



THE LFSA ADVOCATE

LI-FRAUMENI SYNDROME ASSOCIATION – CANADA

WELCOME TO OUR INAUGURAL LFSA CANADA NEWSLETTER

We are excited to launch **THE LFSA ADVOCATE** where we will periodically reach out to stay connected and to pass on information that may be of interest to the Li-Fraumeni Syndrome patient/parent community, friends and family of that community and beyond.

LFSA Canada represents the interests of LFSA patients and families within Canada and has as its goal the aim of raising awareness and improving access to resources and information to those affected. To that end, we encourage the sharing of this newsletter to help spread the word and, as **International LFS Awareness Month** is coming a close, there is no time like the present to help keep the message alive.

In this issue we will introduce you to the Co-Chairs of LFSA Canada, share exciting news on research being conducted in our own backyard, learn a little about the awesome animal that has become the mascot of the LFSA, and more!

We welcome input and feedback too! If you have an idea for, or would like to contribute to future editions of this newsletter, please let us know.

CALL FOR VOLUNTEERS!

LFSA Canada is looking for volunteers! If you are interested in joining our team as we look to expand our reach in Canada, have an idea for our next newsletter and/or have fundraising experience or ideas - **we want to hear from you!**

Reach out at:

lfsassociation.org

CONTACT US

Chiquita Hessels, Co-Chair

chessels@lfsassociation.org or

250-741-7535

Dr. David Malkin, Co-Chair

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General LFSA-Canada Email

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MEET OUR CO-CHAIR, CHIQUITA HESSELS

Chiquita Hessels became involved with the Li-Fraumeni Syndrome Association after her diagnosis with LFS in 2014. In 2016, she took the lead to launch the LFSA Canada Chapter. Her goal is to strengthen the presence of LFSA in Canada, and to offer people with LFS and their families the support and access to information and resources she sought and received from LFSA when she needed it most. Chiquita lives in Nanaimo, British Columbia with her husband and their rescue dog Blossom. She works tirelessly to improve the reality of life with LFS for her two sons, her niece and great niece and for all those afflicted.

Chiquita takes any opportunity to spread awareness and to advocate for the LFS community. She was recently interviewed for a piece in the online publication [Healthing.ca](https://www.healthing.ca). Click on the link to read the full article and then hear directly from our co-chair by clicking on the photo.



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MEET OUR CO-CHAIR, DR. DAVID MALKIN



LFSA-Canada Co-Chair, Senior Staff Oncologist Hematology/Oncology, Director Cancer Genetics Program, SickKids, Professor Departments of Paediatrics and Medical Biophysics, University of Toronto, to name a few.

Dr. David Malkin received his medical degree at the University of Toronto and completed his residency in pediatrics and paediatric hematology/oncology at the Hospital for Sick Children. He completed his post-doctoral research training in molecular genetics at Harvard University, where he contributed to the discovery that the p53 gene mutation was responsible for LFS. Dr. Malkin has continued his research on genetic predisposition to cancer as related to childhood cancers. His team at the UofT has focused on LFS, studying which type of cancers LFS children will develop at what ages, and the development of early detection screening guidelines, coined “The Toronto Protocol.” Dr. Malkin also serves on the LFSA’s Medical Advisory Board.

He is a self proclaimed Einstein enthusiast and a Toronto sports teams super fan.

Click on the photo to hear a few thoughts directly from our co-chair.

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EXCITING NEWS IN RESEARCH FUNDING

On January 18, 2023, the federal government announced "the largest investment in childhood cancer research in Canada to date" in the form of "\$23 million in funding from the Canadian Institutes of Health Research (CIHR) to establish the Canadian Pediatric Cancer Consortium (CPCC)."
The CPCC will be co-led by LFSA-Canada's own Dr. David Malkin, together with Dr. Jim Whitlock, Head of the Division of Haematology/Oncology at SickKids, and paediatric cancer advocate Adrienne Co-Dyre.

QUOTES FROM THE CPCC LEADS

Adrienne Co-Dyre

"This Canadian Pediatric Cancer Consortium sends the message that our call for more supports during and after treatment have been heard, and that our children deserve more – more access to the highest quality care, novel treatments and opportunities to live longer and healthier lives."

Dr. Jim Whitlock and Dr. David Malkin

"By harnessing Canada's collective capacity for world-leading science and clinical programs, the CPCC will establish a foundation for a national paediatric cancer strategy to deliver fast, fair, effective and safe care to all children with cancer."

[Read the full SickKids release here.](#)

"The CPCC's vision is for every child in Canada with cancer to have access to the latest scientific advances, diagnostic tools, therapies, and supportive care to help support better outcomes and a better quality of life. It will do this by strengthening research, health supports, and clinical expertise in pediatric cancers through the creation of a national network of clinicians, researchers, community of practice caregivers, patients and their families. By the end of the two-year funding period, the CPCC will have a framework on which to build and enable Canadian-led early phase clinical trials, faster access for patients to innovative technologies, therapies and care, a collaborative approach to education and training, and a robust network of national and international partnerships."

[Read the full CIHR release.](#)

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MORE EXCITING NEWS IN RESEARCH FUNDING

In May 2022, the Canadian Cancer Society in partnership with the Canadian Institutes of Health Research - Institute of Cancer Research launched the **Breakthrough Team Grants: Transforming Low Survival Cancers** competition. In January 2023 results were announced. A team led by Dr. Trevor Pugh and the CHARM Consortium were successful in their application for funding to carry out research that, "If successful, has the potential to transform our ability to detect multiple cancers in the very early stages, revolutionizing the outcomes, access to testing and quality of life for cancer patients."

ENGAGING PEOPLE WITH GENE MUTATIONS TO DETECT CANCER EARLIER WITH A BLOOD TEST

Principal Investigator:

Trevor Pugh, Princess Margaret Cancer Centre-UHN,
Ontario Institute for Cancer Research

Co-Principal Investigators:

Yvonne Bombard, St. Michael's Hospital

Raymond Kim, University Health Network

Kasmintan Schrader, University of British Columbia

Total Amount Awarded Over 5 Years:
\$7,497,681.15

Notable Mention:

LFSA Canada's own Chiquita Hessels is one of 3 patients/ survivor partners on the team.

This project brings together a team comprised of leaders in the field of familial cancer syndromes (FCS). People with inherited, or familial, forms of cancer carry genes that place them at a high risk of developing multiple cancers throughout their lifetime. Because of their high cancer risk, this population is regularly screened for signs of cancer. The research team is building on previous work to develop a genetic blood test that can detect tumour DNA circulating in the blood stream at the same time or earlier than the conventional annual medical exams for people with FCS, when less aggressive therapies can be used, and treatments are more likely to succeed. The results of this project could have wide-reaching implications for the early detection of cancer above and beyond those people living with FCS.

Since 2017, they have been working with more than 130 clinicians, scientists and patient partners from across Canada to develop the foundation for this project. Now, with funding from the Canadian Cancer Society and the Canadian Institutes of Health Research, they are conducting a clinical trial to directly engage patient participants and prove that cancer for people with FCS at risk for high fatality cancers can be detected earlier with a simple blood test than through conventional methods.

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WHAT'S WITH THE ELEPHANT?

A FEW FUN FACTS ABOUT THIS INCREDIBLE ANIMAL...

Elephants are the largest land mammal with the African Savana (the largest of the 3 elephant species) standing up to 3m tall and weighing up to 6000kgs.

Despite their large size and weight, they can walk up to 40kms per hour.

Elephants are highly intelligent and emotional creatures.

They are one of the few species who can recognize themselves in the mirror.

The gestation period of an elephant is 22 months; the longest of any mammal.

An elephant can stand up within 20 minutes of birth and can walk within an hour.

Elephants' trunks have over 40,000 muscles which are used for breathing, smelling and communicating.

They can pick up something as big and heavy as a horse or as small as a grain of rice.

And of course, an elephant never forgets.

But what does this all mean to the LFS community? Click on the LFSA Elephant above to watch a fascinating video with Dr. Josh Schiffman, a leading physician, researcher and LFSA partner, to learn why elephants have been adopted as the LFSA mascot.



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SAVE THE DATE!!! 2023 YOUTH CONFERENCE IS COMING!

The LFSA Youth Program is made up of young people with LFS, for young people with LFS, helping them live their lives to the fullest and stay connected with one another.

The **2023 LFSA Youth Conference** is a three day event where teens and young adults gather to learn from and engage with experts in the field and connect with other LFS youth to foster friendships and support. This year, the conference will take place from August 18-20, 2023 in New York City! Teens and young adults between the ages of 13 and 26 with LFS are invited to attend. Save the date and watch for more information as it becomes available. Spots will be limited so once registration is open, don't delay - book your spot!

[Subscribe today to receive the latest LFSA Youth Program news and for information on the upcoming LFSA Youth Conference.](#)

ANNA JOY LFSA YOUTH PROGRAM BURSARY

Anna Joy Ryan was the Youth Chair for LFSA-Canada, working in tandem with her friend and mentor, and LFSA-Canada Co-Chair, Chiquita Hessels. She was an original member of the Youth Program and understood that those who participated derived tremendous benefit from the camaraderie, shared knowledge, and friendships forged. Anna Joy's legacy will long endure and to honour her, LFSA-Canada is proud to announce the **ANNA JOY YOUTH PROGRAM BURSARY**.

This year, the \$500 bursary will be awarded to assist with travel expenses to attend the **2023 LFSA Youth Conference**.

To be considered we invite you to submit a one page essay answering the following questions:
Why are you attending this year's youth conference and what do you hope to get out of the experience?
What topics are you most interested in? What social activities would you like to take part in?

To be eligible for this bursary, you must have secured a spot to attend this year's conference, live in Canada and be between the ages of 13 and 26. Please email your submissions to lfsacanada@lfsassociation.org by June 30, 2023. The selected recipient will be notified by July 15, 2023.

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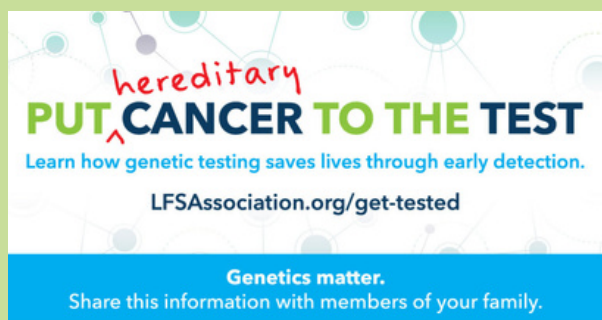
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