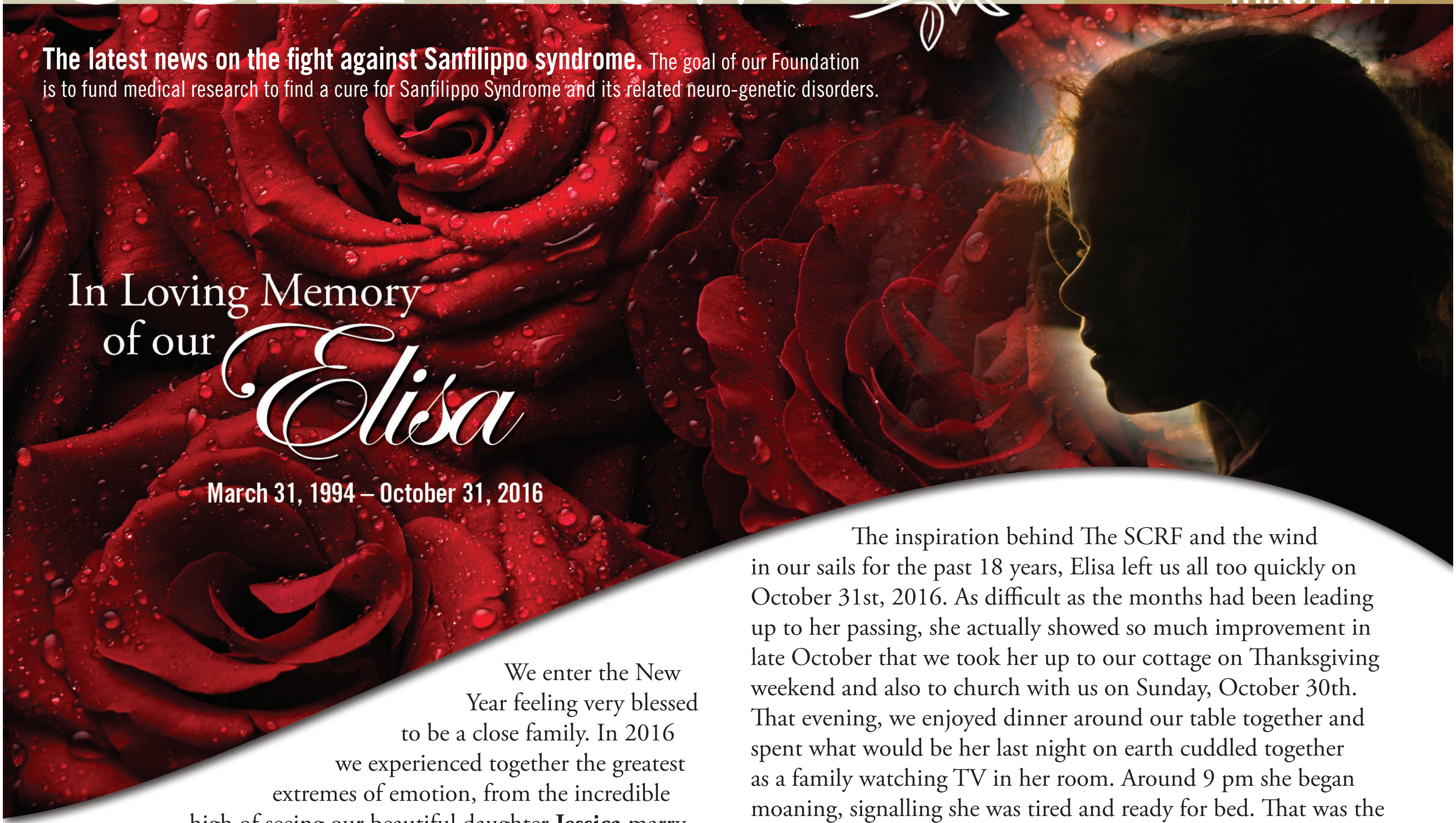
SCRF News

THE ELISAGRAM
Winter 2017

**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.



# In Loving Memory of our *Elisa*

March 31, 1994 – October 31, 2016

We enter the New Year feeling very blessed to be a close family. In 2016 we experienced together the greatest extremes of emotion, from the incredible high of seeing our beautiful daughter **Jessica** marry **Cameron Mason** (whom we were thrilled to welcome into our family), to the deepest sadness imaginable when we said goodbye to our precious Elisa just six weeks later.

Leaving behind the roller coaster of 2016 and welcoming a new year has been bittersweet. We thank God that Elisa's suffering is now over and ask that you will keep her alive in your heart.

Late last year, recognizing that Lissy was regressing and well past her life expectancy, our family made the decision to stop hosting gala fundraisers to allow Elisabeth to focus on Elisa's care. These galas raised millions of dollars and enabled clinical trials for Sanfilippo children to commence in May 2016. Our last full gala was April 6th, 2016, and following that event, there was nothing that Elisabeth wanted more than to spend more time with Elisa.

The day after we celebrated our 31st wedding anniversary on June 1st, Elisa developed pneumonia. For the next three months, we lived day to day, many of them in the ICU ward at North York General, wondering if each day might be her last. There were too many hills and valleys to mention – suffice to say that we have never appreciated friends, community and family more that we did during those three months. Thank you to everyone for your prayers, loving care and the support that you showed to us in various ways.

The inspiration behind The SCRF and the wind in our sails for the past 18 years, Elisa left us all too quickly on October 31st, 2016. As difficult as the months had been leading up to her passing, she actually showed so much improvement in late October that we took her up to our cottage on Thanksgiving weekend and also to church with us on Sunday, October 30th. That evening, we enjoyed dinner around our table together and spent what would be her last night on earth cuddled together as a family watching TV in her room. Around 9 pm she began moaning, signalling she was tired and ready for bed. That was the last time we had the privilege of tucking her in.

Our beloved Elisa is gone, but our fight and determination to find a cure is not over. We know this would be Elisa's wish. As clinical trials continue at Nationwide Children's Hospital to treat a number of children this year we are continuing the work and mission of The SCRF and trust you will continue to remember us with your charitable giving just as you always have. This newsletter will offer you various ways to support our continued efforts in memory of Elisa on behalf of the many children and their families who still rely on our fundraising efforts to find a cure. Because we are not organizing a gala dinner this year, we hope you will be able to sponsor our adventurous cycle around Ireland in memory of Elisa, which will be our main fundraiser for 2017. All funds raised will go towards establishing The SCRF lab and research endowment fund at a leading research institute in Canada so Elisa's legacy will continue to help children in the years to come. More details to follow in the future.

We are eternally grateful for your ongoing faithfulness and support to The SCRF, which continues to bring hope to Sanfilippo families around the world. We sincerely wish you and your families a happy and healthy year full of wonderful moments and memories.

Warm regards, Randall + Elisabeth Linton

# Life Without Elisa

For 18 years we have posted brief updates in our newsletters called **Life With Elisa**, as many friends and supporters were anxious to know how she was doing, especially since she was significantly outliving her life expectancy. We always tried to keep them upbeat and encouraging. We also knew that unless a cure was found in Elisa's lifetime, someday our family would say goodbye to Elisa and that this update would change. Sadly, that time has arrived.

This past year, life with Elisa was quite a roller coaster. It started out encouraging, as new medications appeared to help with her biggest challenge: sleep. This allowed Elisabeth to spend two winter months in Florida last winter with Elisa – a time that will always be a treasured memory. Life for Elisa got more complicated upon returning home in the spring. She developed pneumonia and was admitted to the ICU at North York General on June 2nd. Throughout the nine summer weeks she spent there, there were a number of times we didn't think she would pull through. Doctors said Elisa's only chance at survival was to insert a feeding tube to provide the nutrition she required to fight her long uphill battle. It was difficult to lose the special bonding that came with feeding Elisa – she took such great pleasure in eating, even when she could only have puréed foods. However, as Elisa's lungs collapsed several times throughout her hospital stay, she fought back hard with the help of medications and constant physiotherapy treatments.

Eventually, Elisa returned home and received daily nursing care along with love, prayers and support from family and friends. Thankfully, Elisa had the strength to be the most beautiful bridesmaid in her sister's wedding and was proudly wheeled down the aisle by her brother Connor. He also wheeled her to the podium during the reception, where she received a standing ovation and shared in the honour of being there to deliver the toast to the bride.

Six weeks later, Elisa passed away peacefully in her sleep. She had completed her life's work: rallying the hearts and minds of an international community of supporters and researchers that has culminated in clinical trials on a very promising treatment. We don't believe Elisa gave up: we believe God felt it was time to take her to her heavenly home, sparing her further regression in the days that lay ahead. We prayed a cure would come in Elisa's lifetime, but God chose to heal her in a different way. She lived to see clinical trials start, ones that her life helped to inspire, and to be a bridesmaid in her sister's wedding. God's timing is always right.

With our faith, our love for each other and the support of our family and friends, we are emerging from a place that is very deep and full of sadness. We are learning to accept the immense void that has been left in our lives at the loss of our precious Elisa.

After our Celebration of Elisa's Life and Legacy on November 8th, where we were surrounded by over 1,200 friends and loved ones, our family got away for some alone-time together for a few weeks in Florida. Much of our time was spent reminiscing about the joy and privilege we shared being Woogie's family and the crazy and fun times with her. Woogie is a nickname our crazy kids gave to Elisa many years ago. Elisa is now timeless and forever in our hearts, bringing smiles to our faces daily. Elisa's eulogy video, reflections, and other tributes from her Life and Legacy service can be viewed at *www.alifeforelisa.org.*

Over the past few weeks we have realized that things don't necessarily get better as time goes by, just different. We are now starting to appreciate having flexibility and spontaneity in our lives, things we haven't had much since we became parents 26 years ago. At first, we felt some guilt about enjoying ourselves with family and friends. We know this will pass, as will being able to go out without the usual stresses and complications of having Elisa cared for. We will get back to life's realities, but for now, the time we spend with family and friends is special, meaningful and necessary.

Although we embrace this new chapter in our lives, words can't express how much we miss our precious Lissy. We would give anything to have one more moment with her, one more hug; the chance to hold her hand in ours or just sing her a song. We ask God for the strength and courage to get us through each day and thank him for the gift of Elisa in our lives. We thank God daily because she lived. We know this year will be the hardest, as we experience many firsts without her. Fortunately our close family and friends will always be there for us. We feel both blessed and grateful.

# Research Progress

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 year 2016 was an exciting time for progress in Sanfilippo research we have sponsored.

Firstly, **Nationwide Children's Hospital** in Columbus, OH, along with **Abeona Therapeutics Inc.** in Cleveland, announced last fall that three children were enrolled and treated at Nationwide as part of the first in-man ABO-102 AAV viral vector gene therapy Phase 1/2 human trial for Sanfilippo A. Just recently, they received approval for dose escalation in a second cohort for this trial from the Data Safety Monitoring Board and enrollment for another six children in the high-dose cohort this year has commenced. This ongoing Phase 1/2 study is designed to evaluate safety and preliminary indications of efficacy of ABO-102 in subjects suffering from MPS IIIA. Observations 30 days post-injection for the low-dose cohort demonstrated that ABO-102 is well tolerated in subjects injected with the low dose with no treatment-related adverse events or serious adverse events. In the natural history study evaluating MPS III subjects it was shown that urine and cerebral spinal fluid GAG (heparan sulfate or "HS") are significantly elevated in the subject population as a symptom of disease pathology. All subjects in the low-dose cohort experienced reductions from baseline in both urinary HS and CSF. Moreover, all three subjects demonstrated significant reductions in liver and spleen volume from baseline, as measured by MRI at 30 days post-injection.

Per the design of the clinical trial, subjects in the low-dose cohort received a single intravenous injection of AB0-102 to deliver the AAV viral vector systematically throughout the body to introduce a corrective copy of the gene that underlies the cause of the MPS IIIA disease. Subjects were evaluated at multiple time points over the initial 30 days post-injection for safety assessments and initial signals of biopotency, which suggest that ABO-102 successfully reached target tissues throughout the body, including the central nervous system, to reduce GAG content that underlies the lysosomal storage pathology central to Sanfilippo syndrome type A (MPS IIIA). "We remain encouraged by continued signs of tolerability and by early signals demonstrating reduced urinary and CSF GAG," states **Kevin M. Flanigan, MD**, principal investigator with the **Center for Gene Therapy** at Nationwide Children's Hospital and Professor of Pediatrics and Neurology at **The Ohio State University College of Medicine.**

Abeona's MPS IIIA program, ABO-102, has also been granted Orphan Product Designation in the USA and received the Rare Pediatric Disease Designation, and recently announced Orphan Drug Designation has been granted in the European Union. An orphan drug product is one that is considered commercially undeveloped owing to limited potential for profitability. The U.S. Food and Drug Administration (FDA) also granted Fast Track designation for ABO-102 for subjects with MPS IIIA (Sanfilippo syndrome type A) in children.

Fast Track designation is a process designed to facilitate the development and expedite the review of drugs to treat serious conditions that address an unmet medical need. Advantages of Fast Track designation include opportunities for more frequent interactions with the FDA during all aspects of development, and eligibility for priority review and accelerated approval.

With regards to Sanfilippo B or MPS IIIB (this is the type that Elisa was born with) clinical trials, the FDA approved last year the Investigational New Drug (IND) Application for Abeona's Phase 1/2 Clinical Study with gene therapy candidate ABO-101 (AAV-NAGLU). Plans are currently in progress for clinical trials to commence within the first half of 2017, also to be conducted at Nationwide Children's Hospital (Columbus, OH).

Secondly, **Dr. Brian Biggar at The University of Manchester** has developed a stem cell gene therapy to hopefully reverse Sanfilippo syndrome, and has agreed to work with **Orchard Therapeutics**, a new UL-based clinical-stage biotechnology company, to test it in human trials.

"If we can show that it is possible to treat single-gene brain diseases such as Sanfilippo with stem cell gene therapy, this will pave the way for treating other lysosomal storage and neuro-metabolic disorders," said Dr. Biggar. The new study will take place at **Central Manchester Foundation Trust (CMFT)**. We hope that this work will help to halt the progression of this devastating condition," added **Dr. Simon Jones**, Consultant in Paediatric Inherited Metabolic Disease at **Saint Mary's Hospital and the Manchester Centre for Genomic Medicine.**

This treatment works by genetically correcting the patients' own stem cells and implanting them into bone marrow to release the missing enzyme in a way that reaches the brain, thereby correcting the condition. **Professor Robert Wynn**, Consultant Paediatric Haematologist at **Royal Manchester Children's Hospital** and chief investigator for the clinical study, explained: "This new clinical study aims to explore whether we can use stem cell gene therapy to produce blood cells that express corrected versions of the missing enzyme. We know that, in conditions similar to Sanfilippo, blood cells from a bone marrow donor can deliver such enzymes effectively. This new gene therapy builds on the decades of experience of CMFT physicians in bone marrow transplantation of children with these other metabolic diseases." Earlier attempts to cure the illness with a bone marrow transplant were unsuccessful as not enough enzyme was produced to have an effect, but the Manchester team has developed a way of overproducing the SGSH enzyme specifically in bone marrow white blood cells. This was achieved by developing a lentiviral vector – a tool commonly used by molecular biologists to deliver genetic material into cells – specifically for use in humans, which will be tested in the trial. The lentiviral vector delivers the SGSH gene to bone marrow cells, which, when implanted into the body, are able to traffic to both the bone marrow and the brain and deliver the SGSH enzyme throughout the body, thus correcting the disease.

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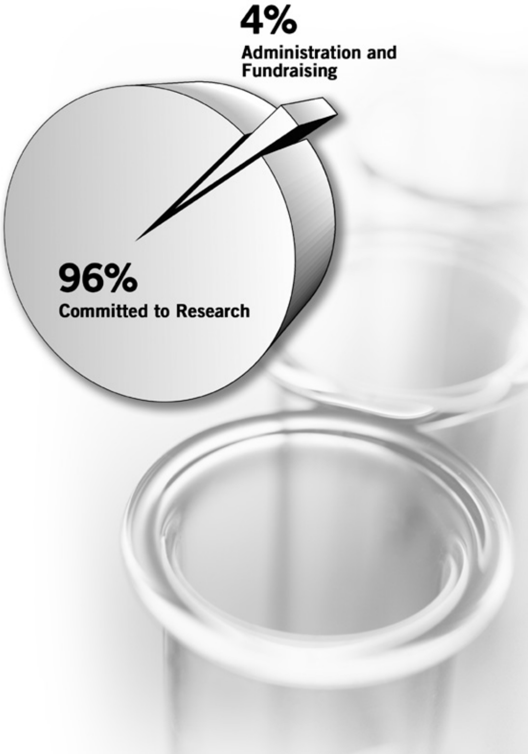
Thirdly, The SCRF continues to support **Dr. Francis Choy** and his team at the **University of Victoria, BC, Canada** with their project "Sanfilippo B syndrome: Establishment of an in vitro disease model using stem cell technology and correction of the gene defect using CRISPR-Cas9". We look forward to receiving updates on Dr. Choy's research in 2017.

## The Sanfilippo Children's Research Foundation's Chair position/ Endowment Fund

In light of Elisa's passing last fall, The SCRF is planning to establish a research chair endowment fund and lab at a leading research institution in Canada that will dedicate its sole focus to Sanfilippo syndrome research. This fund will be a living memorial that will keep on giving, providing strength and stability to a Canadian institution focusing research efforts on Sanfilippo syndrome. It will provide a permanent, predictable source of revenue to support excellent and ongoing research to find new treatments for MPS III (Sanfillippo disease) and create a permanent legacy in support of the institution year after year. This fund will not only support existing researchers within Canada whom we have funded for years, but it will encourage new doctorate students to focus their studies on Sanfilippo and MPS diseases. **All funds raised this year will go to support this important initiative.**

## Elisabeth Linton and The SCRF Recognized by Global Genes

Global Genes is a leading global rare disease patient advocacy organization dedicated to eliminating the challenges of rare disease. Each year they hold a Patient Advocacy Summit and the Champions of Hope Gala at the Hyatt Regency Resort in Huntington Beach, CA. Last year over two hundred nominations were put forward for the Champions of Hope awards and Elisabeth was chosen to receive **The 2016 Champion of Hope in International Advocacy** for her contributions to rare disease through her work with The SCRF. Elisabeth received the award at the Tribute to Champions of Hope Gala, which she attended last September with her husband Randall and son Connor, along with over 700 other guests. Congratulations to Elisabeth for this achievement that brings international attention to Sanfilippo disease and The SCRF!

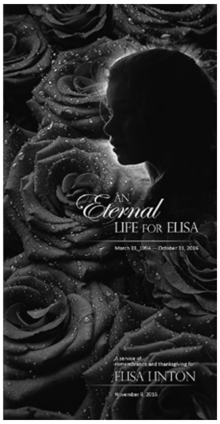


**Thank you for your generous and ongoing support that has enabled these projects to happen. TODAY'S research will lead to TOMORROW'S treatments!**

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

# A Celebration of Elisa's Life and Legacy – November 8th, 2016

One of the most meaningful and emotional days of our lives was the day we said our final goodbye to Elisa. Words can't express our family's gratitude for the 1,200 people – family members, friends, neighbours, and business associates – who came to support us in celebrating our precious daughter's life. We thank all of you who were able to make your way to the **Paramount Event Centre**. We chose this venue, where Elisa had brought a special community together for 10 gala dinners, to gather with her one last time and say our final goodbye. For those of you who missed the opportunity to be with us, Elisa's Life and Legacy service, including the eulogy video, reflections from her special friend **Laura D'Angelo** and the Linton family, and other tributes can be viewed at www.alifeforelisa.org.



We also thank our long-time friend and SCRF Honourary Board member **John Kane** from **R.S. Kane Funeral Home** for directing the event with professional sensitivity and care.

We chose to make this an inclusive event because of what so many of you meant to Elisa and our family. We were completely amazed that **over $90,000** was donated in Elisa's memory to The SCRF to further Sanfilippo research. Our deepest and heartfelt thanks and appreciation for everyone's kindness, love and generosity.

In the week between Elisa's passing and her Life Celebration and Legacy event, we received thousands of emails, Facebook posts, texts and cards expressing condolences for our loss. It has been overwhelming yet beautiful. This helped to carry us as we prepared for this difficult day and beyond. It has been heartwarming and touching to see how Elisa's life encouraged and inspired so many. She was and continues to be well loved. We are forever grateful.

Elisa's life wasn't one with huge successes but one of significance. Elisa never attended university, but she enabled research at universities and hospitals around the world to advance medical science in a significant way. She never drove a car, but drove change in the world of rare genetic disorders, affecting thousands of children worldwide. Elisa never spoke a word past her 12th year, but she spoke on behalf of Sanfilippo children and their families around the globe, silently spreading the word about this horrible disease and the urgency of finding a cure.

Many meaningful tributes have been shared with us about Elisa, however one written by a supporter of The SCRF since its inception, **Wendy Rae**, in the Acknowledgement section of her book *You Are Not The Boss of Me*, summarizes the sentiments people have been sharing. "*Elisa, you have been my silent teacher for almost 20 years now. The lessons you have provided and the love you have shared. I do not think I have met anyone who has impacted more lives than you. Your legacy may very well end up being a cure for Sanfilippo syndrome, but your most far reaching legacy will be the promise of hope inspired by the actions of faith.*"

# Our Foundation's Fundraisers

## Charmed By Chocolate II, Evening for Elisa 2016: Our Final Gala Was Also A Night of Firsts

While the SCRF will continue hosting fundraisers for years to come, the gala committee planned Gala 2016 knowing, sadly, that it would be our last full gala as we have known them. We are grateful that our beloved Elisa, who never missed any of the 17 gala dinners, was there for this important milestone.

**Chantal Kreviazuk**

Many of our long-time supporters know that the *Charmed By Chocolate* theme was back by popular demand – it was a big hit in 2005. But April 6th, 2016 was truly a night of important first-time achievements:

- It was our largest crowd ever, with 830 people in attendance. Thanks to every guest and every volunteer for joining us!

- We raised more than ever – thanks to every sponsor, donor, guest, and auction shopper for helping us raise **an amazing $340,000!!** and to **Lembit & Karen Janes** (pictured below with Elisabeth) for their heartfelt generosity for matching every dollar raised in the auction up to $100,000. What an amazing gift and inspiration that evening.

- It was the first time we were gifted a performance by a Juno-winning vocalist at our gala. Enormous thanks to our friend **Chantal Kreviazuk** for her spectacular show and meaningful song selection.

- It was also the first gala we served our own custom label "Elisa" wine generously donated by **Alex Patinios** of **Dionysus Wines**, paying tribute to our guest of honour that evening.

This gala was a treat for all the senses. The intoxicating fragrance of chocolate filled the air, with our *Chocolate Bar* that featured our Drink of the Gods hot chocolate beverage along with luxurious chocolate bonbons from **Succulent Chocolates & Sweets**, sophisticated chocolate martinis and the sensational new Laura Secord Chocolate Cream Liqueur.

It was also a night for learning. Guests sampled chocolate tastings to compare flavours from different chocolate-producing regions around the world, thanks to sponsors **Cacao Barry**. And Chocolatier **Sergio Shidomi** informed us about cacao production in various regions.

It was a night for fun and fundraising. In addition to selling a selection of home-made chocolate treats, our boutique sold a selection of chocolate-themed aprons that were popular, as were **Eleanor Walters'** hand-crocheted Sanfilippo roses. We added to the fun and fundraising tally with a *Death By Chocolate Raffle* and *Corkers Wine Raffle*. Kudos to everyone who supported these events by either donating or purchasing! Our Emcee of six years, **Anne-Marie Mediwake,** and our Live Auctioneer of 16 years, **Herbie Kuhn,** took their final bows – we are grateful to have had their gracious and charismatic pro bono support through the years.

It was also a night for celebration. **Barry Pettit** of **Pettit Integrated** produced a meaningful video in tribute of Elisabeth Linton, celebrating her dedication to the cause of Sanfilippo disease and the research to find a cure, as well as her inspiring leadership of The SCRF gala team over the past 17 years. Elisabeth's personal strength, faith, creativity and commitment to devoting her life to finding a cure have edified all her supporters and given hope to Sanfilippo families around the world.

Of course, more important than the delicious chocolate, gourmet dinner, auction bargains, video tributes, celebrity performance, elegant dresses and avid socializing, this gala – like all our galas – was a night for freeing terminally ill children from a cruel, degenerative disease and supporting the families who love them. Gala 2016 was dedicated to the memory of Sanfilippo angel **Warren Dendekker**, the son of dear friends of the Lintons, who passed away on October 1st, 2015.

Our annual galas may be over, but the fight against Sanfilippo syndrome is far from over. There are many children who still need our unflagging support to keep research progressing, so we look forward to seeing you at future fundraisers. Until that time, we thank every one of our generous and steadfast sponsors, donors, guests, and volunteers for helping the final *Evening for Elisa* to create powerful possibilities for Sanfilippo researchers while offering support to the dedicated and inspiring Linton family.

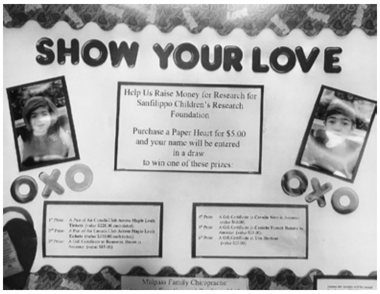
*Written by Honourary Board and Gala Committee Member Tracy Keenan*

# Our Caring Community

We are grateful to all those who want to do something to help us find a cure or treatment for Sanfilippo children. We have an amazing caring community. Every dollar raised is important. Much of the money donated to the Foundation comes from individual donations and from fundraising efforts organized by others.

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

## Show Your Love Fundraiser



Last February, **Dr. Sandra Malpass** and **the staff of Malpass Family Chiropractic Clinic in Ancaster, Ontario** launched a fundraiser for Valentine's Day in honour of two of her patients, **Warren Dendekker** (who passed away October 1st, 2015) and his sister **Katherine Dendekker**. They raised **over $5,150** for Sanfilippo research. Heartwarming donations were made with love and hope for a cure. Thank you to all those who gave generously and supported the Dendekker family through this unique and special initiative.

## SCRF Annual Garage Sale

A huge thank you to the 50+ families who contributed to the SCRF's annual garage sale at the home of the Lintons last May. Once again, crowds from across the city arrived by the hundreds taking with them used treasures, purchasing treats from the annual bake sale and delicious BBQ sausages donated from **Chicago 58**. Over **$3,700** was left for the SCRF. Thank you to the many wonderful volunteers who arrived at 7:00 am and didn't leave until clean-up late in the afternoon and to the dozens of families who contributed items. Please mark your calendars for **Saturday, May 13th, 2017** for our next Garage Sale. Reduce, reuse and recycle. Please save your unwanted items and we'll gladly receive them in the days leading up to the event.

## 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 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 on this Friday evening in July were generously donated to the SCRF, contributing almost **$700** 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.

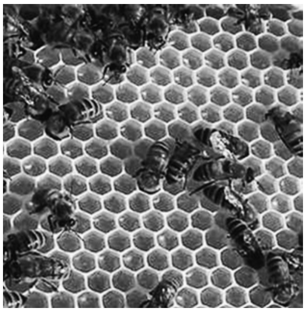
## Red Roses and Bumble Bee Fundraiser Continue to Plant Seeds

One of the great joys of operating a charity is meeting people who randomly enter our lives and make significant contributions. **Eleanor Walters** has become one of The SCRF's greatest ambassadors. Invited to one of the gala workshops three years ago, this retired grandmother devotes much of her time to crocheting small roses in a variety of colours and selling them at flea markets, shopping malls and community events in order to raise money and awareness for The SCRF. Eleanor has now added bumblebees to her list of creations in honour of **Sophie Hamza**, whose family created **Strides for Sophie (StridesforSophie.ca)**, using a bumblebee as a symbol of faith despite unfathomable odds. She has raised thousands through these sales and loves the opportunity to tell Elisa's story every chance she gets.

On the morning of Elisa's passing, Elisabeth paid a special tribute to Eleanor by pinning one of the red roses she had lovingly created on Elisa's ponytail as she left our home for the final time. We thank you, Eleanor, for your love of Elisa and your tireless efforts and dedication to help The SCRF.

## H&R REIT is Buzzing With Support for The SCRF

Last spring **H&R REIT's** management office at 310 Front Street, Toronto teamed up 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 resale. This past fall the honey was harvested, bottled and sold to tenants with all proceeds going to The SCRF. H&R REIT has been a huge supporter of The SCRF for years in various ways, but this is the most unique and creative fundraising initiative on their part ever, raising **$2,500** for research. Thank you to **Mary De La Franier** and her team for their sweet contribution and ongoing support!



# Acknowledgements

## Thank You to Our Corporate Contributors for Your Donations

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**Thank you also to the hundreds of individual personal donations last year!**

## Thank You to These Companies for Supporting The SCRF in Various and Unique Ways

Clarke Henning LLP • Compremed • H&R REIT • Interior Care Ltd. • Pettit Integrated • S4 Sound • Lazy Poet Creative • Turck Chartwell Inc. • Wizbot Inc.

# Contributions

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

### Memorial Contributions

Warren Dendekker • Rosanna Giglio • Frances Keenan • Herb Lebane • Elisa Linton • Chung Mah • Ashley and Lindsey Olsen • Quen and Si Quach • Estate of Lydwin Redmond • Eric Timms

### Milestone Contributions

Jake and Tali Aikenhead's wedding • Dayna Christie's bridal shower • Eleanor Dean's 85th birthday • Jim and Nancy Garbutt's 50th wedding anniversary • Ken Gin's 60th birthday • Sophie Hamza • Hudson Hill • Donald and Sandra Hayes' 35th wedding anniversary • Hannah Hayes' 29th birthday • Hilde Nardone's 60th birthday • Muriel Macleod's 85th birthday • Norman Macleod's 80th birthday • Jessica and Cameron Mason's wedding • Jeff and Becky Morella • Marilyn Quinton's 80th birthday • Will Whyte's 70th birthday

### 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.

### SCRF Annual Garage Sale, Bake Sale and BBQ – Saturday, May 13, 2017

Please join us for our annual SCRF Garage Sale on Saturday, May 13th at the Linton's home in North York, at 41 Gwendolen Avenue.

Not only do we have thousands of new and used items for sale, we also offer baked goods from the kitchens of Elisabeth Linton and Jessica Mason and we'll also be grilling hot dogs donated by **Chicago 58**. All proceeds go to Sanfilippo research. Please stop by to say hello and take some treasures. We'd love to see you.

Reduce, reuse and recycle. Please save your unwanted items and we'll gladly receive them in the week leading up to the event.

### Lace Up With Us for The SCRF on Sunday, October 22nd, 2017

Running or walking for the SCRF has become an annual fun community event. Please consider joining us on **Sunday, October 17th for The Scotiabank Toronto Waterfront Marathon!** Nothing beats the feeling of crossing that finish line. Come meet the challenge – for Sanfilippo children and For Life! If you plan to participate on behalf of the SCRF and secure pledges, please contact us at **events@alifeforelisa.org or (416) 223-1911**. We'll give you an SCRF t-shirt to wear and more details. Donations of $20 or more receive a tax receipt. Every dollar is appreciated and needed.

### "Fore Elisa" Golf Funraiser Has a New Date: Monday, June 12th, 2017

Last September we were unable to host the 17th Annual "Fore Elisa" Golf Funraiser so this year we're moving the event to a new date! Come give us your best shot at this fun, worthwhile event on **Monday, June 12th, 2017** at the **Don Valley Golf Course** at 4200 Yonge Street. A delicious dinner is included at **Mezza Notte Trattoria** on Yonge Street. Interest in this event continues to grow as new participants of all ages join us each year and gather pledges for their round of golf. The event fills up quickly as it is limited to 32 players.

In this funraiser we ask that you pay for your round of golf (Adults $56, Seniors $33, Juniors $30). Golf carts can be rented for a minimal cost. In addition, we ask that you gather pledges totaling at least $300 from your family, friends and associates. If you prefer to make a single donation of $300, that's fine, too! Full tax receipts will be given for all donations over $20. Last year was a record-breaker: our golfers raised **$20,000!**

Please contact us as soon as possible to secure your participation or to register your foursome at events@alifeforelisa.org or call Elisabeth at (416) 223-1911.

### TheAnswerIs.ca
### A Creative New Way to Support the SCRF While Building a Long-Term Portfolio – Without Advisor Fees

Our good friend and SCRF supporter, **David Jenkins**, HBA, ICD.D, is a Toronto real estate executive, entrepreneur and long-time investor who has just launched **TheAnswerIs.ca.**

It's a non-profit website to simplify the complex world of investing, to give 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.

**Best of all, instead of charging advisor fees, David simply asks users to donate to The Sanfilippo Children's Research Foundation (SCRF).**

David and his wife Paula made the trek up Machu Picchu in support of The SCRF in 2015.

**About the Author, David Jenkins:** After having enjoyed a successful career in business in C-suite and board roles, David has a strong foundation in valuations, acquisitions and business expansion. He has built a 30-year track record of success with his own personal long-term, low-cost investment portfolios. David was motivated to give back by building TheAnswerIs.ca as a learning tool in appreciation for the significant financial assistance he and his three brothers received from Canadian taxpayers through university tuition grants from Veterans' Affairs Canada. In addition, his three daughters and their friends were keen to take control of their own future financial liberty, but wanted to learn through an approachable, easy-to-understand website. He wished to help people avoid the advisory fees that water down their investment returns, so he kindly asked investors to support The SCRF in return for his guidance. Almost $2,000 has been donated to The SCRF through TheAnswerIs.ca since the website's inception in the fall of 2016.

TheAnswerIs
Independent Investing Intelligence

**About TheAnswerIs.ca:** The site conveys key lessons; chief among them the fact that financial advisor and mutual fund fees of only 2% per year can consume 40–50% of an investor's long-term returns. The site also educates people about tapping into the power of compound interest, which Einstein called "mankind's greatest discovery;" and much more. It delivers succinct answers to essential questions such as:

- What questions should I ask about investing?
- What are the four secrets of being a successful investor?
- How can I make my TFSA *really* work for me?
- I earn minimum wage. Will I ever have money to invest?
- How much will it cost me if I wait just one more year before I start to invest?

David hopes TheAnswerIs.ca will help to put answers into Sanfilippo researchers' hands while answering the call for affordable long-term investing guidance to help people avoid pitfalls and perform intelligently in the ever-changing markets. We thank him for creating this creative fundraising avenue! For more information, contact **David Jenkins, TheAnswerIs.ca Inc., djenkins@theansweris.ca or 647 926 8941.**

**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, donation, 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!**

## Join Us for Our Third Overseas Fundraising Adventure

### RIDE FOR A CURE Bike Tour of Southern Ireland in memory of Elisa. Help us reach our goal of $100,000!

**On September 7th, 2017, The SCRF is embarking on its third exciting fundraising adventure: Cycling Southern Ireland for six days and touring the historic and beautiful sights of Northern Ireland for four days.** As promised two years ago, we are putting our hiking boots away for now and replacing them with bikes to take on the rich and beautiful hills and countryside of Ireland. We have resumed planning this exciting bike tour, now in memory of Elisa, which we briefly put on hold as Jessica and Cameron's wedding plans took priority last September.

This adventure is limited to 14 participants who will join the Linton family on this unforgettable tour of back roads, stunning countrysides, hills and seascapes. There will be history galore, as our package also includes accommodations in historic inns, along with some good *craic* in the Irish pubs. Cycling distances will range from 45km – 60 km per day for six days. We may even find time to take in a round at one of their many renowned golf courses. Our tour of Northern Ireland will include a visit to the Titanic exhibit in historic Belfast where the ship was built, as well as the famous Giant's Causeway and other scenic highlights.

For those interested, the Linton family will be stopping in Iceland on the return trip to Toronto for a three-day tour of Reykjavik, Iceland's capital, the Blue Lagoon and other attractions (possibly even having a chance to see the Aurora Borealis). No obligation, but we'd love you to join us for this unique and memorable additional tour if you can. This exciting experience will be led by **Verstraete Travel & Cruises**, who have done a fabulous job of organizing our last two overseas fundraising endeavours.

## Costs:

### A

**The Ireland adventure:** Sept. 7th through Sept. 17th – Includes flights, other transportation costs, guides, all visits and admissions to events in itinerary, all breakfasts, bikes and accommodations. **Not included** are lunches and dinners, incidentals, insurance, applicable visas, airport taxes, tips and gratuities.

**Total per person: Approximately $4,000 Cdn** (per person/double occupancy – details to be finalized).

**Optional Iceland visit:** The additional cost will be approximately **$1,500 Cdn** per person.

### B

**Fundraising:** Each participant is required to raise a minimum of **$3,000 Cdn** for The SCRF. We of course provide everyone with fundraising strategies, ideas and tools to support you in your fundraising efforts. All participants have been successful fundraisers in past years.

Please note that this fundraiser will be on a first-come, first-served basis and we only have room for 14 participants. Deposit cheques will be accepted after March 1st, 2017.

Please consider joining us on this amazing cycling adventure through Ireland! If you're not up for the adventure, we trust you will consider sponsoring the participants to help raise funds for The SCRF research chair endowment fund.

More details of our proposed itinerary are posted on The SCRF website, alifeforelisa.org. An information meeting will be planned for the spring of 2017 for those considering participating.

For more information about booking, or any trip or travel questions, please contact **Elisabeth Linton** at The SCRF: **elisabeth@alifeforelisa.org (416-223-1911).**

## Please Sponsor Us! Help our major fundraiser this year reach its $100,000 goal

We are grateful for your generous support of our past excursions and would appreciate your sponsorship of the Linton family or a member of The SCRF's dedicated team committed to cycling the hills of Ireland in memory of Elisa and continuing her legacy through The SCRF's research chair endowment fund. You can very easily **donate online**. Simply:

**1**

Login to our website at **www.alifeforelisa.org** and click on "Ride for A Cure." It's very easy to follow from there!

OR

**2**

Fill in the sponsor sheet below with your contribution and mail it back to us at **SCRF, 41 Gwendolen Ave., 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 research projects we are committing to this year.

## Ride for a Cure in Memory of Elisa Donation Form

**Name of cyclist**

Yes!! I would like to make a donation to **The Sanfilippo Children's Research Foundation** in honour of The Linton Family and The SCRF team's commitment to cycling the hills of Ireland in memory of Elisa. All proceeds will go to help establish **The SCRF's research chair endowment fund**.

$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!***

# Ride for a Cure

September 2017

Bike Tour of Southern Ireland
in memory of
Elisa

See pages 10–11 for trip details and donation information.

## 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 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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