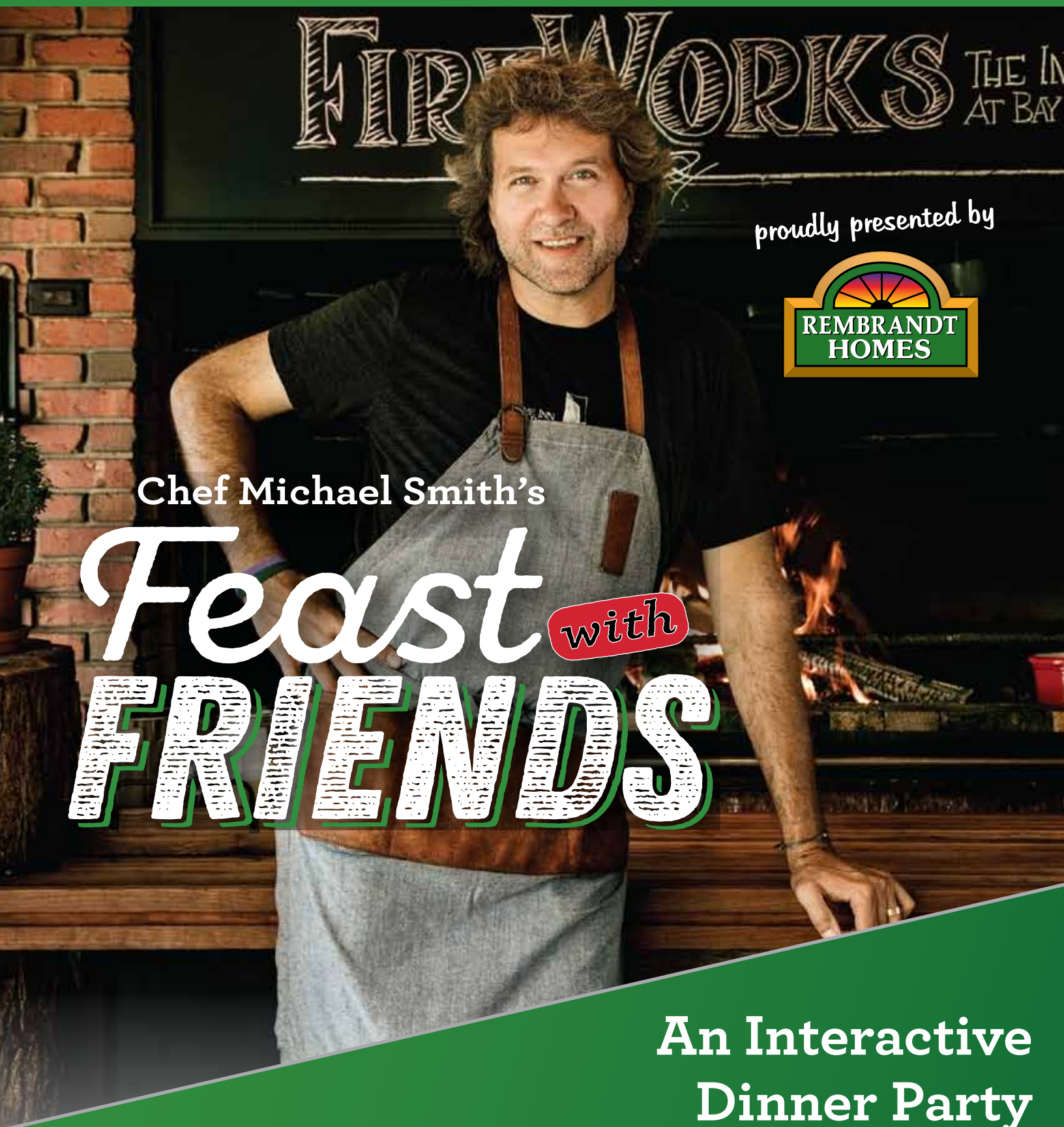
APRIL 5th 2018 at the LONDON CONVENTION CENTRE



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"Feast with Friends ...*an interactive dinner Party*" - 2018 Charity Dinner

Dear friends,

Bethanys Hope Committee hosted the very first Spring Gala in May 1996 to raise funds for Research into a treatment and cure for Metachromatic Leukodystrophy (MLD), the devastating disease our daughter Bethany had been diagnosed with in August of 1995. We are thrilled to welcome all of you to our 23rd annual Spring Gala! Thanks to this community and an amazing Medical Team under the leadership of Dr. Tony Rupar we are now face to face with a goal we have worked so vigorously to reach. We are journeying from "*hope* to a *cure"*, not just for our MLD kiddos, but for many of our leukodystrophy babies! Your joining us this evening means more than ever as we now shift our focus from basic science to funding Clinical Trials right here in London!

We are thrilled to welcome Chef Michael Smith once again. We are so grateful to call Michael a friend .... his commitment to Bethanys Hope along with his generosity of time and talent means the world to us, and let's just say…he sure knows how to throw an unforgettable Party!

We would like to thank our London Convention Centre family for always welcoming us with open arms. Chef David Van Eldik, Director's David DeClark and Chris Waugh and the entire team. We are very grateful for the overwhelming support we have had from the local business community and beyond. Please consider their commitment to our children during your day to day business decisions. Have an amazing evening!

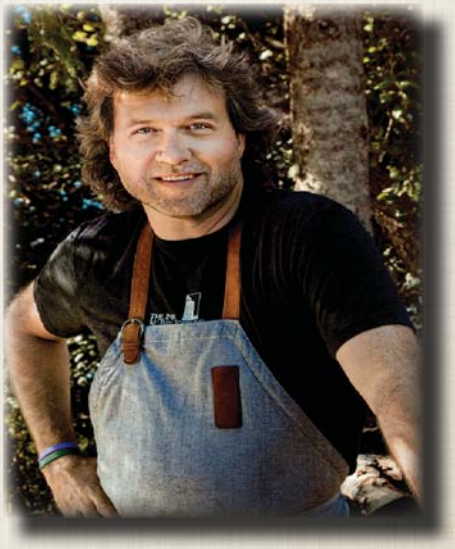
Gratefully,

Lindey

Lindey L. McIntyre, *M.S.C.*
Executive Director

Chef Michael Smith

Food Network Host, Nutritional Activist, Food Media Producer, Innkeeper



Chef Michael Smith, one of Canada's best-known chefs is a passionate advocate for simple, sustainable home cooking and an inspiration for families creating their own healthy food lifestyle. He's the host of *Chef Michaels Kitchen*, *Chef Abroad* and *Chef at Home* seen on Food Network Canada, and in more than 100 other countries. He's a judge on *Chopped Canada* and traveled the world for his innovative web series, *Lentil Hunter*.

Chef Michael and his wife Chastity are the proprietors of *The Inn at Bay Fortune* on Prince Edward Island. They've re-launched the property where Michael gained international fame in the 1990's with a new spirit of five-star hospitality and an innovative dining experience, the *FireWorks.*

Michael is Prince Edward Island's food ambassador; Canada's best selling cookbook author, an innkeeper, educator, professional chef and home cook. He led the team of Sodexo chefs that cooked for the worlds Olympians in the Whistler Athletes Village in 2010. His tenth award winning cookbook, *Real Food, Real Good,* launched in September 2016 and immediately landed on the Globe & Mail best-sellers list. His food media production company is breaking new ground and his social media platforms are Canada's top choice for foodie fun.

While Michael is a true chef at large his favourite role is Dad, at home on Prince Edward Island with his wife Chastity and his children: Gabe, Ariella and Camille! Michael is an avid map collector, long-time windsurfer and novice kite sailor.

Julie Simpson

Co-Master of Ceremonies

Julie is delighted to be part of the Bethanys Hope Foundation family and is looking forward to co-hosting this year's "*Feast with Friends"* with her new friend Jon Munn.

Now in her 5th year at VON Middlesex-Elgin, Julie feels blessed to enjoy a profession and organization that continues to inspire her every day. It's been more than a decade since Julie left her 21 year career with CFPL Television. In addition to her love of journalism, she found her inner passion for health care and health related projects doing the "Health & Home" segment. Julie's current role is particularly meaningful as one of the caregivers to her 89 year old Mum. As Fund Development Coordinator Julie is busy visiting communities benefiting from VON services across Middlesex and Elgin counties, getting ready for the 19th annual VON Community Walk Fundraiser in June and the 22nd annual VON Trivia Challenge in November. VON is one of Canada's most respected registered charitable healthcare organizations providing services that help people live safely and independently, wherever they call home, for as long as possible.

Julie's 20 year old son JJ is enjoying life out of the nest in Banff, and teenage daughter Meghan an "*only child*" at home. Still newlyweds, Julie and husband Colin look forward to welcoming grandson #5 this summer.

Jonathan Munn

Co-Master of Ceremonies

Jon Munn is a former Eastern Canadian radio news anchor and broadcaster turned marketer and strategic communicator. Jon has been at the forefront of the communications and marketing evolution, working in higher education, journalism, broadcast and working in provincial and federal politics in numerous advisory roles, most recently serving as a Senior Specialist under Prime Minister Stephen Harper.

An accomplished freelance photographer, Jon founded J*on Munn Photography* in 2011, a lifestyle and portrait service consultancy agency and has worked with brands all over the world, most recently with WestJet airlines.

Jon obtained a Bachelor of Arts degree from St. Thomas University in Fredericton, New Brunswick, and recently finished a *Masters of Media in Journalism and Communication* at Western University. Jon continually seeks to amplify the organizations and agencies he works for by exercising practical on-the-ground communication and marketing skills to effectively and continually drive innovation and success. Jon now serves as the Director of Marketing and Communications at Huron University College: Canada's only university providing elite, yet accessible education while challenging its students to be Leaders with Heart.

Jon was appointed to the Board of Directors - Bethanys Hope Foundation on January 3rd, 2018.

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Chef David Van Eldik

Executive Chef - London Convention Centre

London, Ontario

LONDON CONVENTION CENTRE

Born and raised in London Ontario, Executive Chef David Van Eldik was lured into the culinary world when his passion for this industry was realized in his youth. David studied culinary arts under the guidance of several European Chefs, during which time he developed his own unique style, flair, and depth of knowledge. He began his career in the hotel industry where he was able to establish a wide range of culinary skills and earned his Red Seal.

David joined the London Convention Centre Culinary Team in 1996, at the age of 29, as Sous Chef. Here he developed and honed his skills in a banquet style kitchen. By 2002, David was leading the LCC Culinary team as Executive Chef. More than a decade later, David remains at the helm of the talented team of Chefs who are well versed in many styles of cooking.

In 2005, David took on the challenge of the Culinary Chef de Cuisine program through the Canadian Culinary Institute and is now part of a very elite group of Chefs with the accreditation of CCC (Certified Chef de Cuisine). In 2016, he was awarded Chef of the Year by the Ontario Restaurant Hotel and Motel Association (ORHMA).

David's culinary philosophy and passion reflects the growing trend towards a healthier and down to earth lifestyle. Working with local farmers, artisans, and purveyors to seek out the finest regional and local products is the essence of his cuisine. David strives to allow the natural flavours of food express themselves.

Over the years David has given back to the culinary industry by encouraging young chefs from local high schools and colleges discover their own unique style and talent. In 2011, David was honoured and won the Apprenticeship Network Employer Award for his efforts in the development of young chefs. David also supports and encourages the growth and development of his staff, proudly boasting that six chefs from his Culinary Team have achieved their Red Seal Certification. David has been proud to be involved with Bethanys Hope for the last ten years and has been honoured to invite visiting Chefs into his kitchen to work alongside him for the last seven years; all in support of research for Metachromatic Leukodystrophy (MLD).

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Ryan Gauss

Chairperson, Bethanys Hope Foundation

On behalf of the Board of Directors of the Bethanys Hope Foundation, I would like to personally welcome you to our foundation's annual gala! This event has become one of the premier engagements on London's social calendar and this year it is better than ever! It is my absolute honour and privilege to serve as the Chairperson of this extraordinary community organization. Tonight, we celebrate together as this foundation – a pillar of hope in London, Ontario – marks a significant milestone in finding a cure for Metachromatic Leukodystrophy (MLD).

The Bethanys Hope Foundation is a world leader in fundraising, research and raising awareness for MLD. Driven by the commitment, passion and steadfast leadership of Lindey and Dave McIntyre, thousands of volunteers have fought tirelessly over the past two decades to help us reach the point where a treatment for this terrible disease is within reach. I would like to sincerely thank everyone who has given of their time, talents and hard earned money to support us in providing hope to those families dealing with the cruelty of MLD on a daily basis.

It is truly exciting that our research team - led by the dedicated Dr. Tony Rupar - continue to make incredible strides towards the finish line. With a pre-clinical trial application in the que with Health Canada there is tangible progress that is giving so many something to cheer about. Though there are no guarantees when it comes to scientific research, the work being done by our world class research team is inspiring.

With that said, I am asking that tonight you dig deep and please consider helping us take a final leap forward in our Bethanys Cure capital campaign. We must raise essential funds so that when the green light is given for clinical trials we are ready to support those families that will be taking part. I know we are all asked to support many causes, however we cannot achieve our ultimate goal alone. Only with your help will we be able to once and for all end the devastation that MLD families have to face. It will be because of you that one day soon a diagnosis of MLD will no longer be fatal.

Again, I thank you for your continued support. I look forward to celebrating with everyone in the very near future when a treatment for MLD is found right here in London, Ontario.

Sincerely,

Ryan Gauss
Chairperson, Bethanys Hope Foundation

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Building a stronger community, together.

"Feast with Friends" .... *an Interactive Dinner* in support of

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April 2018

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Peter Fragiskatos

Member of Parliament, London North Centre

Peter Fragiskatos is the Member of Parliament for the riding of London North Centre, and a Member of the Standing Committee on Foreign Affairs and International Development. A former political scientist at King's University College at Western University, Peter is now combining his passion for politics with a drive to serve his community. He is committed to working tirelessly in order to effectively represent the people who entrusted him with this responsibility in October 2015.

Prior to being elected, Peter also served as a media commentator. His works have been published by major Canadian and international news organizations including Maclean's Magazine, The Globe and Mail, The Toronto Star, BBC News, and CNN. Peter served on the Board of Directors of Anago Resources and the Heritage London Foundation. He is an active volunteer who ran a youth mentorship program and has worked with many local not-for-profit groups such as the London Food Bank, the Cross Cultural Learner Centre, and Literacy London – a charity dedicated to helping adults improve their reading and writing skills.

Peter has a Political Science degree from Western University, a Master's degree in International Relations from Queen's University, and holds a PhD in International Relations from Cambridge University.

HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Peter Fragiskatos

Member of Parliament
London North Centre

April 5, 2018

Dear Friends,

As the Member of Parliament for London North Centre, I would like to extend my best wishes to Bethanys Hope Foundation and the London community as you come together for the annual fundraising gala this evening.

In 2016, Bethanys Hope Foundation marked its 20th anniversary. The Foundation, along with its research partners at Western University, London Health Sciences Centre and the Children's Research Institute continues to work tirelessly to provide hope for children battling the devastation of metachromatic leukodystrophy (MLD). By participating in tonight's *Feast with Friends* event, you are supporting the Bethanys Cure Campaign that aims to raise two million dollars to fund up to 5 MLD clinical trials.

Once again I am delighted to join you for this important event. I would like to extend my heartfelt appreciation to Dave and Lindey McIntyre and all the volunteers who dedicate their time, energy and resources to assist Bethanys Hope Foundation with its efforts.

Contributions from members of our community are critical to funding the research that will lead to a cure for MLD. There are many causes you could support, and I genuinely appreciate that you invest in Bethanys Hope Foundation. Through your generosity, families affected by MLD can have hope that a cure is on the horizon.

Kindest Regards,

Peter Fragiskatos
Member of Parliament (MP)
London North Centre

Ottawa
Room 1210, The Valour Building, Ottawa, Ontario K1A 0A6
Tel.: 613-992-0805 Fax.: 613-992-9613

London
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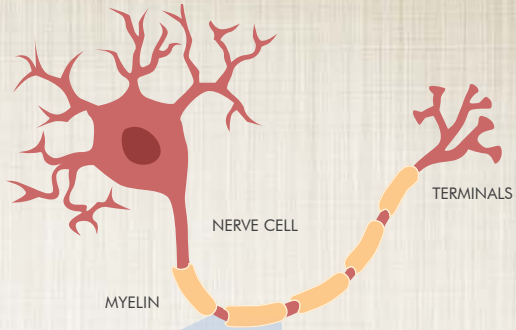
What is MLD?

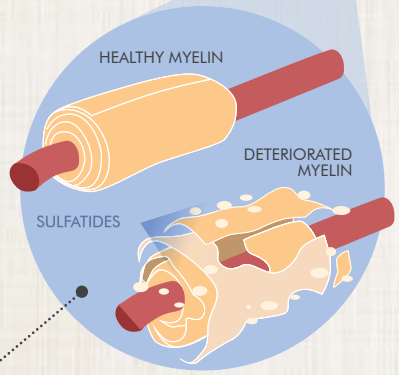
Metachromatic Leukodystrophy, or MLD, is a rare genetic disease that causes part of a person's nerves to degenerate, eventually causing the body to shut down.



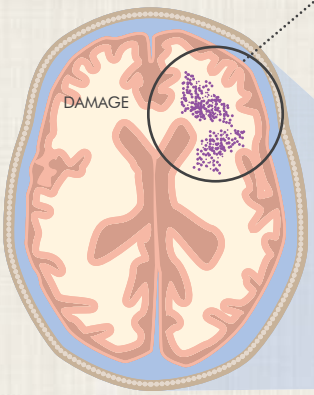
How does it affect the body?

Due to the genetic defect, patients with MLD are unable to produce an enzyme that normally breaks down fatty substances called sulfatides.

The sulfatides accumulate in various tissues but the damage is to the brain and the nerves outside the brain.



The excess sulfatides cause the myelin sheaths that insulate the body's nerves to break down. The loss of functional myelin damages the nerves that control major body functions and keeps the brain from connecting with the rest of the body.

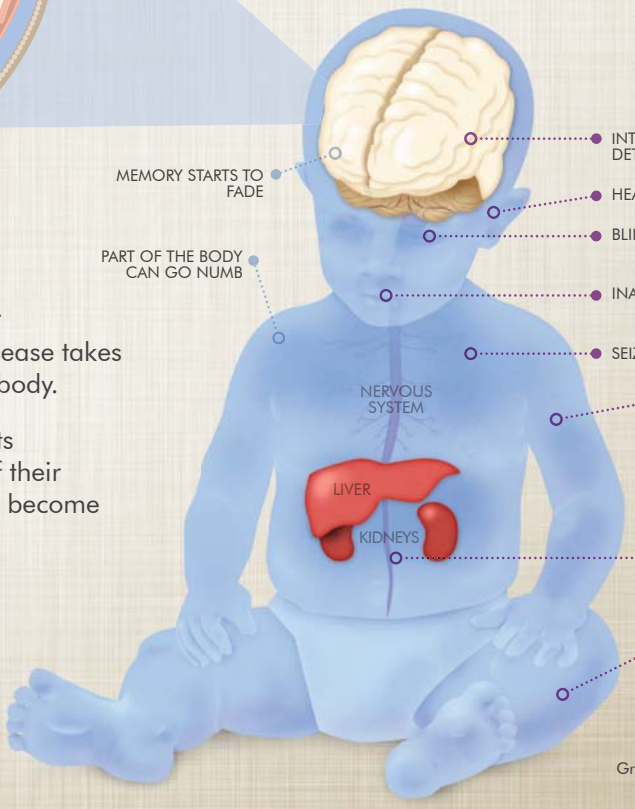


What are the symptoms?

STAGE 1 Usually, the first symptoms are subtle.

STAGE 2 Gradually, the disease takes over more of the body.

STAGE 3 Eventually, patients lose awareness of their surroundings and become unresponsive.



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Graphic courtesy of the Tampa Bay Times, Meredith Ruthland, Lee Glynn I Times. Research assistance: Natalie Watson. Sources: mldfoundation.org, nih.gov, ulf.org, rarediseases.org, All Children's Hospital staff and doctors, mayoclinic.org.

Let's charge towards the cure.

A cure for Metachromatic Leukodystrophy is in sight.

Let's all put the horns to this debilitating disease and raise the funds needed to put an end to MLD by bringing the cure to market.

RedRhino is proud to be on Team 2018. You can help too. Give to the Bethanys Hope Foundation and join Team 2018 at bethanyshope.org/team-2018/

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Farm Tour 5pm • Oyster Hour from 6pm • Feast begins at 7pm
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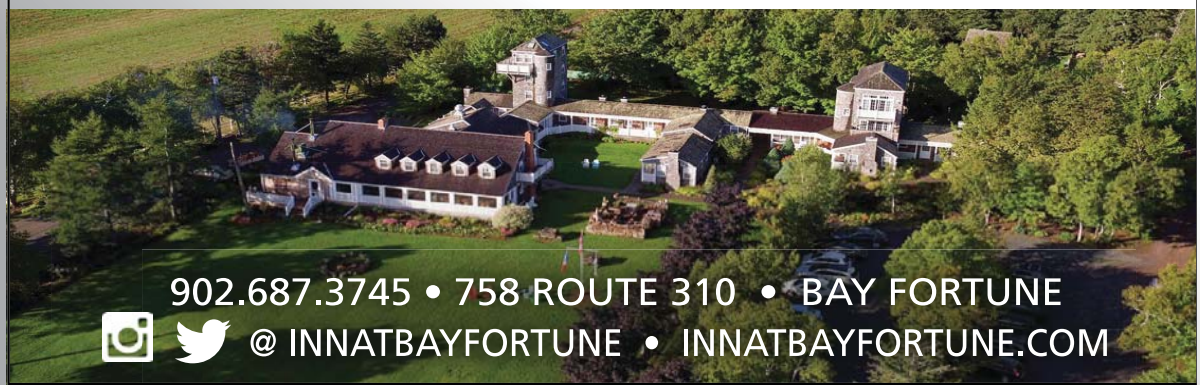

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Our Research

Dr. Tony Rupar

The Bethanys Hope Leukodystrophy Research Laboratory was established by Bethanys Hope Foundation to conduct research to find a treatment and cure for Metachromatic Leukodystrophy (MLD). Dedicated on November 5th, 1999 it was, and still is, the only lab conducting clinical research into the treatment of MLD in Canada.

As with other lysosomal storage disorders, MLD is characterized by the deficiency of an enzyme identified as arylsulfatase A.

The treatments under investigation include those designed to replace the missing enzyme in tissues that are affected by this deficiency, specifically the brain.

Our objective is that this approach will lead to a clinically useful treatment for MLD and other neurodegenerative disorders. The critical path in drug development has five stages that are identified as basic research, prototype design or discovery, pre-clinical development, clinical

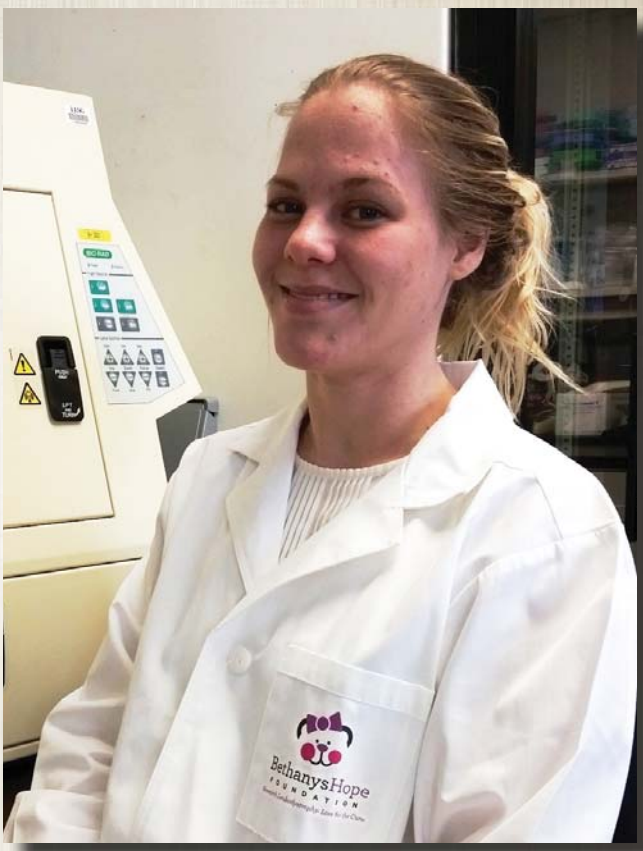
development (including clinical trials) and the final stage of filing for approval and launch preparation. We are excited to be at the pre-clinical stage of treatment.

Our Research uses a mouse model to understand the disease process and develop treatments based on providing arylsulfatase A through gene therapy or stem cell approaches. The laboratory has focused on developing several viral derived gene transfer vectors to treat MLD, as well as evaluating stem cell based approaches.

Regulatory authorities in Canada require specific adherence to safety with regards to any gene therapy vectors. To this end, data is also being accumulated to demonstrate that the treatments are safe.

These experiments are designed to meet the requirements of Health Canada to proceed with clinical trials

Dr. Stephanie Newman



Stephanie Newman has completed her PhD from the University of Oxford, UK. The University of Oxford is rated as the best University in the world and has a long-term reputation of excellence. From a world-renowned research institution Dr. Newman has established a specific research focus in inborn errors of metabolism with a focus on rare lysosomal storage disorder Niemann Pick Disease Type C (NPC).

Dr. Newman has uncovered a specific innate immune abnormality in NPC where results determined NPC macrophage cells display reduced phagocytosis of several targets. Phagocytosis is a physiologically ancient process by which cell engulf and degrade invading particles and microbes. Defective phagocytosis can initiate abnormal immunological and inflammatory responses that we suggest contribute to NPC phenotype. Abnormal phagocytosis also impacts the ability to fight off infection, therefore showing obvious clinical interest in NPC. From this work, Dr. Newman has been presented with both the Peter Carterton Jones memorial award from NPC UK and the WORLD Symposium on lysosomal diseases Young Investigator Award.

Dr. Newman returned to London, Ontario to begin her Post-Doctoral training under the direction of Dr. Tony Rupar, where she will assist in moving the MLD clinical trial forward, bringing new ideas for MLD therapies.

Her research is currently focused on gene therapy to target the central and peripheral nervous system in MLD as well as CRISPR/ Cas-9 gene editing in human MLD fibroblasts. Both projects are aimed at developing successful treatments for MLD. Her career goals are to remain in the field of rare disease research, continuing to focus on discovery of new therapeutics.

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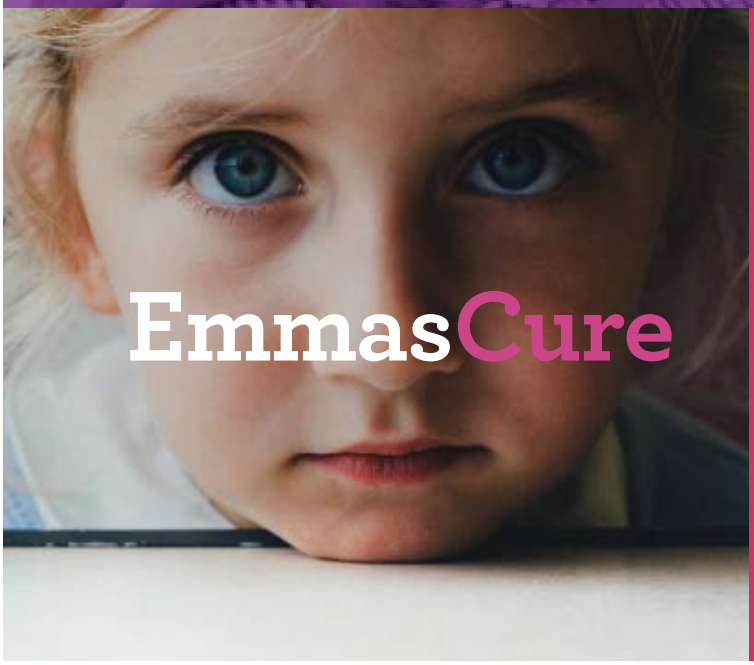

The Cure is in Sight.

Your support could be life-saving. BethanysCure is raising funds for human clinical trials that could finally put an end to MLD.

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BethanysHope FOUNDATION

How do you turn $20 into $100,000?

If every one of us here asked **10** people we knew to donate **$20** each, we could raise **$100,000.**

1. Go to bethanyscure.ca
2. Click the Big Button and Donate.
3. Share to social media and ask 10 people you know to donate too.
4. Watch the progress bar fill up!

Let's keep the momentum going. We can do this!

#hopetoacure

We Can't Quit Now.

We've built the research lab. We've found the doctors. They've set their sights on a cure. We need YOUR help to fund the clinical trials and finish the story.

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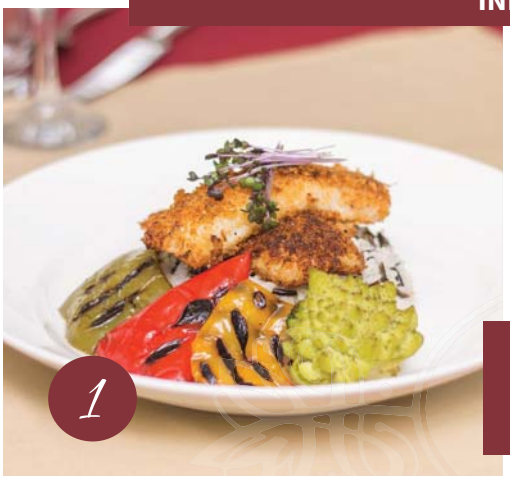

Feature Dishes

1. **CATCH**
   PARMESAN CRUSTED PICKEREL OVER WILD AND BASMATI RICE WITH GRILLED PEPPERS AND BRAISED BROCCOFLOWER
2. **PASTA**
   SQUID INK FETTUCCINE WITH CALAMARI, TIGER SHRIMP AND SCALLOPS IN A BUFFALO MOZZARELLA CREAM SAUCE
3. **GAME**
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"Tournament of Hope"

Absolutely Amazing !!

"Tiger in the Woods" - reaches nearly a Half a Million $$!!

Incredible!! We are many, many steps closer to the answer for Metachromatic Leukodystrophy!

Yet another Record! We hit an amazing goal this year at another extremely successful Tiger Jacks -***"Tiger in the Woods"*** - Charity Golf Tournament in support of Bethanys Hope Foundation. The 2017 Annual Charity Tournament raised another **$43,620** bringing their total to almost a 1/2 Million $$ in just 19 years !!

There is no other Charity Golf Tournament like this! This is a first class Event! Fundraisers such as our ***"Tiger in the Woods"*** would not be possible without great corporate partners & friends! We are extremely grateful to everyone who donated to the Live & Silent Auctions, the amazing Raffle, the Prize Table as well as all our Hole Sponsors. Their continued commitment and amazing generosity is deeply appreciated. Our Researcher's are making new advancements in unlocking the key to a treatment /cure for Metachromatic Leukodystrophy (MLD) and the need for funding is all the more imperative.

Thank-you for joining our "***TEAM for 2018***".... as we prepare to support the children/families and the much anticipated MLD Clinical Trial !

We could not do this without you !!

Special thanks to Mr. Rick DeJager and the Tiger Jacks TEAM !!

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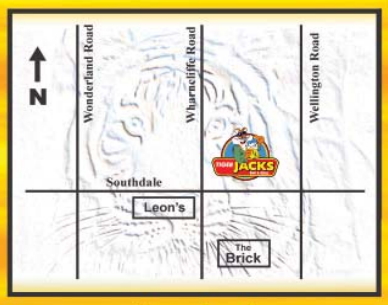

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Layne performs across Canada as a Benefit Auctioneer Specialist, Professional MC/Host and Speaker.

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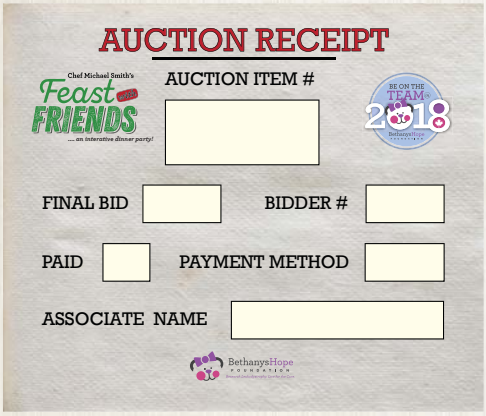
Auction Information

We would like to thank all those who donated the wonderful gifts that make up our Silent and Live Auctions this evening. We understand the enormous demands of our business community for charitable contributions but we also realize we cannot find these medical answers without their ongoing generosity. Their leadership and most importantly their partnership are needed more than ever! We sincerely thank our many corporate and local business friends and all our Guests here this evening for making a difference!

To avoid delays later in the evening we encourage and welcome all the successful bidders to go to the Registration/Cashier - Table anytime during the evening to pay for your treasures.



We gratefully accept payment with the following…….

Ken Girard - Autographed Jersey Package

No. 18 - Toronto Maple Leafs

A beautifully framed *period* Toronto Maple Leaf Hockey Jersey signed by Right Winger - # 18 Kenny Girard who played for Toronto in the late 50's

Ken Girard
Right Wing -- shoots R
Born Dec 8 1936 -- Toronto, ONT
[81 yrs. ago]
Height 6.00 -- Weight 184 [183 cm/83 kg]

List Cards

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			Regular Season						Playoffs					
Season	Team	Lge	GP	G	A	Pts	PIM	+/-	GP	G	A	Pts	PIM
1954-55	Toronto Marlboros	OHA	47	15	14	29	0						
1955-56	Toronto Marlboros	OHA	41	20	12	32	0						
1956-57	Toronto Marlboros	OHA	35	23	11	34	4						
1956-57	Toronto Maple Leafs	NHL	3	0	1	1	2		--	--	--	--	--
1957-58	Rochester Americans	AHL	52	13	10	23	2		--	--	--	--	--
1957-58	Shawinigan Falls Cataracts	QHL	9	0	5	5	6						
1957-58	Toronto Maple Leafs	NHL	3	0	0	0	0		--	--	--	--	--
1959-60	Sudbury Wolves	EPHL	15	5	2	7	0		9	0	1	1	4
1959-60	Toronto Maple Leafs	NHL	1	0	0	0	0		--	--	--	--	--
1960-61	Rochester Americans	AHL	9	0	3	3	0		--	--	--	--	--
1960-61	Sudbury Wolves	EPHL	65	23	18	41	6		--	--	--	--	--
1961-62	Pittsburgh Hornets	AHL	21	4	2	6	2		--	--	--	--	--
1961-62	San Francisco Seals	WHL	31	9	11	20	2		2	0	0	0	0
	NHL Totals		7	0	1	1	2						

Embed Ken Girard stats! | View as text

Generously Donated by:

Mr. Ken Girard - # 18 Toronto Maple Leafs

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Value: Priceless

Dec 8--Ken Girard

Ken Girard

Right-winger Kenny Girard played a few games for the Toronto Maple Leafs in the late 50s. He was a decent scorer and checker who enjoyed a fine career in junior and the minors.

The Toronto native scored 58 goals in three seasons of junior with the Toronto Marlboros. He played a few games for the Leafs late in 1956-57 and at the start of the season. He spent most of his first pro season in 1957-58 as a useful two way player on the Rochester Americans of the AHL.

A fine golfer, Girard devoted the 1958-59 season to playing pro on the links before dressing for one game with Toronto in 1959-60. He played parts of the next three years in the AHL, WHL and EPHL before retiring in 1962. His NHL totals were 7 games played with 1 assist and 2 PIM.

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Generously Donated by:
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Value: Priceless

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Grand Cayman Island Package

TAKE YOUR INNER PIRATE TO THE CARIBBEAN !

Looking for a Fall 2018 Holiday? The water is the VERY WARMEST this time of year, and for the fans of scuba and snorkeling this is as good as it gets. Spend a week, from Oct. 6, 2018 – Oct. 13, 2018 at The Reef Resort on Grand Cayman Island where your biggest decision will be whether to walk out of your two bedroom two bath condo to one of the three pools on site or to take a short stroll along the nearly 1/4 mile of oceanfront beach right on the property! Your beautifully appointed two bedroom OCEANFRONT accommodations sleep six (6) and includes a full kitchen. Located in a secluded part of Grand Cayman, near the Botanical Gardens, world famous Rum Point and the friendly little town of East End, you'll feel far removed from your busy everyday life. Excellent snorkeling, windsurfing equipment, pools, beach bars, and dive boats are just steps away. If you like, the hustle and bustle of Georgetown, a busy cruise port with fabulous shopping, is only 20 miles away.

This is a perfect holiday for a couple who needs some quality time together.

The Fine Print:

Two bedroom OCEANFRONT apartment style condo
Maximum occupancy of SIX (6) people - Includes a full kitchen
Fixed date of (October 6, 2018 – October 13, 2018) is cast in stone!!
Electricity is extra and is surcharged at $325 $US per week, as well as a $70 US weekly tax
Additional incidentals may be extra - this is a self-catering holiday (not an "all inclusive")
Check it out on line at: https://wyndhamcayman.com
AIRFARE IS NOT INCLUDED but there are easy flights from Detroit or Toronto !!

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Chef Michael's PEI Package

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On our farm see how we grow *all* our own vegetables and taste the days harvest. At our legendary Farmers Table overlooking Bay Fortune enjoy the flames as The Fire Brigade prepares your meal from the FireWorks, Chef Michael Smith's wood burning, fire-breathing brick-lined beast.
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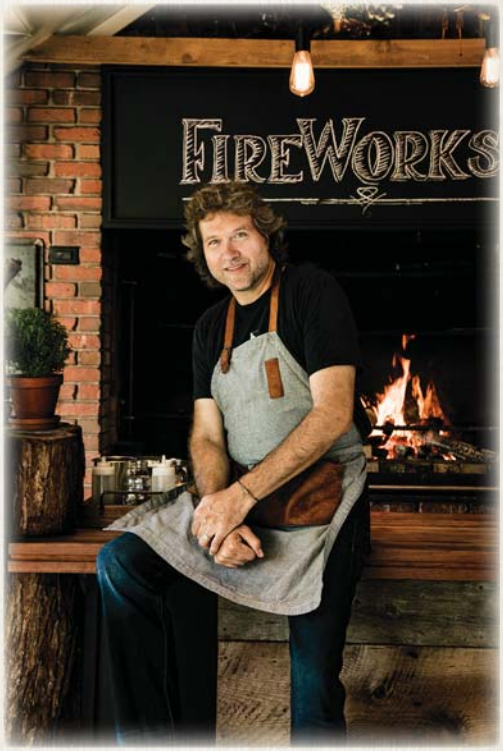

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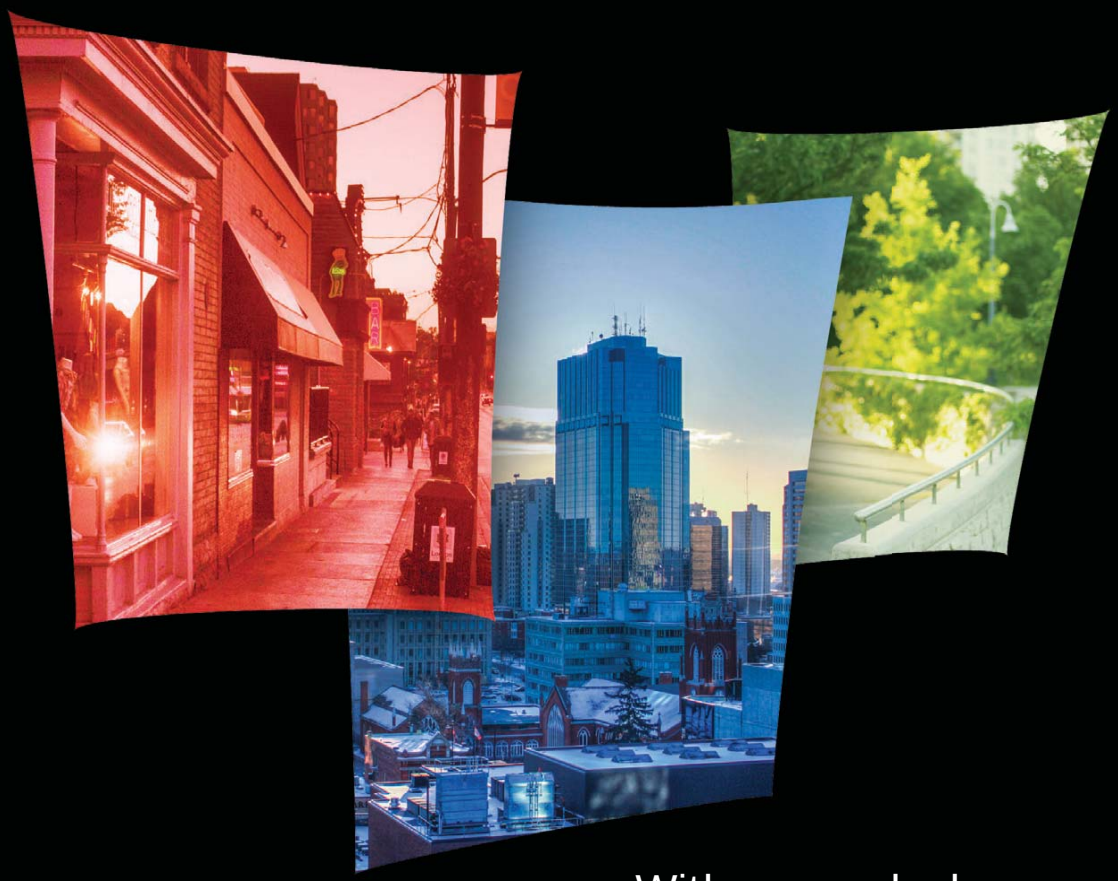

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