SCRF News

June 2026
Special Update

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.

Greetings Friends,

It has been too long since we sent out a newsletter and communicated with you with updates on the latest medical research toward a treatment for Sanfilippo syndrome. We share our sincerest apologies for this. Since our daughter Elisa passed in 2016, other priorities have become important in our family. We've become grandparents to five beautiful grandchildren and have been caring for elderly parents. We lost our two dads, Leonard Linton in July 2023 and Norman Macleod on October 31, 2025, nine years to the day after Elisa passed away. We continue to be caregivers to our two moms in their 90s.

That's not to say that we have not continued to nurture the Sanfilippo Children's Research Foundation. We are thankful to share that the SCRF continues to receive monthly and yearly donations and the SCRF Board of Directors continues to fund medical research here in Canada at Ste. Justine Children's Hospital in Montreal, where the Elisa Linton Sanfilippo Research Laboratory is making significant research gains in small molecule therapy research. Dr. Pshezhetsky's team there is advancing a translation of a neuroprotective drug that has shown promising results in preclinical studies for Sanfilippo and they are in preliminary discussions with regulatory authorities as they see positive results in mouse models. We are also excited to share that the gene therapy clinical trials that the SCRF was instrumental in funding, along with Abeona Therapeutics several years ago, has had significant and promising findings which have inspired the formation of a new biotech company, Sangrail Biologics. Sangrail has recently announced its commitment to continue funding of these clinical trials with Nationwide Children's Hospital, Columbus Ohio. Find the latest details of these research projects on our website at **www.alifeforelisa.org**.

Lastly, we are excited to share the launch of a book that Randall has been working on for the last six years – *This Little Light of Mine: A Father's Memoir of his Daughter's Brief but Deeply Significant Life*. We invite you to attend the book launches in June and to purchase a copy either at the launch or online. All proceeds from the sale of this book will support the SCRF. For more details, please see the following page or click here. Hope to see you at one of the two dates.

With continued heartfelt thanks for your ongoing support to finding a treatment for Sanfilippo syndrome,

Randall + Elisabeth Linton

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.*

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Join us to celebrate Elisa's life and the book that will carry it forward.

We're excited to announce the launch of Randall Linton's book:

This Little Light of Mine: A Father's Memoir of his Daughter's Brief but Deeply Significant Life is the story of my daughter Elisa and her 22 years living with a rare, terminal childhood disease called Sanfilippo syndrome. It is also the story of how our family responded to the devastating diagnosis, prognosis, and challenges of having to witness Elisa's slow cognitive and physical regression before finally succumbing to this disease.

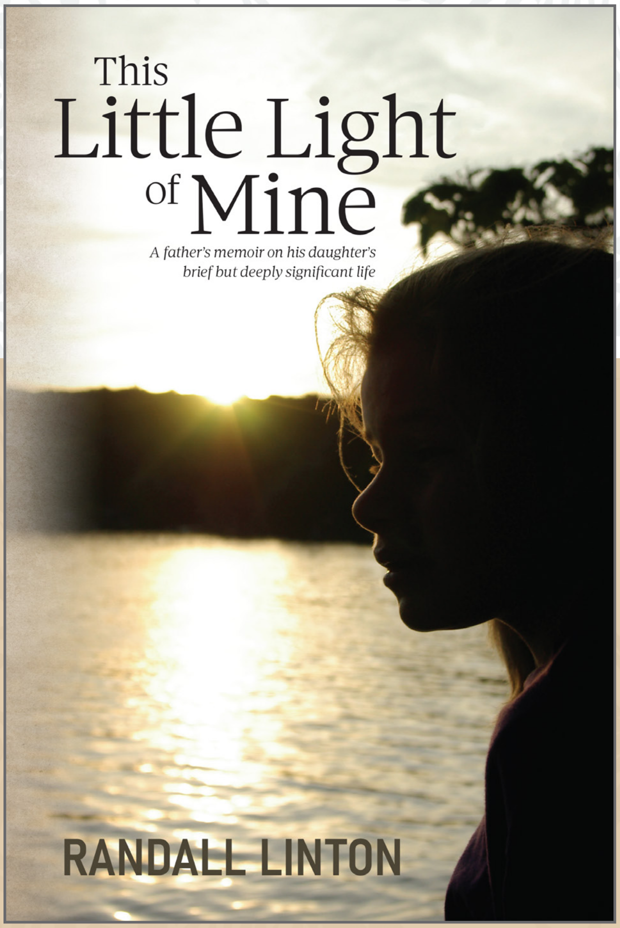
In my memoir, I share how my daughter sparked a global community of doctors, medical researchers, families and so many unlikely allies – from grandmothers to celebrities – to advance medical research and bring hope to families facing the unthinkable.

I include my personal journal entries as I watched my daughter grow up and slowly fall victim to her cruel degenerative disease. The book includes moments of joy and humour that our family managed to experience while faced with impossible odds. I have also included our experiences with several friends, many of whom became our lifeboats during Elisa's lifetime.

This book went from being a manuscript originally intended only for my grandchildren to enable them to learn about the life of a relative they never met. When a few dear friends heard that I was writing this, they asked to read the manuscript. This book is the result of their encouragement to me to write something for a wider audience and to perhaps help parents who may be going through the pain of living with and losing a terminally ill child.

I am deeply grateful in advance for your support and trust you find inspiration and hope from the five years I invested in writing this.

All proceeds will support medical research through The Sanfilippo Children's Research Foundation. Learn more at *ALifeforElisa.org*.



BOOK LAUNCH

Please join us to celebrate the release of the book, enjoy refreshments, hear some inspiring and heartwarming stories, reunite with Randall and our family, reconnect with other SCRF supporters, and purchase your copy of the book:

> **Saturday, June 13** *10:00 a.m. to 11:30 a.m.*
> *Spring Garden Church, 112 Spring Garden Avenue*
>
> **Wednesday, June 17** *7:00 p.m. to 8:30 p.m.*
> *Spring Garden Church, 112 Spring Garden Avenue*

The book is available now:

> 1. Through us for **$20.00 per copy, no HST**. To order, contact us at randall@interiorcare.com OR elisabeth@alifeforelisa.org.
>
> 2. Online via FriesenPress, Indigo, Amazon, and Barnes and Noble.

Please share this invitation and bring your friends! We look forward to seeing you.