA PLUS 15 Lemon Lime powder	Maple Syrup Urine Disease
PKU Sphere 20 Liquid, vanilla	PKU
PKU Easy Microtabs	PKU
Phenylade GMP Ready, plain	PKU
PKU Air 20 Yellow (mango breeze)	PKU
PKU GMP Mix In, can	PKU

Newly covered low protein food (For low protein diet only)

These are Cambrooke foods

Product
Wel-made baking mix
Readi-dough
Cheddar shreds
Yuca Tater Home Fries
Sausage Patty Mix
Chicken Patty Mix
Beef Patty Mix

Suzanne's Corner
Newsblast—continued

Supply Issues

Supply chain issues have been a big problem over the 2 plus years. During that time, we have seen shortages for toilet paper, car parts, vitamins and minerals and many other items. Off and on, different metabolic medication, formula and food have been in limited supply over this time.

Unfortunately, in February 2022, the Abbott plant that manufacturers a huge amount of metabolic formulas for the world was shut down temporarily. This supply chain disruption greatly impacted the the metabolic world. Other manufacturers of metabolic products stepped up to increase production of alternate products; however, shortages of raw materials, plastic and other items as well as people has affected how much can be produced.

It has been very trying and difficult times for those whose formula are in short supply or simply not available. It not easy to switch to another formula which tastes differently.

Within Canada, the dietitians have been working tirelessly with patients, distributors, formula companies, provincial governments and Health Canada to ensure that no patient goes without formula. We have been sharing product between clinics. Unfortunately, there still have been some of you who have gone without your standard formula. My apologies.

Good news: Abbott plant has started manufacturing formula. They will start with specialty NON Metabolic formula first, then switch to metabolic formula. It will still be months before we start to see their product coming back into Canada. There is no set date.

Recommendations
1. Closely keep track of your formula supply
2. Aim for a 1 month supply, if possible. Some products in short supply are being distributed for a few days or a week supply only.
3. Do not order excessive amounts. The shortages are worldwide. We need to ensure that there is enough product for everyone.
4. Do not wait until Friday afternoon to check out the supply.
5. Contact me if your supply is low, we will need to look at alternate products

We will get through this together.

Thank you,
Suzanne

Recipe

Lemon Berry Parfait by Chef Kevin Brown

Several years ago, Chef Brown provided this delicious recipe at a low protein cooking demonstration. It can be modified so that everyone in the family to enjoy this summer time treat.

Serves 4
Ingredients
- 2 cups fresh or thawed frozen blueberries
- 4 Hunts Lemon Pudding
- 4 gingersnaps, crumbled

Directions
In each of four parfait glasses or tall wineglasses, put 1/2 cup blueberries, followed by 1/2 cup pudding, then crumbled gingersnaps

To make this very low fat, switch pudding for 0% MF yogurt and use only 2 gingersnaps for 4 servings

Protein	1.1 g
Phenylalanine	41 mg
Leucine	68 mg
Fat	3.8 g

Serving size: One parfait glass

Bon appetit!
Suzanne

Staff Updates — From Goodbyes to Hellos

Melanie Napier

After 10 and a half years working with the Metabolic Genetics Clinic at London Health Sciences Centre, the time has come for me to say farewell. I have accepted an opportunity in the genetic testing industry, working with a research team to help advance the knowledge for those with uncertain genetic testing results.

I cannot believe it has been over 10 years since I began working here – time flies when you enjoy the work that you do on a daily basis! It has truly been a pleasure working with the patients and families that receive care through our clinic; you have made this a very positive and rewarding experience for me. I will always think back on my time in the Metabolic Genetics Clinic with fond memories and will miss interacting with so many fantastic individuals (both patients/families/caregivers and members of our clinical team).

I wish everyone all the best!
Melanie

Vanessa So

Hi there! My name is Vanessa So and I'm a Registered Dietitian who recently joined the metabolic team. I completed my dietetic practicum here at LHSC and shortly after, started working here in adult inpatient. I was then fortunately given the opportunity to work in paediatrics and have already learned so much from our brilliant team! In addition to metabolics, I am also the dietitian for the ketogenic diet team with the pediatric epilepsy program. I love all kinds of food and am excited to join our fantastic metabolics/genetics team and look forward to meeting you!"

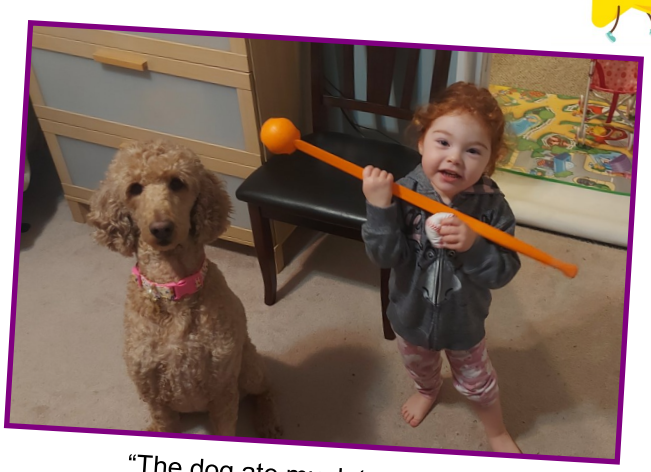
Jack Rip

It is with mixed feelings to share that Dr. Jack Rip is retiring. Dr. Rip joined the Biochemical Genetics laboratory in the 1989 when he assumed primary responsibility for the lysosomal storage diseases diagnostic tests. This has continued for 33yr and he has made significant contributions to our understanding of lysosomal storage diseases. Dr. Rip has published about 50 peer reviewed research papers and contributed to the training of many biochemistry students. He was always willing to share his knowledge and experience. It has been a pleasure to work with Dr. Rip and we will miss him and his quiet demeanor. We wish him all the best in his retirement.

The Inherited Metabolic Disorders News

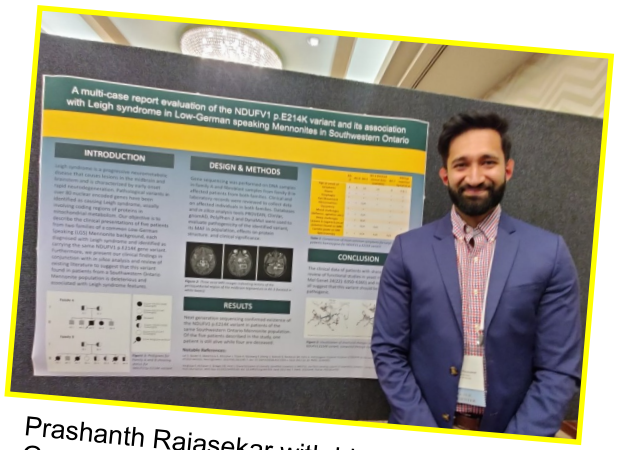
Our Stars!

Kaitlynn, PKU



"The dog ate my dot card!"
Daphne, PKU

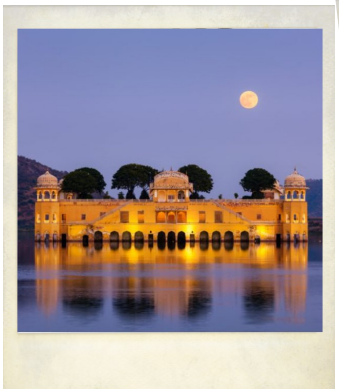
GARROD Symposium



Prashanth Rajasekar with his poster at the Garrod Symposium

Samuel Tholl, Dr. Tony Rupar, and Dr. Chitra Prasad at the Garrod Symposium

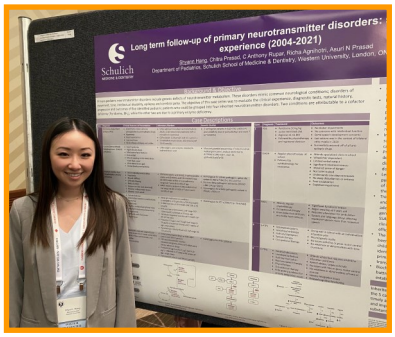
Dr. Andrea Yu and Dr. Chitra Prasad at the Garrod Symposium



Check out these photos: One of Jaipur, and one of the Jaipur bridge being built in the sister city of Calgary, where the symposium was held!

Research and Presentation Updates

GARROD Symposium



Shyann Hang

Long-term follow-up of primary neurotransmitter disorders - single centre experience (2004-2021) **Shyann Hang**, Chitra Prasad, C Anthony Rupar, and Asuri N Prasad.

The Japanese Society of Child Neurology has sent a certificate of recognition for Shyann's work. Congratulations!

Samuel Tholl

Late-onset ornithine transcarbamylase deficiency: biochemical, clinical, and functional consequences of a rare promoter region variant **Samuel Tholl,** Wendy McCaul, C. Anthony Rupar, Melanie Napier, Natalya Karp, Andrea Yu, Suzanne Ratko, Michael Geraghty, Aneal Khan and Chitra Prasad.

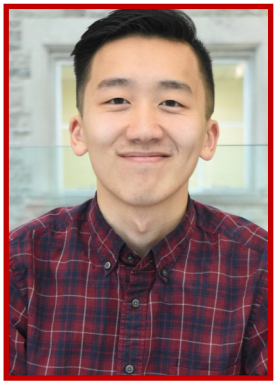
Congratulations to Samuel for receiving the platform presentation award at Garrod!

Derek Nguyen

Phenotypic variability and impact of newborn screening on patients with severe Biotinidase Deficiency Y210C in Southwestern Ontario. Steven Zhang, Derek Nguyen, Melanie P. Napier, Natalya Karp, Chitra Prasad, Wendy McCaul and C. Anthony Rupar.

Culturally sensitive provision of rapid biochemical and molecular diagnosis at birth in children at risk for Maple Syrup Urine Disease in Southwestern Ontario. Derek Nguyen, Steven Zhang, Melanie P. Napier, Suzanne Ratkob, Natalya Karp, Victoria M Siu, Chitra Prasad, Wendy McCaul and C. Anthony Rupar.

A multi-case report evaluation of the NDUFV1 p.E214K variant and its association with Leigh syndrome in Low-German speaking Mennonites in Southwestern Ontario. **Prashanth Rajasekar**, Asuri N. Prasad, Victoria M. Siu, C. Anthony Rupar, and Chitra Prasad.



Steven Zhang

Emily Dzongowski

A good news story: Two cases of citrin deficiency presenting with neonatal cholestasis. Chitra Prasad, Emily Dzongowski, Andrea C. Yu, Andreanne Zizzo, Natalya Karp, Suzanne Ratko, Melanie Napier, and Charles A Rupar.

Research and Presentation Updates—continued

CIMDRN (CANDIAN INHERITED METABOLIC RESEARCH NEWORK)

(Dr. Chitra Prasad, Dr. Natalya Karp and Suzanne Ratko are part of this Canadian research network).

Al-Baldawi et al. Parent perspectives on health care networks of young children with inherited metabolic diseases (IMD): a mixed methods study.

Chow et al. Caregiver perspectives on family management of care for children with inherited metabolic diseases: results from a cross-sectional survey.

Chow et al. Caregiver perceptions of effects of the COVID-19 pandemic on health care access and management for children with inherited metabolic diseases: a cohort analysis.

Chow et al. Family-centred care interventions for children with ongoing, elevated health care needs: a rapid scoping review

Dr. Judy Ibrahim

Dr. Stephanie Newman

Royal College of Pediatrics UK

Carbonic Anhydrase (CA-VA) deficiency: an under recognized cause of neonatal hyperammonemia with excellent outcome on proactive management. **Judy Ibrahim,** Suzanne Ratko, Melanie P. Napier, Natalya Karp, C. Anthony Rupar and Chitra Prasad.

De novo STXBP1 Mutations in Two Patients With Developmental Delay With or Without Epileptic Seizures. **Ping Yang** , Robert Broadbent , Chitra Prasad , Simon Levin, Sharan Goobie, Joan H Knoll , Asuri N Prasad Front Neurol. 2021 Dec 24;12: 804078.

Dr. Mia Sethna

SIMD (US) (Society of Inherited Metabolic Disorders)

The Impact of Gender Identity and Transgender Related Issues on the Management of Inborn Errors of Metabolism. **Stephanie Newman**,** Andrea C Yu**, Suzanne Ratko, Natalya Karp, Melanie Napier, Sue MacLean, Ranjit Singarayer, C.A. Rupar and Chitra Prasad

MCAD Deficiency Caused by Uniparental Disomy: Implications for Families. **Sethna, M,** Prasad, C, Rupar, CA, Napier M, Karp, N.

Dr. Asuri N Prasad

Japanese Society of Neurology

Long-term follow-up of primary neurotransmitter disorders - single centre experience (2004-2021). **Shyann Hang,** Chitra Prasad, C Anthony Rupar, and Asuri N Prasad.

Leigh Syndrome Seventy Years on: A reappraisal with a focus on the NDUFV1 mutation. **P Rajashekhar,** CA Rupar, V Siu, C Prasad, and Asuri N Prasad

Srinitya Gannavarapu

SSIEM Annual Symposium

Predicted impact of HSPD1 heterozygous variants in hypomyelinating leukodystrophy. **Srinitya Gannavarapu,** Chitra Prasad, Asuri N Prasad, Tugce B Balci, and Tony Rupar

Celebrating the achievements of our adult patients!

Our metabolic community is so diverse and inspiring. This issue, we wanted to put the spotlight on some of our adult members and see what they're up to, check it out!

Paul Kuntz

I work full time at Foodland in Walkerton. My latest accomplishment is head of decorating for Formosa Homecoming. Back in March my committee and myself made 1400 bows in gold, royal blue and white to decorate Formosa for Formosa Homecoming 2022. A Homecoming is when they invite all former residents who lived in Formosa to come home. This event is happening on July 28 to August 1. We now have bows up in town. When the tents and stage goes up on the ball diamond for the weekend I have to finish decorating this area. It is a big job but I enjoy decorating very much.

Samantha Riolo

My name is Samantha Riolo and I am finishing up my 5-year program at the University of Windsor to become an Elementary school teacher. I also work as a Montessori educator at Brightchild Montessori as I love being able to apply my passion for educating and teaching the importance of spreading kindness.

Celebrating the achievements of our adult patients!

Vanessa Riolo

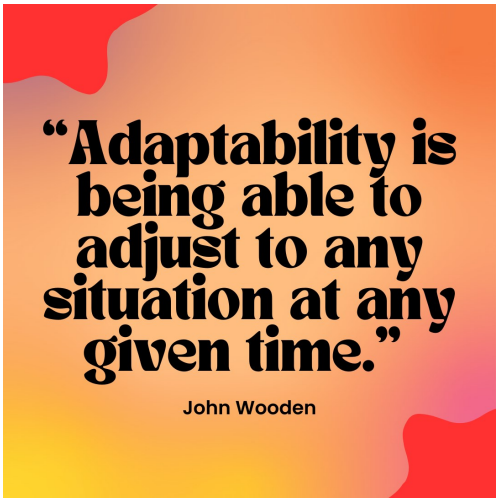
My name is Vanessa Riolo, I'm an 18 year old student entering my second year in Biochemistry and Biomedical Sciences at the University of Windsor. I also work part time as a competitive gymnastics coach at Rose City gymnastics, and I love getting to share my passion for the sport with young athletes in the Windsor-Essex area!

Jesse Davidson

Congratulations to Jesse Davidson, PKU
Jesse is graduating from the Mechanical Engineering (Aerospace) program at the University of Windsor.
His team from the university participated in the Spaceport America Cup 2022 in New Mexico in June launching the rocket that they made into space! The rocket safely landed.
The team finished exceedingly well:
- 2nd out of 12 Canadian teams
- 4th in their category
- 16th out of 100 teams

Shout out to Jesse and the University of Windsor! AMAZING!!!

Adaptability and Adjusting to Change



Life inevitably is filled with ups and downs. While change certainly can seem daunting, there are strategies we can use to weather these changes and use them as opportunities to grow. Check out some of these tips from Licensed Professional Counselor, Steven Sellars!

Tips on Adjusting to Change

Compiled from: https://centerstone.org/adjusting-to-change-adapt-and-overcome/

Recognize that change is happening

Remind yourself that things will be okay and you've endured change before and been fine on the other side.

Write down the positive

Think back to times in your life when you feared change, but in the end, what you feared most didn't happen at all. In fact, you thrived.

Quiet your mind

In the midst of a change we fear, our thoughts can be our worst enemy. Be conscious of what your mind is telling you. Are your fears rational or are you possibly only allowing yourself to focus on the worst possible outcome?

Be kind to yourself

In times of change we can feel a bit out of control. This is normal. Remember to give yourself a break and be kind to yourself.

Talk it out

Finally, if you still find yourself truly struggling with the changes you are facing, seek help. Knowing yourself well enough to realize you need assistance is a sign of strength. No one goes through life alone. Confiding in family or friends can give you the added support you're needing. So can seeking help through therapy.

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, please do so on **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 in the payment area 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 for donations of $20 or more.
Thank you!

Contact Information

Editor: Maria Bata
LHSC - Medical Genetics Program of Southwestern Ontario
Tel: 519 685 8140

Email: maria.bata@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