



**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.

“There are special people in our lives who never leave us, even after they are gone.”

– D. Morgan

## Thanksgiving Greetings,

It's hard to believe that it's been over twelve months since we wrote an update to our friends and supporters on what's been happening in the world of Sanfilippo fundraising and awareness-building. The last issue paid tribute to Elisa's life; in this issue, we share many exciting events that have taken place since her passing October 31st, almost two years ago. You will read about how Elisa's life has been honoured as she touched and inspired so many, positive research progress with the gene therapy clinical trials, and new research endeavours being supported by The SCRF.

While we have reduced our fundraising recently compared to our intense efforts over the past 18 years, we are not stopping. Too many children have passed away from Sanfilippo this past year much younger than Elisa was. Families with Sanfilippo children worldwide depend on The SCRF to support research and bring them hope of a treatment. Galatians 6:9 NLT 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”*. These truthful and inspiring words encourage us to keep working towards our goal.

**We have recently made a pledge of \$300K to SickKids Hospital to purchase equipment needed for Sanfilippo and other genetic disease research. We have raised \$100K to date towards this pledge and ask you to please continue supporting our efforts to raise the balance.**

You can help us reach our \$200K goal by making a donation to our upcoming fundraisers this October:

- **The “Chorus for a Cure” Concert on October 5th and**
- **The Linton family's half marathon this fall in memory of Elisa.**

**We don't think we could ever adequately express our appreciation for our community of supporters for bringing research to where it is today and how thankful we are that Elisa's life has contributed to this.**

As Thanksgiving approaches, we also want to thank our family, friends and community for being there for us on a personal level as we have struggled through an emotional first year and a half without Elisa. There were many opportunities to enjoy the memory of who Lissy was, what she meant to our family and the amazing community she built around us. You have all been a blessing to our family as we've celebrated so many firsts. These past months have brought about events and moments we never could have imagined. Read on to learn more.

And lastly, we can't help but share our wonderful news from our daughter Jessica and her husband Cameron: we became grandparents this past September 5th to a dear little girl named Chloe Elisa Amy. Needless to say, we are thrilled for them and are excited about the new life entering the Mason and Linton families.

Thank you again for your continued love and support and we wish you a happy and safe fall and holiday season fast approaching.

With warm regards and appreciation, and wishes for a blessed Thanksgiving,

Randall, Elisabeth and family

## Remembering Elisa...

### Gwendolen Park Bench Dedication

In May 2017, a park bench was dedicated in Elisa's memory in Gwendolen Park, three houses down the street from her home. This amazing act of love was initiated by our dear family friend **Tracy Keenan**, who rallied friends and neighbours of West Lansing to donate money to make it happen. Tracy and her husband **Bill** made sure the bench was strategically placed so that it faced the playground where Elisa loved to sit in her wheelchair and watch children play. It's also in line with the south-west corner of our home, facing both of Elisa's bedrooms, where she resided all of her 22 years. A big thank you to Tracy and our amazing community here in West Lansing for making this lasting tribute possible. We think of our dear Elisa every time we sit in the shade on her bench.



### Red Maple Tree Planting – July 1st

To honour Canada's 150th birthday and Elisa's life, our family felt it appropriate to bury Elisa's ashes on July 1st, 2017 at our family cottage in Minden, Ontario. The cottage is where we have so many happy memories of Elisa, and a place she loved to be. Elisa spent her last Thanksgiving with family here, sitting on the porch to enjoy that weekend's beautiful warmth and sunshine.

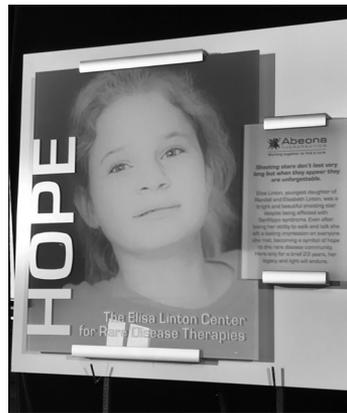
We planted the tree in clear view of the screened-in porch where she spent many hours protected from both the "skitos" and the elements, while looking at the lake and feeling the cool



breeze. Appropriately, the leaves of this red maple tree, called "Red Sunset," will turn a vibrant red in the fall, which is the time of year when Elisa left us.

### The Elisa Linton Center for Rare Disease Therapies

In 2013, Abeona Therapeutics was created to transform scientific discoveries in genetic research into breakthrough gene therapies for children and adults living with rare and life-threatening diseases such as Sanfilippo syndrome.



In October 2017, Abeona celebrated the groundbreaking of the first medical gene therapy manufacturing facility in Ohio. This Cleveland-based facility is graciously named **The Elisa Linton Center for Rare Disease Therapies** and will house the development of next-generation gene therapies for patients with rare diseases and facilitate the commercial entry of

pipeline products. This 6,000-square-foot centre was built and validated in the months after the groundbreaking and the grand opening took place this past May. The Linton family and friends were honoured to attend both the groundbreaking and opening ceremonies, during which both Elisa's life and Abeona's progress were celebrated.



"We are very excited to announce the creation of The Elisa Linton Center for Rare Disease Therapies, which will be a global resource for production of gene therapies with the potential to bring new treatments to rare disease patients around the world," said **Timothy J. Miller, Ph.D.**, Chief Scientific Officer and President of Abeona Therapeutics. "It is especially fitting that this center is named for Elisa Linton, who was born with Sanfilippo syndrome, a rare terminal disease. The memory of Elisa and the courage of her family continue to be a great inspiration to all members of the rare disease community."

## Linton Family Honoured with The Rare Heroes Award

This past May, the Linton family was invited to attend The Canadian MPS Society's annual fundraising dinner at the Vancouver Club in BC, where Elisabeth was to be presented with The Rare Heroes Award for her 18 years of advocacy and fundraising for Sanfilippo disease. When **Kim Angel**, Executive Director of The MPS Society, introduced the award, it was actually being presented to the entire Linton family to honour Elisa's life and their amazing and collective efforts in bringing awareness and moving vital research forward globally. The Lintons were most grateful for the honour and thank Kim and The MPS Society for this humbling acknowledgement.



## Elisa Linton Friendship Award

This past June, The Elisa Linton Friendship Award was created at **Willowdale Middle School (WMS)**. It will honour the graduating student whom the schools feels is most deserving of recognition for leadership in creating an inclusive environment and positively impacting the lives of students with special needs and learning challenges, at school or after hours. The recipients will have strong academic standing along with a positive reputation and character.



Because Elisa's illness significantly affected her physical and mental abilities, her early years at school were truly enriched by friends who cared for, included and embraced her and helped her reach her full potential. It is to honour young people with this caring spirit that this award was created.



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 15 years ago and have raised thousands for The SCRF. The inaugural Elisa Linton Friendship Award was proudly presented to **Morgan Greenaway**.

Without your faithful support over the past years, the research projects discussed below would not be at the exciting stages they are today. Thank you for your support enabling them to happen. The past two years has been an exciting time for progress in Sanfilippo research.

## SCRF Endowment Fund to Sainte-Justine Children's Hospital

On Wednesday, November 8th, 2017, one year to the day after saying our final farewell to Elisa, the Linton family and friends joined the team at Ste. Justine Children's Hospital in Montreal for the dedication of **The Elisa Linton Sanfilippo Research Laboratory**. This was all made possible through a **\$1 million** grant to establish **The SCRF Endowment Fund** at this fabulous institution. The SCRF felt it was important at this time to establish a lab here in Canada with a dedicated research team that will ensure Sanfilippo research continues indefinitely.



This lab, headed by **Dr. Alexey V. Pshezhetsky**, professor at the Université de Montréal and researcher with the Metabolic Health and Complex Diseases Research Axis at CHU Sainte-Justine's Research Centre, discovered the gene mutation for Sanfilippo C with funding from The SCRF back in 2006, and continues to research potential treatments and therapies.



Dr. Pshezhetsky and his team were chosen because of their contributions to the advancement of Sanfilippo knowledge worldwide and their ongoing work with the disease.

Dr. Pshezhetsky states, "This donation will significantly accelerate the development of therapy for serious childhood diseases like Sanfilippo and will

pave the way for a cure for other pediatric neurodegenerative disorders caused by protein defects.”

The Ste. Justine Foundation team hosted a most memorable and meaningful reception with the event themed so appropriately after Antoine Saint-Exupery’s classic book *The Little Prince*, in which he writes, “**It is the time you have spent with your rose that makes your rose so important.**” (The red rose is the emblem of the SCRF because Elisa loved to pick red roses from our vine at home.)

And one final note: outside the north window just below the research lab, there is a street that runs east-west. Its name? Linton Avenue.

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### **Dr. Kevin Flanigan – Nationwide Children’s Hospital in Columbus, Ohio, along with Abeona Therapeutics Inc. – Cleveland**

#### **Sanfilippo B Clinical Trials**

Earlier this year, the first child was enrolled in the Phase 1/2 clinical trial investigating ABO-101, AAV delivery of the NAGLU gene via a single intravenous injection for MPS IIIB. Reports show that the investigational gene transfer has been well-tolerated so far. This is a sign of safety, but more time and reported information are needed before the next child can be enrolled.

Clinical data shows there is a reduction in sugars (glycosaminoglycans or GAGs, and specifically heparan sulfate) in the urine, plasma, and cerebral spinal fluid. This latter result supports what we saw in the animal studies: ABO-101 is crossing the blood-brain barrier.

Enzyme levels were 300% greater than those seen when tested at baseline, which is the time of testing just before the investigational gene therapy was administered. This is a positive result in that we wouldn’t expect this to happen by chance based on the results in the Natural History Study, which monitored the disease progression without intervention in 25 children (10 of which were impacted by MPS IIIB; the remaining were 15 impacted by MPS IIIA) over 12 months of observation.

Next steps before additional enrollments can take place will include a full review of the data to be completed by a group called the Data Safety Monitoring Board (DSMB), an independent group of experts who determine if we can continue. They have no affiliation with Abeona or Nationwide Children’s Hospital. If given their allowance, we will proceed with the enrollment of two additional participants at the low dose cohort or group (for a total of three). If continued safety and tolerability are confirmed, we will then move to the next dose level, again with the support of the DSMB.

#### **Sanfilippo A Clinical Trials**

This past February, Dr. Flanigan, the lead clinical investigator at Nationwide Children’s Hospital in Columbus, Ohio, shared the latest data resulting from the ongoing global (Columbus, OH – USA, Santiago de Compostela, Spain, and Adelaide, Australia) Phase 1/2 clinical study at The WORLDSymposium regarding ABO-102, gene transfer of SGSH gene for individuals impacted by MPS IIIA.

A total of 11 participants have been enrolled to date, one after another: three at a low dose, three more at double the dose, and the rest at triple the original dose.

Results continue to show tolerability and safety in the three cohorts or groups receiving three dose levels, with no drug-related severe adverse events seen. Sustained reduction of glycosaminoglycans, specifically heparan sulfate, as measured in the cerebral spinal fluid and urine, are seen and look to be dose-dependent. Continued reduction of the size of the liver as measured by MRI is evident. Encouraging results from neurocognitive assessments in Cohorts 1 and 2 are seen by comparison to natural history study results. We are still awaiting more information on Cohort 3.

This study has now received allowance by the Food and Drug Administration (FDA), the regulatory agency that oversees clinical research in the United States, to reduce the enrollment age to six months from two years old. This allows us to investigate and understand the results that early intervention with ABO-102 might have before significant build-up of the GAGs and damage might occur. Even though six months is the lowest age for enrollment, the three clinical sites will continue to enroll participants who meet the selection criteria and are over the age of six months.

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### **Dr. Francis Choy – University of Victoria, BC**

The SCRF has funded Dr. Choy for many years and last year his recent work “Identification and characterization of NAGLU mutations in a Sanfilippo B syndrome patient with a novel genotype” was recently published in the Archives of Clinical and Biomedical Research 1(4):200-208, 2017. DOI:10.26502/acbr.50170021.

His team’s work entitled “CRISPR/Cas9-mediated correction of Sanfilippo B syndrome Naglu mutations E153K and R259X in cultured human induced pluripotent stem cells and skin fibroblasts” was also presented at the American Society of Human Genetics Annual Meeting in Orlando, Florida in October 2017.

## New Initiatives

### Dr. Andreas Schulze – SickKids Hospital, Toronto

The SCRF has made a **\$300,000 pledge**, which will be matched by SickKids, 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.

Our funding over the years has advanced research at SickKids and it's now at an exciting stage at which Dr. Andreas Schulze's research group is accelerating promising work to find a treatment for Sanfilippo syndrome. They are involved in a

# SickKids®

highly-anticipated drug discovery research project that will screen thousands of chemical compounds for their potential to treat Sanfilippo syndrome. Researchers will develop a cell model that will allow them to screen a collection of more than 6,000 compounds, and then use computer modeling to narrow down over seven million potential drugs.

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.

Sanfilippo syndrome is caused by the build-up of sugar chains called glycosaminoglycans or GAGs within the cells due to a lack of certain enzymes that would normally break them down. This build-up has catastrophic consequences for the cells, especially those in the brain. Rather than replacing the missing enzymes, Dr. Schulze and his team are looking for drugs to reduce the production of the harmful sugars in the first place. To do this, they will search for medication that could target an enzyme essential for the production of toxic GAGs. This approach could be effective for Sanfilippo types A, B, C, D and E and also MPS I, II and VII (Hurler, Hunter and Sly syndromes).

Critical to the success of the project will be validating the effectiveness of promising drugs. The ability to analyze individual GAG species would allow the researchers to find treatments specifically tailored for each of the diseases.

**We have raised \$100,000 towards our commitment. We need your help to raise the remaining \$200,000. Please make a donation now or the next time you are able. Thank you!**

**Your donations are bringing hope to Sanfilippo kids. Thank you from a few more of our friends here in Canada.**

Clockwise from top left: Katherine, Sophie, Hudson, Farheen & Aslam, Michaela, Mathew & Rachel, Danika, and Merighan.



## A Heartfelt Note to SCRF Supporters from a Thankful Family

Our daughter, **Charlotte Cecile Quesnel**, was born January 25, 2004. As an infant, she was the model of good health. Looking back, it seems like nothing could have predicted the health outcome she would ultimately face.

Between the ages of two and five, Charlotte's development would start to yield hints that all was not right. We surmised that every child is unique, and our family doctor assured us everything would fall in place in the long run.

By grade two, it became very clear that the gap was widening between her and her classmates. In grade three, we had to start considering an alternative path.

At age nine, Charlotte contracted bacterial meningitis and was admitted to hospital for three weeks. Although frightening at the time, what followed with medical attention was a remarkable group effort that culminated in a consultation with a geneticist.



It was then we heard this word for the first time: mucopolysaccharidosis (MPS).

It took another three and a half years to get an official diagnosis. Our fears were confirmed: at 12 years old, we learned that Charlotte had Sanfilippo Type C (or MPS IIIC), a rare form of a rare disease. There was no treatment and the prognosis was tough: the condition would slowly progress over time and inevitably shorten her life, taking with it most neurological functions, making her unable to walk, speak or even eat.

No parent can prepare for a diagnosis like this – we were utterly devastated. In fact, we remain devastated. We don't imagine our grief will ever subside. That being said, we would be doing a disservice to ourselves and our healthy son, Mathis, if we didn't lift ourselves and channel our grief into positive endeavours. Now, together with Mathis, we take pride in facing the future with grace and courage. We take solace in the fact that we already know what our lives' greatest accomplishment will be: caring for and ensuring Charlotte is as happy and comfortable as possible as we all face the future.

Today, Charlotte is doing well given the nature of the condition. With a better understanding of the impact of Sanfilippo C, we are able to adapt and focus on giving her the opportunity to live her best life. She is doing remarkably well for her age. She has a sunny disposition – always wanting to engage in lighthearted games. Her communication skills have regressed and continue to do so, but her emotional attachment to her family, school community and caregivers only seem to strengthen.

**In essence, Charlotte's intellectual disabilities are outsized by her capacity for love and engagement. As kids with challenges often do, Charlotte radiates a kind of magic state of being that is uniquely endearing and we feel blessed to be with her through this journey.**

Thankfully, there is promising research that may help Charlotte in her lifetime as a result of the funds raised over the years through The SCRF. We're also excited about the new research lab established at Ste. Justine Children's Hospital in Montreal that will focus on MPS IIIC.

Ultimately, we are infinitely grateful to the Lintons and Dr. Pshezhetsky and his team as we look to the future and the work that is being done. We continue to have hope – hope that the kids and families affected by this disease will have a better quality of life, and hope that one day, there will be a cure.

Hardships can bring out the best in people. Many of our families, friends, neighbours and colleagues have shown tremendous support. This isn't true of everyone, of course. We have also learned that, for some, dealing with our tough reality and our raw (and not always positive) emotions can be too much. We have experienced how lonely it can be when your child is faced with a terminal disease.



**But to those who continue to provide much-needed support – whether emotionally or financially – thank you! We can't overstate what a difference even a small act of interest and kindness makes.**

We also take strength from having met other incredible families affected by rare diseases. The strength they exhibit, and the inspiration and encouragement they provide to us, make them simply heroic in our minds as we continue to adjust to our new reality. They have also shown us what can be possible, which compels us to raise awareness and inspire others to overcome adversity or contribute to this worthy cause.

– By Julie Larocque and Michel Quesnel

## Successful SCRF Fundraisers

### Our Ride for a Cure Bike Tour of Southern Ireland Raised Over \$100K!

In September of 2017, my wife, **Tamiko**, and I joined the Linton family in the Republic of Ireland for a cycling adventure to help raise funds for The Sanfilippo Children's Research Foundation and, more particularly, for a dedicated research lab in Montreal's Sainte-Justine Children's Hospital. This was our first SCRF adventure. We reasoned that cycling would be easier than mountain climbing and envisioned a gentle pedal through the countryside as we rolled from pub to pub. We were so naïve!



There are certain things one needs to know about Ireland. First, it rains there. Although assured that September is Ireland's dry month, this wisdom failed to account for the tail end of hurricane Maria, which lashed precisely that bit of coastline where we were cycling. As we rode along one stretch – the road into Ahakista – the rain was horizontal and forced us from the road. Admittedly, it forced us into a pub, but it forced us all the same.



The second thing to know about Ireland is that it has hills. I had assumed I'd be able to get a nice pedalling rhythm going and sustain it all day long. What I got, instead, was a lot of huffing and puffing on the up slopes, and a lot of hoping my brakes would work on the down slopes.

All of this is to say: we earned our sponsorships. Although there were several

moments when it was sorely tempting to phone for a van, we pressed on, in part because of a sense of accountability to our many sponsors. But there was more to it than mere accountability. There was a sense in which we were being cheered on, a reminder that, since its inception, SCRF has been more than simply a vehicle for raising funds; it has been a community of support and a beacon of hope – for children,



IN MEMORY OF  ELISA LINTON

their families, researchers and medical professionals, and the wider circle of friends and donors who embrace them.

As we gathered for dinner at the end of each day, Randall would go from person to person, asking each of us to name a highlight. By the end of the trip, there was a consensus around the table. Our favourite place was Gougane Barra. The beauty we saw there spoke of hope. We arrived in Gougane Barra to the chaos of a religious pilgrimage at the site of St. Finbar's Oratory. But by the next morning, with the pilgrims gone, a peace had descended on the valley. A mist settled over the glassy lake and, as the sun rose above the surrounding hills, it cast the Oratory in a brilliant light. It was like stepping into a cathedral; one felt obliged to whisper.

There was one other memory which stood out among all the others. It was that bittersweet moment at the end of our adventure, as we gathered with our bicycles in a parking lot in Cork, and Lis pulled a photo of Elisa from its protective zip-lock bag. It was the same photo that had travelled with Lis to the summit of Kilimanjaro and on the trail of Machu Picchu. And now it – and the spirit of Elisa – had accompanied us through the beautiful terrain of West Cork.

**Tamiko and I are grateful for the time we have spent with the Linton family. It is inspiring to witness the strength of purpose they bring to all they do, even in the face of such loss. It is doubly inspiring to witness the selflessness at the heart of their efforts. While they have been driven by their own daughter's need, they know full well that the practical benefit will fall to people they may not even know, to children not yet born.**



Let the journey continue!

– David Barker

## SCRF Annual Garage Sale, Bake Sale and BBQ Raises \$6,000!

This year's event this past May raised over \$6,000 thanks to your wonderful support and donations. Despite the forecast of rain, where our day started out with everything covered by tarps, it remained overcast but stayed relatively dry long enough for us to sell out of the great hot dogs donated by **Chicago 58** and all the baking done by **101Temptations.com**.

Please support us again next year by saving your donations for next May 11th, always the Saturday of Mother's Day weekend.



## "Fore Elisa" Golf Funraiser Swings In \$16,000 Again!

For the second year in a row, we have hosted this fun and intimate tournament for 32 golfers in June instead of September. No matter the time of year, it continues to be a fabulous event. This year was a wonderful sunny day for the golfers at **Don Valley Golf Course** for their 18-hole challenge and a delicious dinner was once again enjoyed afterwards at **Mezza Notte Trattoria**.



Huge thanks to all the golfers and their sponsors, who raised **\$16,000** for The

SCRF as well as Don Valley Golf Course and Mezza Notte for their significant contributions. We hope to see you all again next June. New players are always welcome, too!

## Our Caring Community

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

### TheAnswers.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 TheAnswers.ca last year 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. It's much like many robo-advisor sites online today in that users register to be guided to purchase a balanced blend of ETF investments designed for long-term growth and diversification. Dave has had the opportunity to speak with students at a variety of universities and high schools, including Western University – Ivey Business School, York University – Schulich School of Business, White Oaks High School – TechUnderTwenty, as well as several businesses and Rotary clubs, raising \$2,000 this past year.

**Instead of charging advisor fees, David simply asks users to donate to The SCRF.** If you know of an organization that would like to find out about booking a free, interactive presentation on TheAnswers.ca, please contact David at: [djenkins@theansweris.ca](mailto:djenkins@theansweris.ca) or 647 926 8941.

### 101Temptations Sweetens Up Hope For a Cure

Five years ago, Elisa's sister **Jessica Mason** wondered how she was going to raise \$4,000 to honour her quota for The SCRF Mount Kilimanjaro expedition. From the beginning of November to the end of December that year, she baked literally non-stop throughout the holiday season for family and friends, raising much more than required.

Throughout the year requests kept coming in and, as a result, **101Temptations.com** was born.



Five years later, this part-time "home business" has raised thousands of dollars for The SCRF. Now that Elisabeth has flexibility with her time, she has teamed up with Jessica to create unique and tasty treats with the hopes of raising more funds and awareness for Sanfilippo research. Although they are known for their butter tarts, they've done everything from a

single or wedding cake order to 3,000 cookies and cupcakes. No order is too big or small!

Check out [101temptations.com](http://101temptations.com) and let them know what they can prepare for your next family celebration, corporate event, wedding or anniversary celebration, or sudden craving!



### Slippers for Sanfilippo

When Charlotte Quesnel was diagnosed with Sanfilippo C over a year ago, her family and community in the eastern Ontario area surrounded them with amazing love and support. With a heart for making a difference, they held a fundraising sale with delicious homemade baking and adorable baby slippers, raising \$1,000 to contribute to The SCRF's work.

They have dozens of baby slippers of all different colours and styles for sale. **Please contact us if you are interested in purchasing some "Slippers for Sanfilippo."**

### Tough Mudder for Heston

On June 17th, 2017, **Michelle Alexander** completed her first Tough Mudder in Whistler, Alberta in honour of **Heston Letcher**, her friend's six-year-old son who has Sanfilippo A. Plodding, crawling through water and mud and climbing huge walls terrified her, yet she was up for the challenge. She'd do anything to help find some answers to help Heston. Thank you, Michelle, for the hundreds of dollars and awareness you raised through your heroic efforts and for successfully completing the challenge!



### A+ for Willowdale Middle School!

Willowdale Middle School is an amazing caring community in the Lintons' neighbourhood where Elisa's brother and sister, Jessica and Connor, and her many friends attended. For the past 17 years, the **Student Council** has worked diligently on many unique events and again this past year raised another **\$600** to support The SCRF. This school is filled with loyalty, big hearts and love! We can't thank you enough for your continued help and dedication for Sanfilippo children.

### 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 again with beekeepers from **Alvéole, The Urban Beekeeping Company**. They're making use of its tower roof space to put 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 for sale. This past fall, the honey was harvested, bottled and sold to tenants. It raised over \$1,500 for The SCRF! Thank you to **Mary De La Frasier** and her team for their sweet contribution and ongoing support!



### Cultura Cultivates Local Support

Once again, The SCRF was one of the charities chosen to benefit from North York's **Cultura** event this past summer. Thank you to Councillor **John Filion** and local residents who together organize this annual exciting summer series of weekly Friday night events at Mel Lastman Square. This entertaining evening celebrates food and the arts, featuring street food, musical performances, street buskers, artists' displays, a free outdoor movie and, of course, our SCRF booth. All proceeds raised were generously donated to The SCRF, contributing almost **\$1,000** for research. We are very grateful to Cultura for sharing word of The SCRF with our city's residents and for bringing us this generous donation.

### Roses for Sanfilippo Continues to Bloom

Five years ago, North York senior **Eleanor Walters** showed up at a workshop at the Linton's home to prepare decorations for an upcoming gala. Since then, she has become one of The SCRF's greatest ambassadors. This dedicated retired grandmother still devotes much of her time to crocheting small roses in a variety of colours and putting them on pins, hair clips, head bands, mitts, etc. and selling them at schools, flea markets, shopping malls, businesses and community events to raise money and awareness for The SCRF. This year, she raised another \$8,000, totaling over \$26,000 to date! Eleanor loves the opportunity to tell Elisa's story and the plight of Sanfilippo children every chance she gets.



Last November, Eleanor was honoured with the **Canada 150 Medal for Outstanding Community Service**, presented by Willowdale MP **Ali Ehsassi**.

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 The SCRF office.** Thank you!

## Scream in Memory of Elisa – Oct. 31st, 2017

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 and donated funds raised to The SCRF. This past Halloween it was renamed “Scream in Memory of Elisa” to remember the first anniversary of her passing. This year, 101Temptations donated “spooktacular” Halloween cookies for the first 400 visitors. It was a scary, fun, creative and significant event. And best of all, **over \$1,500** was raised! Heartfelt thanks to the hard work and leadership of **Devyn Di Nardo** along with the entire Di Nardo family, their many volunteers and our trick-or-treating community for your support.



# 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!

## Acknowledgements

Thank you to our corporate contributors for your donations:

101Temptations  
1882498 Ontario Inc.  
Aerloc Industries  
Ampere Electric  
Applied Systems Technologies Inc.  
Avenue Dental Centre  
Bayview Sheppard RMT  
BDS Consultants  
Bee Clean  
Begley Door  
Benevity Community Impact Fund  
Benson Kearley Insurance  
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Mattel Canada  
Menkes Property Management  
Morella & Associates  
O.M.T. Janitorial  
ORA\*DBA Systems Consulting Ltd.  
Paragon Security  
Particular Janitorial Inc.  
Paul the Button Person  
Perimeter Fence & Deck Inc.  
Platinum Glass & Curtain Wall Ltd.

## 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 the following:

### Memorial Contributions

Matthew and Kerrin Bankert	Rosemary Jenkins
Marg Carter	Rudy Leudecke
Warren Dendekker	Elisa Linton
Jack and Lyla Galvin	Alessandro Nardone
Rachel Gilhuis	Elisabeth "Lisa" Schramm
Rachel Hamilton	Eric & Lilian Timms
Tom Janes	Corradina Tumminieri

### Milestone Contributions

Ron and Sandra Cook's wedding  
Katherine Dendekker  
Kim Dunski's 50th birthday  
Tom and Lisa French's 30th wedding anniversary  
Sophie Hamza  
Tracy Keenan's 60th birthday  
Dannika Powell  
Mary and Stan Smith  
Charlotte Quesnel

Precision Developments  
Preston Human Capital Group  
QAIR  
Radius Air Systems Ltd.  
Rochester Midland  
Salesforce.org  
Seradex  
Skyreach Window Cleaning Inc.  
Solucore  
Splash International Marketing Inc.  
United Way  
University of Guelph Real Estate and Housing Students' Assoc.  
Terrazzo Mosaic & Tile Company Ltd.  
Thacker Consulting and Investigations Inc.  
The Sixty Three Foundation  
Whitebird  
Willowdale Middle School

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

Clarke Henning LLP  
H&R REIT  
Interior Care Ltd.  
Lazy Poet Creative  
Wizbot DI Inc.

### 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. Thanks!

### 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.

## Upcoming Fundraisers

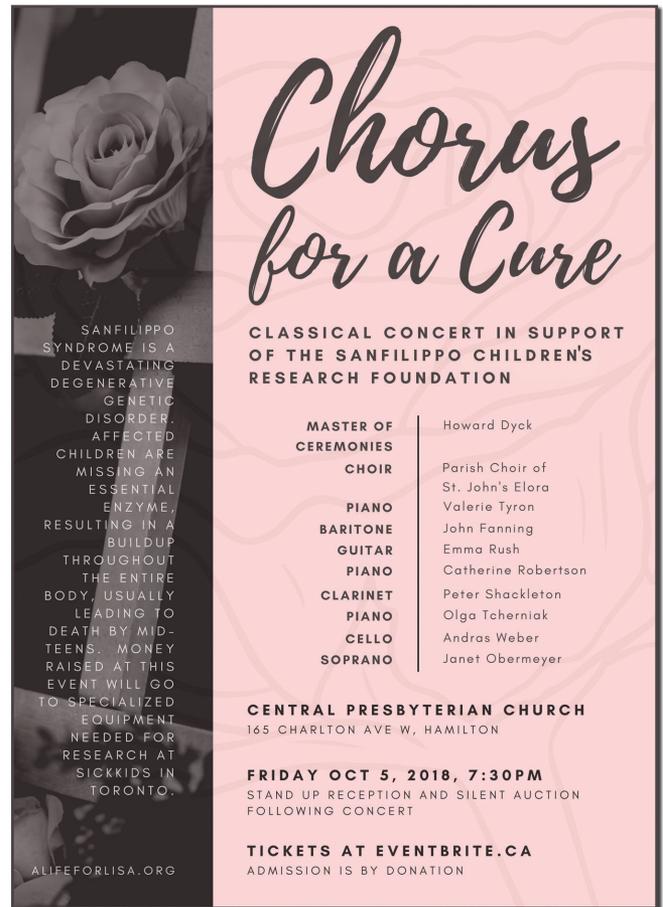
### Chorus for a Cure

Four 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 almost three years ago at the age of 10. Katherine is now 10 years of age. Their family just heard the tragic news that a cousin's son was also just diagnosed with Sanfilippo at the age of four. Over the years, this family has rallied to raise several hundred thousand dollars through their community's support and fabulous concerts to support research. They will not give up hope of saving their kids.

**Let's show them we care. Join us at this wonderful concert on Friday, October 5th, 2018. If you can't attend, please make a donation in support of their efforts to raise money for the project at SickKids hospital.**

**Admission is by donation. Receipts will be issued for donations of \$50 or more.**

**Please contact [Sandrarendekker@hotmail.com](mailto:Sandrarendekker@hotmail.com) or call 905-975-8383 to reserve your seats.**



**SANFILIPPO SYNDROME IS A DEVASTATING DEGENERATIVE GENETIC DISORDER. AFFECTED CHILDREN ARE MISSING AN ESSENTIAL ENZYME, RESULTING IN A BUILDUP THROUGHOUT THE ENTIRE BODY, USUALLY LEADING TO DEATH BY MID-TEENS. MONEY RAISED AT THIS EVENT WILL GO TO SPECIALIZED EQUIPMENT NEEDED FOR RESEARCH AT SICKKIDS IN TORONTO.**

**ALIFORELISA.ORG**

# Chorus for a Cure

**CLASSICAL CONCERT IN SUPPORT OF THE SANFILIPPO CHILDREN'S RESEARCH FOUNDATION**

<b>MASTER OF CEREMONIES</b>	Howard Dyck
<b>CHOIR</b>	Parish Choir of St. John's Elora Valerie Tyron
<b>PIANO</b>	John Fanning
<b>BARITONE</b>	Emma Rush
<b>GUITAR</b>	Catherine Robertson
<b>PIANO</b>	Peter Shackleton
<b>CLARINET</b>	Olga Tcherniak
<b>PIANO</b>	Andras Weber
<b>CELLO</b>	Janet Obermeyer
<b>SOPRANO</b>	

**CENTRAL PRESBYTERIAN CHURCH**  
165 CHARLTON AVE W, HAMILTON

**FRIDAY OCT 5, 2018, 7:30PM**  
STAND UP RECEPTION AND SILENT AUCTION FOLLOWING CONCERT

**TICKETS AT [EVENTBRITE.CA](http://EVENTBRITE.CA)**  
ADMISSION IS BY DONATION

### The Linton Family Laces Up to Walk a Half-Marathon for The SCRF and SickKids Hospital This Fall!

This October, the Linton family will be walking a half marathon (21 kms) in Haliburton, Ontario in honour of Elisa and the many children and families who suffer with Sanfilippo disease. Let's help them raise the outstanding funds needed for SickKids Hospital.

**Sponsoring the Linton family is easy. This year, you can donate online:**

1. Login to our website at [www.aliforelisa.org](http://www.aliforelisa.org) and click on "Walk for A Cure." It's very easy to follow from there.

**OR**

2. Fill in the sponsor sheet with your contribution and mail it back to us at **The SCRF, 41 Gwendolen Avenue, Toronto, Ontario M2N 1A1** or fax it to **416-223-0864**.

**Receipts will be given for donations of \$20 or more. THANK YOU! Every dollar will go to funding the new equipment for SickKids Hospital we have committed to purchasing.**

### Walk for a Cure Donation Form

Yes!! I would like to donate to **The Sanfilippo Children's Research Foundation** in support of the Linton's walk and to honour Elisa's memory.

\$200  \$100  \$50  \$25  Other \$  \*Donations of \$20 or more will receive a tax receipt. Charitable Foundation #87391 3628 RR0001

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Postal Code: \_\_\_\_\_ Home Phone: ( ) \_\_\_\_\_

Cheque: Please make your cheque payable to The Sanfilippo Children's Research Foundation.

Credit Card:  VISA  MC

Name (as it appears on the credit card): \_\_\_\_\_ (please print)

Card Number: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Signature on Card: \_\_\_\_\_ Cardholder's Name: \_\_\_\_\_

*Thank you for your kind and generous support and for keeping Elisa's legacy alive!*

### 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.

The Sanfilippo Children's Research Foundation  
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Web: [www.aliforelisa.org](http://www.aliforelisa.org)  
Charitable #87391 3628 RR0001