



The latest news on the fight against Sanfilippo syndrome. The goal of our Foundation is to fund medical research to find a cure for Sanfilippo syndrome and its related neuro-genetic disorders.



Clockwise from top left: Sophie Hamza with sister Grace; Kirby Wilson age 4, Kirby age 18, Brad and Sue Wilson in front of "Kirby's Korner."

These words the Apostle Paul from Galatians 6:9 reads, "Let's not get tired of doing what is good. At just the right time we will reap a harvest of blessing if we don't give up."

We are inspired and encouraged to keep working towards our goal of finding answers for a treatment so no more families will lose their children at such a young age.

The SCRF Celebrates 20 years

Twenty-two years ago this June, our youngest daughter, Elisa, was diagnosed with a rare terminal illness called Sanfilippo syndrome. There was no treatment or cure for the disease. Desperate for a glimmer of hope, we soon connected with another family whose daughter had the same disease. **Brad and Sue Wilson**, who live in Chicago, had started the "Cure for Kirby" fundraising campaign just after their daughter **Kirby** was diagnosed four years earlier. We thank Brad and Sue for being pioneers in getting Sanfilippo research off the ground and for encouraging us to do the same in Canada.

Kirby passed away on October 22, 2019 at the remarkable age of 28. Her beautiful life inspired many, and will continue to do so. Two years ago, a room was suitably named "Kirby's Korner" at Abeona Therapeutics in Columbus, Ohio, the facility where The Elisa Linton Center for Rare Disease Therapies was established.

This past year, we know of several children who passed away from Sanfilippo disease, many of them much younger than Elisa and Kirby. One of these children was a part of our Sanfilippo family here in Canada: **Sophie Hamza**, our "sweet bee", from Stratford, Ontario.

Inside this issue, we invite you to attend our final gala. Our "**Sugar Sugar, Honey Honey**" 20th Anniversary Gala Celebration will be held on **Thursday April 23rd, 2020** at The Paramount Event Centre. Although our fundraising efforts will continue through garage sales, golf fundraisers, your donations and other events, this will be our last gala. There will be a limited number of tickets available and already one third of our tickets have been sold. We hope you will join us!

We are thrilled that Canadian singer/songwriter **Andy Kim**, who has been a friend to Elisa and our family and wrote and recorded *Sugar Sugar, Baby I Love You, Rock Me Gently*, and many other hits, will join us to perform with his band. **Bill Carroll** from **Talk Radio 1010** returns as our Emcee. For more information, see the enclosed invitation or visit www.alifeforelisa.org to purchase tickets.

Families with Sanfilippo children worldwide continue to depend on The SCRF to support research and bring them hope of a treatment. We thank you for helping us to keep that hope alive.

With warm regards and appreciation,

Randall + Elisabeth Linton

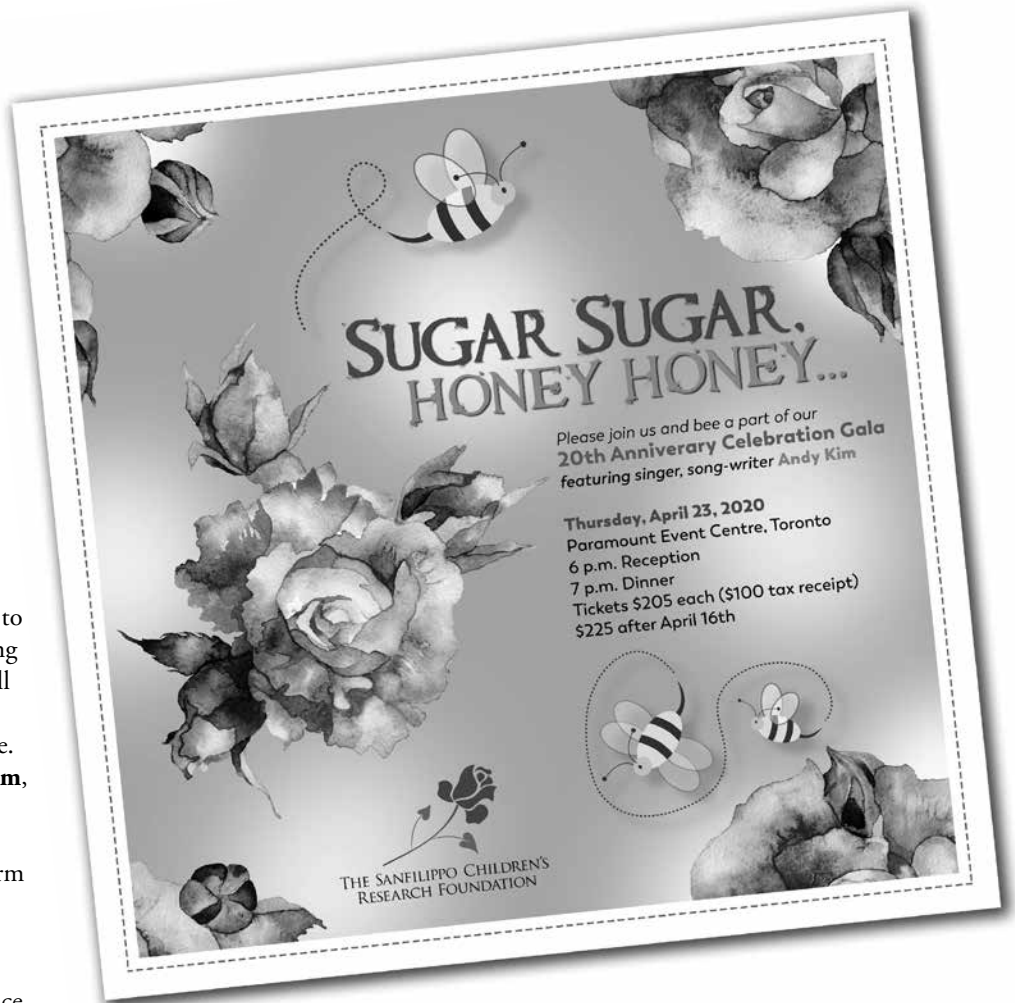
Come BEE a part of our 20th Anniversary Gala Celebration on Thursday April 23rd, 2020!

The Gala committee is working hard to make The SCRF's final gala an evening to remember. This special evening will take place on **Thursday April 23rd, 2020** at The Paramount Event Centre. Canadian singer/songwriter **Andy Kim**, who wrote and recorded *Sugar Sugar*, *Baby I Love You*, *Rock Me Gently*, and many more hits, will join us to perform a benefit as we celebrate our 20th anniversary gala.

We are approaching the 20th year since our first gala event, where 350 guests came together at the King Edward Hotel in Toronto. Our last gala three years ago attracted over 800 guests and we're expecting to fill the Paramount one last time to celebrate all The SCRF has been able to accomplish. Our goal is to raise \$200,000, required to support promising research at the The Elisa Linton Sanfilippo Laboratory in **St. Justine Children's Hospital, in Montreal**.

You can support us by:

- Being a sponsor at the event
 - Gold Sponsorship - \$5,000
 - Silver Sponsorship - \$3,500
 - Bronze Sponsorship - \$2,500
- Providing a special item, product or experience, for our auction or raffle prizes
- Purchasing tickets and/or making a financial donation.



Tickets are \$205 each before April 16th (\$225 after that date) and sponsorship opportunities can be made online at www.alifeforelisa.org or contact Elisabeth at elisabeth@alifeforelisa.org. A tax receipt will be issued in the amount of \$100 for each ticket purchased. Charitable Foundation #87391 3628 RR0001

If you'd prefer to make a donation or pay for tickets by cheque (payable to **The Sanfilippo Children's Research Foundation**), mail it along with your address, the number of tickets you need, and the names of people in your party to:



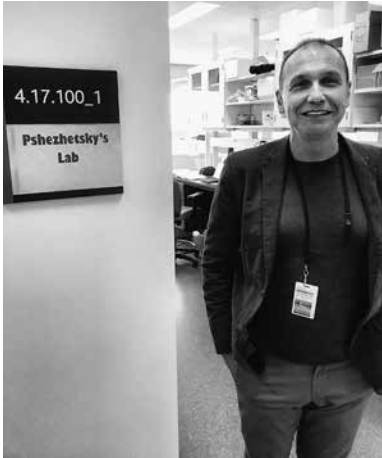
The SCRF
41 Gwendolen Avenue
Toronto, ON M2N 1A1

If you have an auction / raffle contribution or any questions, please contact Elisabeth@alifeforelisa.org or 416-223-1911.

Thank you for BEElieving in our dream and supporting our important work as we work together towards finding a cure.

Without your faithful support over the past years, none of the research projects we've collaborated on over many years would have been possible. The past year has been an exciting time for progress in Sanfilippo research where funds from The SCRF have been involved.

Dr. Alexey Pshezhetsky **The Elisa Linton Sanfilippo Research Laboratory,** **Sainte-Justine Children's Hospital, Montreal**



This past year, we've continued to move forward in our research, focusing on four key areas that show the most promise in leading us closer to developing effective therapies.

Stem-cell gene therapy: targeting neuroinflammation to treat the disease

Previously, we produced mouse models with genetic defects similar to those found in Sanfilippo patients to gain a better understanding of how the disease affects children. Through this research, we found that certain brain cells called microglia are especially affected by the disease; as a result, it causes inflammation of brain tissue (neuroinflammation) and the death of brain neurons (neurodegeneration). We are now using Sanfilippo mice to verify new treatments that could potentially cure or mitigate the disease.

In October 2019, we transplanted the first group of four Sanfilippo mice with the gene-corrected cells. Importantly, all animals survived the procedure. With this current group, our objective is to access the level of gene-corrected microglia and note the level of inflammation in the brain. If this first step proves to be conclusive in altering neuroinflammation, we will proceed with transplanting new groups of mice to test whether the treatment improves their memory and behaviour and increases their lifespan. Ultimately, the goal would be to move to clinical trial in human patients.

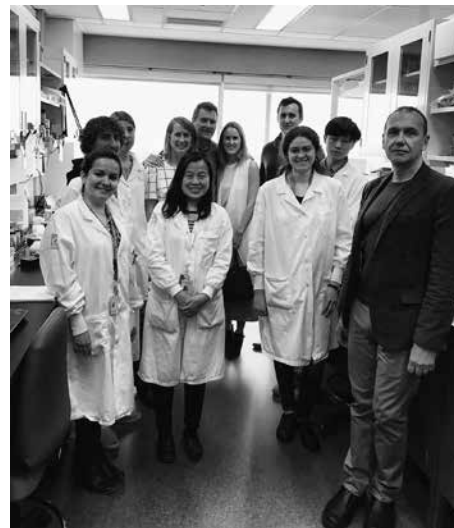
Importantly, this project is part of a group effort by several researchers and clinicians of CHU Ste-Justine who want to develop gene and stem cell therapies for monogenic diseases. This research team has recently initiated a multi-million-dollar application for equipment for a "Center for Gene, Cell and Tissue Engineering for Treatment of Rare Diseases and Cancer" to conduct this research and future clinical trials.

Synaptic deficits in Sanfilippo disease

One of the most distressing aspects of Sanfilippo syndrome is the rapid mental decline that ensues in affected patients. In this ongoing research project, we aim to understand why Sanfilippo syndrome causes problems in the behaviour, learning and memory of affected children even before massive neuronal death occurs.

Previously, we hypothesized that these problems could be caused by defects in neurotransmission (transmission of signals between the neurons). More specifically, we proposed that the synapses (the structures through which neurons communicate) were altered in Sanfilippo patients' neurons. We tested this hypothesis and demonstrated that CA1 pyramidal neurons of the Mucopolysaccharidosis (MPS)IIIC mouse model show drastic synaptic and neurotransmission defects preceding the first cognitive symptoms and originating from disrupted microtubule structure and transport of vesicles carrying the synaptic proteins. A manuscript describing these results has been produced.

Throughout 2019, this project has advanced greatly. Our new major finding is that only one out of several types of neurotransmission is affected in Sanfilippo type C: the excitatory



(also known as glutamatergic) transmission. Moreover, we have discovered a drug that can correct this deficit in mice, which leaves us hopeful that we will obtain similar outcomes with human patients.

This finding now allows us to start expanding

beyond our scope of Sanfilippo type C to other models of Sanfilippo (A and B), as well as to MPS type I, to see if the effect is common across all neurological mucopolysaccharidoses. We are also in the process of discussing collaborations with the industry to find treatments and cures for Sanfilippo syndrome. We plan on submitting a grant proposal to the Canadian Institutes of Health Research on this subject.

An important part of the preclinical studies will be to test the drug on human neurons derived from stem cells. We have already obtained pluripotent stem cells (iPSCs) from Sanfilippo C patients' skin cells and started converting them to neuronal progenitor cells, and then to further differentiated neurons.

This will pave the road to two new treatment avenues for Sanfilippo:

- Stem cell therapy, through which we produce iPSCs from patients, correct the mutations by editing the genome invitro, and then re-inject cells back into the patient
- Drug screening, through which we test different drugs on the patient's cells to see which therapy works best.

Secondary changes in neuronal glycosylation in Sanfilippo syndrome

In this project, we analyze the chains of sugar molecules that cover the surface of brain cells. They are especially important as they promote the differentiation of neuronal progenitor cells and ensure their correct migration to appropriate areas within the brain, as well as their connection with other cells.

Last year we established that, in the brains of Sanfilippo mice, one of these sugars called sialic acid existed in greater quantities due to a lack of the enzyme that normally removes it from the cell surface. Over the course of the last year, we were able to prove that this phenomenon extends to all subtypes of Sanfilippo disease and to other neurological MPS disorders. After obtaining these results in the animal models of MPS, we filed a request with the NeuroBioBank at the National Institute of Health (NIH) to obtain autopsy materials from the patients' brains – unique samples that are rarely granted to researchers. With this, we were able to confirm that the effect extends to the human patients and is common for neurological MPS diseases.

Our goal for the next year would be to understand the pathological consequences of neuronal glycosylation changes in MPS patients.

Evolutionary history of Sanfilippo C syndrome

With clinical trials approaching the step of testing therapies for Sanfilippo syndrome, the consolidation of data on the disease's history as well as exhaustive patient registries become crucial for their success. The knowledge of distribution and the frequency of MPS IIIC mutations in the populations should enable faster detection of patients and, in the future, lead to more efficient therapeutic approaches.

In this study, they analyzed molecular defects in the HGSNAT gene in the largest group of MPS IIIC patients studied so far, thus increasing the total number of HGSNAT variants associated with MPS IIIC to 71. This project was in its final stages last year but the paper that we wrote on this subject was published in August 2019. It was voted as the editorial choice in the peer-reviewed journal *Human Mutation* and featured on its cover.

Dr. Francis Choy University of Victoria, BC

WORLDSymposium Young Investigator Awards

Rhea Ashmead and Chloe Christensen, two doctoral graduates who are working on Sanfilippo research projects funded by The SCRF under the leadership of Dr. Francis Choy, both won the prestigious 2019 WORLDSymposium Young Investigator Awards for Basic Science. The award recognized their work and paper entitled "Cell and Gene Therapies for Mucopolysaccharidoses: Base Editing and Therapeutic Delivery to the CNS" that was published in the MDPI journal *Diseases* in 2019. The award was presented at the Symposium's opening reception last year and reflects the excellent candidacy of Rhea and Chloe as scientific trainees as well as the significance and impact of their research in the field.

Abeona Therapeutics Inc. Cleveland, Ohio

Update on gene therapy clinical trials which commenced May 2016. Abeona is still currently enrolling eligible patients into Phase 1/2 gene therapy clinical trials for MPS IIIA and IIIB.

transpher A study **transpher B** study
ABO-102 for MPS IIIA ABO-101 for MPS IIIB

Abeona is continuing to conduct global clinical trials to assess the safety and efficacy of gene therapies for patients with MPS IIIA (Transpher A) and IIIB (Transpher B). On July 25, 2019, Abeona reported positive interim data from the Transpher A study. The data suggests that ABO-102 has a favourable safety profile and therapeutic potential for the treatment of MPS IIIA. Neurocognitive development was preserved in the three youngest patients enrolled in high-dose cohort 3 and they were tracking within normal age equivalent development 12-18 months after treatment. Robust and sustained biomarker improvements were seen across all dose cohorts, 8-24 months after treatment, and no product-related serious adverse events were reported in the study.

Abeona has expended its trial sites outside the US. The Transpher A study is being conducted at clinical sites in the U.S., Spain, and Australia, while the Transpher B study has sites in the U.S, Spain, and France. Travel assistance is available for patients and their families enrolled in either study.

At Abeonatrials.com, you can find a six-question survey to see if a child may be eligible for the Transfer A study. If the survey results suggest that the child may be eligible for the study, there is an option to send the information to the nearest clinical study site for evaluation by a study investigator. Completing the survey does not mean a child is eligible; the doctor overseeing the clinical study at each site (principal investigator) will still

need to evaluate and decide if the child can undergo screening for enrollment in the study. Only after the full screening process is complete at the site will the investigator be able to determine if the child is eligible to participate in the study.

Abeona has also expanded its clinical trials to enroll patients with middle and advanced phases of MPS IIIA who may not be eligible for the Transpher A study. Study ABT-003 clinical trial is evaluating a single dose of ABO-102 that is delivered using an intravenously administered AAV9 vector. While there is no age requirement in this study, potential volunteers must have a cognitive DQ lower than 60 to be screened for enrollment. They must also be ambulatory, with or without assistance. A full list of inclusion/exclusion criteria for study ABT-003 is available at ClinicalTrials.gov by searching “NCT04088734.”

Dr. Adreas Schulze SickKids Hospital, Toronto

Thanks to your support The SCRF fulfilled its commitment last year of **\$300,000**, which was matched by the SickKids Foundation, to purchase an analytical ultra-performance chromatography coupled with tandem mass spectrometer (UPLC-MSMS) necessary for Sanfilippo research to move forward at SickKids Hospital in Toronto.

Dr. Andreas Schulze & Ilona Tkachyova, Research Project Coordinator, next to equipment we purchased for SickKids Hospital



Our funding over the years has moved research forward at SickKids and it's now at an exciting stage. Dr. Andreas Schulze's research group is advancing promising work to find a treatment

for Sanfilippo syndrome. They are involved in a highly anticipated drug discovery research project that will screen thousands of chemical compounds for their potential to treat Sanfilippo syndrome. Promising compounds will be tested and screened using this new equipment against approved drugs, therefore shortening the time it takes to move discoveries into the clinic. The project will focus on a particular process inside the cells that is involved in causing Sanfilippo syndrome and other MPS disorders.

Over the past 20 years The SCRF has contributed over \$1million towards Sanfilippo research grants at SickKids Hospital and to recognize our support they have named Dr. Schulze's lab "The Sanfilippo Children's Research Laboratory."

96%

Thank you for your generous and ongoing support that has enabled these projects to happen. **TODAY'S** research will lead to **TOMORROW'S** treatments!

We are proud that we are still able to report that **96% of every dollar** donated to the SCRF goes directly to research!

Let us know if you...

- Plan to move, and want to give us your change of address so that you can continue to receive newsletters;
- Have an idea, comment, auction item, or another contribution you would like to share;
- Require more information about Sanfilippo or The SCRF;
- Wish to receive a copy of our Annual Report;
- Wish to be taken off our mailing list; or
- Want to know how you can get involved...

Call us at (416) 223-1911 or email elisabeth@alifeforelisa.org.

Giving Made Easy

If you'd like to help The SCRF but don't have much money or time to spare, consider these ideas. They're easy on your schedule and pocketbook!

- Next time a **special birthday, anniversary or Christmas** approaches, consider donating to the SCRF in lieu of another gift.
- Does your company have a **matching gift** program? They might be willing to double your support of the Foundation.
- Did you know that you can donate to The SCRF through the **United Way** program at your workplace? Just designate your contribution to the SCRF through the section "Others." Thanks to those who have already contributed this way—your support has been significant. **Our Foundation number for reference is #87391 3628.**
- **Give stocks to the SCRF and reduce your taxes.** By donating stocks to The SCRF instead of cash, you can support our cause while reducing your capital gains taxes. Please contact us for more details.
- Become a **Monthly Donor.** Spread your donation throughout the year by signing up through CanadaHelps.com. The link can be found through our website www.alifeforelisa.org. Thank you!

Our Caring Community

Our heartfelt thanks to these individuals and organizations for their fundraising efforts:

Chorus For A Cure

Six years ago, the Dendekker family from Dundas, Ontario joined in the efforts to support The SCRF when their son Warren and daughter Katherine were diagnosed with Sanfilippo syndrome. Warren passed away four and a half years ago at the age of 10. Katherine is now 11 years of age. In October 2018, **the Dendekker family** and their community built on the success of three previous musical fundraisers and provided a memorable evening of classical music in Hamilton raising



over **\$105,000**. A stellar line-up of classical musicians donated their time to showcase their musical talents for over 600 guests. Funds were raised that evening through donations and a wonderful silent auction. We are grateful for all the Dendekkers have

contributed and their determination to keep hope alive for Katherine and other children.



TheAnswersIs.ca

Our good friend and SCRF supporter, **David Jenkins, HBA, ICD.D,**

is a Toronto real estate executive, entrepreneur and long-time investor who launched TheAnswersIs.ca to share investing tips and create awareness and funds for The SCRF.

His non-profit website helps simplify the complex world of investing, giving people – especially millennials with long time horizons – the knowledge, aptitude and confidence to invest successfully. Users register to be guided to purchase a balanced blend of ETF investments designed for long-term growth and diversification. But **instead of charging advisor fees, David simply asks users to donate to The SCRF.**

David has had the opportunity to speak with students at several universities and high schools, including Western University's Ivey Business School, York University's Schulich School of Business, White Oaks High School's TechUnderTwenty, as well as several businesses and Rotary Clubs, raising **over \$2,000** this past year for the SCRF.

If you know of an organization that would like to book David for a free, interactive presentation on long-term investing and TheAnswersIs.ca, please contact David at djenkins@theanswersis.ca or 647-926-8941.

101Temptations Sweetens Up Hope For a Cure

Six years ago, Elisa's sister, **Jessica Mason**, wondered how she could raise \$4,000 to honour her quota for The SCRF Mount Kilimanjaro expedition. She decided to put her passion for baking to work for her sister's cause. From the beginning of November to the end of December 2012, she baked non-stop, creating holiday treats for family and friends, raising much more money than required. Word got out and requests kept coming in. As a result, **101Temptations.com** was born.



Elisabeth Linton teamed up with Jess to create unique and tasty treats in hope of raising more funds and awareness for Sanfilippo research. Eight years later, this part-time home business has raised **nearly \$20,000** for The SCRF. Although they are known for their butter tarts, Jessica and Elisabeth have satisfied orders ranging from one single cake to 3,000 cookies and cupcakes. No order is too big or small!

Check out **101Temptations.com** and let them know what they can prepare for your next family celebration, corporate event, wedding, anniversary celebration or sudden craving!

H&R REIT Continues to Buzz with Support for The SCRF

Last spring, **H&R REIT's** management office at 310 Front Street in Toronto teamed up once again with beekeepers to make use of its tower roof space by putting thousands of bees to work for a good cause. Over 80 beehives were placed there for the summer to enable bees to work diligently producing honey. This past fall, the honey was harvested, bottled and sold to tenants. It raised **\$2,000** for The SCRF! Thank you to



Mary De La Franier and her team for their sweet contribution and ongoing support!

We will have this honey available for purchase this year at the Sugar Sugar, Honey Honey Gala Celebration on Thursday April 23rd.

Acknowledgements

Thank you to our corporate contributors for your donations:

101 Temptations • AMT Mechanical Ltd. • Ampere Electric • Applied Systems Technologies Inc. • Atlantis Restoration Contracting • Carson Dunlop & Associates • Certa Pro Rosedale • Constant Controls Ltd. • Copperhead Mechanical • DeSousa Painters • Hill & Knowlton • Hospice Care Avon Maitland • Indigo Parc Canada Inc. • Interior Care Ltd. • Joseph Kelly Professional Corp. • Lazy Poet Creative • Macgregors Meat & Seafood Ltd. • Method O.M.T. Janitorial • ORA*DBA Systems Consulting Ltd. • Orr Insurance & Investment • Paragon Security • Patricia & Doug Markle • Q-Air • R.S. Kane Ltd. • Rochester Midland • Royal Lepage Signature Realty • Safe-T Lock & File Services Inc. • Salivan Landscaping • Skyreach Window Cleaning • Solar Group Inc. • Terrazzo Mosaic & Tile Company Ltd. • Thacker Consulting and Investigations Inc. • Tri-Can Contract Inc. • Wasteco

Special thanks to these companies for supporting The SCRF in various and unique ways:

H&R REIT • Interior Care Ltd. • Lazy Poet Creative

Memorial Contributions

Many donations have been made to The SCRF over the past year to honour or in memory of a loved one or friend. We thank those who have recently contributed to honour:

Andrew Aikenhead • Kerrin Bankert • Matthew Bankert • Faye Boehmer • Jim Boehmer • Jeffrey Collins • Joan Crone • Donald Crone • Warren Dendekker • Charlie Dominico • Sophie Hamza • Elisa Linton • Christine Macleod • David Markle • Lawrence Nakamura • Edna Power • John Radford • Bernie Smith • Eric Timms • Corradina Tumminieri • Richard Nicola Venditti • Kirby Wilson • Audrey Woodcock • Emily Yeskoo

Milestone Contributions

We thank everyone who recently contributed to honour:

Paul & Marilyn Barker • Tamiko Barker • Paul & Marilyn Barker • Lorrie Boehmer's 60th birthday • Jonathan Chayer • Peter & Sandra Dendekker • Warren Dendekker • Kim Dunski • Fiona Humphry • Michaela Kameka • Randall Linton's 60th birthday • Henry Lucas • Sharon Mah-Gin's 60th birthday • Paul & Cindy Mosey • Charlotte Quesnel • Catherine Robertson • Louise Stefancic • Adrienne Taylor's 85th birthday • Mary & Doug Turner's Anniversary and Birthdays

Roses for Sanfilippo Continues to Bloom

Eleanor Walters, a grandmother and avid crocheter, devotes much of her time to crocheting small roses in various colours and putting them on pins, hair clips, headbands and mitts to sell at schools, flea markets, shopping malls, businesses and community events. She donates all the money raised to The SCRF and uses these events to tell Elisa's story and spread awareness of Sanfilippo children. Last year, she raised another **\$8,000!**

We thank you, Eleanor, for your tireless efforts and dedication to help The SCRF. **If you know of an opportunity for Eleanor to sell her roses or wish to donate colourful yarn to support her efforts, please contact Elisabeth at The SCRF office.** Thank you!

Scream in Memory of Elisa – Oct. 31st 2019

For a number of years, **the Di Nardo family** in our community has rallied the help of dozens of student volunteers to stage an amazing "Scream for Elisa" Haunted House on Halloween night. All funds raised have been donated to The SCRF. Three years ago, after Elisa's passing on Halloween, the event was re-named "Scream in Memory of Elisa." This past year the Di Nardos put on another scary, fun, creative and significant event. And best of all, **\$3,500** was raised! Heartfelt thanks for the hard work and leadership of **Riley Di Nardo** along with his rugby team, **Toronto City Amazons**, the entire Di Nardo family, their many volunteers and our trick-or-treating community for your support.

Elisa Linton Friendship Award

The Elisa Linton Linton Friendship Award was created at **Willowdale Middle School (WMS)** in 2018. It honours a graduating student who creates an inclusive environment while impacting the lives of students with special needs and learning challenges, at school or after hours. The recipients have strong academic standing along with a positive reputation and character.



WMS is the school where Jessica and Connor Linton and many of Elisa's community friends attended. The school "adopted" Elisa and her cause about 17 years ago and has raised thousands of dollars for The SCRF. This year The Elisa Linton Friendship Award was proudly presented to **Dylan Smith**. Congratulations, Dylan!

Dendekker siblings inspire Spring into Health fundraiser

Dr. Sandra Malpass' family chiropractic office in Ancaster, Ontario held its annual raffle and fundraiser in honour of Warren and Katherine Dendekker, and raised over **\$1,000** for The SCRF. Thank you to all for your faithful efforts in helping us spring research forward.

Upcoming SCRF Fundraisers

20th Anniversary Gala Celebration Thursday April 23rd, 2020!

For details, see page 2.



SCRF Annual Garage Sale, Bake Sale and BBQ Saturday, May 9th, 2020, 8 am – 3 pm

Please join us for this annual community event. We welcome any new and used “treasures” for us to sell. People come, literally, from all over the city for our great deals, the best hot dogs donated by **Chicago 58**, and home-made baking by **101Temptations.com**. This year we welcome back 10-minute massages by the amazing therapists at **Bayview Sheppard RMT**. Last year your support raised **over \$6,000!** Please contact **elisabeth@alifeforelisa.org** if you have donations to contribute. The closer to the date in May the better as we have limited storage. Thank you.



“Fore Elisa” Golf Fundraiser Swings In \$16,000! Join us this September 14th

For the last two years, our golf fundraiser has been in June, but this year we’re moving it back to September due to our gala this spring. Please consider joining us for this fun and intimate tournament for 32 golfers on Monday, September 14th at the **Don Valley Golf Course**. The event includes an 18-hole challenge, a delicious dinner at **Mezza Notte Trattoria** as well as prizes and favours. Golfers are asked to raise or contribute \$300 to participate.

Huge thanks to all the golfers and their sponsors who raised **\$16,000** for The SCRF last year as well as the Don Valley Golf Course and Mezza Notte for their significant contributions. We hope to see you all again this September. New players are always welcome, too!



Our Sweet Bee, **Sophie Hamza** passed away unexpectedly in her sleep on the morning of Friday, August 23rd, 2019. When Sophie was diagnosed at the young age of 2 her parents, family and community jumped in and initiated *Strides for Sophie*. It felt natural that the bee – whose shape should make it impossible to fly – would be her symbol of hope.

Tom and Sarah Hamza organized walkathons in Straford where they live, and have rallied large numbers of family and friends to participate in the Scotiabank Waterfront Marathon over the years. They have raised almost **\$500,000** through these events with all of it donated to The SCRF. Over **\$110,000** was donated this past September in Sophie’s memory.

Sophie’s journey was defined by how she touched so many people. In her 11 1/2 years, she made us remember to live with each other in the moment and to love the people around us. Her friends and supporters at school made inclusive education an opportunity for her to learn from normally abled kids, and to teach them too. She grew up with kids that saw her as equal, but



different, and who treated her as a friend. She went to their birthday parties and grew up with them. She travelled extensively and experienced a world of sights, sounds, and tastes.

Those that worked around her in the schools and the medical system worked like mad to build playgrounds, fund research and create an inclusive community. She inspired change and made us work harder, like any Queen Bee would do.

If we measure life in love, instead of years, she lived to be an old woman. She was kissed with the love that we will be fortunate to get in a 100-year lifetime.

We thank the Hamzas for sharing their BEEautiful daughter with us and for their courage and determination to work together with us to find a treatment for Sanfilippo. Sophie will remain forever in our hearts as her legacy of hope lives on while our bumblebee flies free.

Sanfilippo syndrome?

Children with Sanfilippo syndrome are missing an essential enzyme that breaks down a complex body sugar called heparan sulfate. This sugar slowly builds up in the bones, the brain and other organs, stopping normal development and causing hyperactivity, sleep disorders, loss of speech, mental retardation, dementia, and finally death by the mid teens. There is no cure or treatment yet.

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