THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA

Summer 2026

WELCOME

LFSA Canada represents the interests of LFSA patients and families within Canada and has as it's 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.

In this issue we will share exciting news on LFS Global events, research being conducted in our own backyard 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**!
Email us at:
lfsacanada@lfsa.org

THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA

Summer 2026

OUR CO-CHAIRS

CHIQUITA HESSELS

After being diagnosed with Li-Fraumeni Syndrome (LFS) in 2014, Chiquita Hessels became actively involved with the Li-Fraumeni Syndrome Association (LFSA). In 2016, she led the launch of the LFSA Canada Chapter, with a mission to expand support, information, and resources for Canadians affected by LFS and their families.

Chiquita lives in Nanaimo, British Columbia, with her husband and rescue dog, Blossom. She is a dedicated advocate for the LFS community, working to improve the lives of her two sons, niece, great-niece, and others affected by the syndrome.

Chiquita was recently featured in an interview with Healthing.ca.
Read the full article and hear directly from our co-chair by clicking the photo.

DR. DAVID MALKIN

Dr. David Malkin, LFSA-Canada Co-Chair, is a Senior Staff Oncologist in Hematology/Oncology and Director of the Cancer Genetics Program at SickKids, as well as a Professor in the Departments of Paediatrics and Medical Biophysics at the University of Toronto.

After earning his medical degree and completing specialty training at SickKids, Dr. Malkin pursued postdoctoral research in molecular genetics at Harvard University, where he helped identify p53 gene mutations as the cause of Li-Fraumeni syndrome (LFS). He has since dedicated his career to researching inherited cancer risk, particularly in children with LFS.

His team at the University of Toronto developed the internationally recognized “Toronto Protocol,” which guides early cancer detection and surveillance for individuals with LFS. Dr. Malkin also serves on the LFSA Medical Advisory Board.

Outside of medicine, he is a passionate Albert Einstein enthusiast and devoted Toronto sports fan.
Click on the photo to hear a few thoughts directly from our co-chair.

THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA
Summer 2026

TORONTO HOSTS THE 20TH INTERNATIONAL P53 WORKSHOP

From April 27 to May 1, Toronto welcomed the 20th International p53 Workshop, a globally recognized conference that brought together leading scientists, clinicians, and industry experts to explore the latest discoveries surrounding TP53—one of the most important genes in human biology and the most frequently mutated gene in cancer.

Co-organized by three of Canada's premier research institutions—University Health Network (UHN), Lunenfeld-Tanenbaum Research Institute at Mount Sinai Hospital, and The Hospital for Sick Children (SickKids)—the workshop continued a distinguished tradition of advancing excellence and collaboration within the international p53 research community.

The conference showcased groundbreaking research and emerging innovations related to TP53, highlighting its critical role in genomics, human health, disease, and the development of next-generation cancer therapeutics. Researchers from leading institutions around the world gathered to share discoveries, exchange ideas, and foster interdisciplinary collaborations aimed at accelerating translational research.

Scientific sessions explored the multifaceted functions of p53, including its regulation of metabolism, inflammation, immunity, tissue microenvironments, and the roles of its isoforms and family members. Participants also examined novel strategies for targeting p53 in human disease and translating fundamental biological insights into therapeutic approaches. Discussions focused on identifying new ways to manipulate or restore p53 function in cancer and other diseases, with the potential to unlock entirely new frameworks for understanding disease biology and treatment.

Workshop Attendees Opening Day
Toronto Sick Kids Hospital

- Dr. Trevor Pugh • CHARM Co-Founder
- Chiquita Hessels • Co-Chair LFSA Canada
- Dr. David Malkin • Co-Chair LFSA Canada
- • Co-Chair & Speaker P53 Workshop

THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA
Summer 2026

EXCITING NEWS IN RESEARCH
CHARM2 RESEARCH STUDY

CHARM2 (Cell-free DNA in Hereditary and High-Risk Malignancies 2) is a Canada-wide research project. It is looking at whether a simple blood test can help find cancer sooner in people who are at higher risk, including those with Li-Fraumeni syndrome (LFS).

The study is run by the CHARM Consortium, a group of researchers and doctors working to improve cancer care, especially for people born with a higher risk of cancer. The aim is to include 1,000 participants from across Canada. People can join if they have certain genetic changes, such as a change in the TP53 gene, and have been cancer-free for at least three years. The study is open across six provinces including British Columbia, Alberta, Ontario, Quebec, Nova Scotia, and Newfoundland and Labrador. So far, about 750 of the 1,000 spots have been filled, including 34 people with LFS.

In the CHARM2 study, participants continue with their regular cancer screening and some also give a blood sample every four months. The study's blood test looks for tiny signals in the blood that might show cancer is present, even before it can be seen on scans or causes symptoms. Researchers want to find out if this approach can detect more cancers earlier and help improve quality of life.

The main goal of the CHARM2 study is to help spot cancer earlier and improve care for people and families living with LFS, where frequent screening can be challenging. This blood test is still being studied and does not replace regular screening. However, CHARM2 is an important step toward improving care and overall health, including for those with LFS.

If you or someone you know may be interested, please visit
charmconsortium.ca/recruitment.

SCAN ME

DEVOTED TO A WORLD WITHOUT INHERITED CANCER

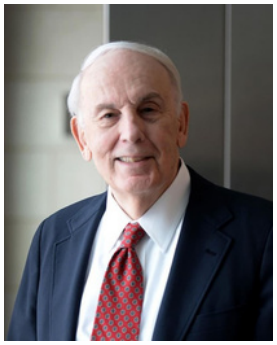
THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA
Summer 2026

We are deeply saddened to learn of the passing of Dr. Joseph F. Fraumeni, Jr. (1933–2026).

For the Li-Fraumeni syndrome community, Dr. Fraumeni's work is deeply personal. Over a career spanning more than 50 years at NIH, Dr. Fraumeni shaped and directed a national and international research program designed to identify the environmental and genetic determinants of cancer and the means of prevention. His personal research focused on genetic susceptibility to cancer, particularly by investigating familial aggregations of various malignancies. Most notable was his discovery in 1969, with fellow NCI researcher Frederick P. Li, of a rare, inherited syndrome featuring an array of multiple cancers in young people that came to be known as Li-Fraumeni syndrome. This observation eventually led to collaborative molecular studies that uncovered inherited mutations in the TP53 tumor suppressor gene.

Because of Dr. Fraumeni's dedication, generations of families, clinicians, researchers, and advocates have had a clearer path forward. His work gave our community knowledge, language, and hope. It continues to shape how Li-Fraumeni syndrome is studied, diagnosed, and cared for today.

We honor Dr. Fraumeni with deep gratitude. His legacy lives on in the families impacted by LFS, the researchers and clinicians he inspired, and the continued work toward better surveillance, treatment, support, and ultimately, a future with fewer cancers.



THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA

Summer 2026

HELP US SUPPORT FAMILIES WITH LFS

The Li-Fraumeni Syndrome Association Canada is a volunteer-driven, not-for-profit organization dedicated to supporting individuals and families affected by Li-Fraumeni Syndrome (LFS). Your donation helps us provide vital educational resources, patient support programs, advocacy initiatives, and opportunities to advance research and awareness across Canada.

Every contribution, no matter the size, makes a meaningful difference in the lives of families facing the challenges of LFS. By donating today, you become part of a community committed to improving outcomes, fostering hope, and helping create a future where those affected by LFS can thrive.

E-transfer

chessels@lfsassociation.org

or

PayPal

Donate Today

UPCOMING EVENTS

October 2–5, 2026

The 8th International Li-Fraumeni Syndrome (LFS) Association Symposium (REACH26)

This hybrid event—hosted by the MD Anderson Cancer Center in Houston, Texas—unites scientists, medical professionals, researchers, and families to advance inherited cancer care and share knowledge.

More information

https://www.lfsassociation.org/event/8th-international-lfs-association-symposium/

THE LFSA
ADVOCATE
LI-FRAUMENI SYNDROME ASSOCIATION – CANADA

Summer 2026

CONTACT US

Chiquita Hessels, Co-Chair :- chessels@lfsassociation.org
+1-250-741-7535
Dr. David Malkin, Co-Chair :- david.malkin@sickkids.ca
Dana Gudelis, Volunteer :- dgudelis@lfsassociation.org
Hailey Stack, Volunteer:- hailey.stack@sickkids.ca
General LFSA-Canada Email:- lfsacanada@lfsassociation.org

QUICK LINKS RESOURCE CENTRE

LFSASSOCIATION.ORG CANADA

LFSASSOCIATION.ORG

LFSA CANADA

LFSASSOCIATION TOOL KIT

LFSASSOCIATION.ORG YOUTH PROGRAM

LFSA