

Resources for LFS Families and Medical Providers

Jenn Perry – LFSA President & CEO, Co-founder, LFS Patient
Megan Frone, MS, CGC – LFSA Genetic Counselor Advisory Group Co-
Chair

May 12, 2026

Holly Fraumeni, MSW, Vice President and Chief Executive Assistant to the President



Family Support & Advocacy

LFSA Youth Program

Webinars & Conferences

Insurance Basics

wbMRI

Reference Library

Family & Care Provider Toolkit

Genetic Counselor's Library

Genetic Testing, Early Detection & Screening

Nutrition & Exercise

Lifestyles, Research & Survivors

Financial Concerns

LFS News

Whole-Body MRI

Home - Whole-Body MRI

Consensus Statement by the Li-Fraumeni
Association Regarding Surveillance of those affected with
Li-Fraumeni syndrome



DOWNLOAD LFSA'S WBMRI
CONSENSUS STATEMENT



DOWNLOAD THE WBMRI
WORKSHEET



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- Family Support & Advocacy
- LFSA Youth Program
- Webinars & Conferences
- Insurance Basics**
- wbMRI
- Reference Library >
- Family & Care Provider Toolkit

Insurance Basics for Individuals with Li-Fraumeni Syndrome (LFS)

Insurance Basics for Individuals with Li-Fraumeni Syndrome (LFS)

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Insurance and Financial Support



- Information on insurance basics, financial support, help paying bills, coverage for whole body MRI, and insurance appeals
- Downloadable PDF of Insurance Guide:
 - <https://www.lfsassociation.org/wp-content/uploads/2024/01/LFSA-Insurance-Info-Sheet.pdf>
- Downloadable wbMRI coverage worksheet (to help determine coverage with insurance company):
 - <https://www.lfsassociation.org/wp-content/uploads/2024/01/LFSA-wbMRI-Worksheet.pdf>
- Health insurance appeals templates for peer-to-peer appeals for adults and peds

wbMRI COVERAGE WORKSHEET

First step: Call your provider and/or the billing office of the center where you will be having your wbMRI and ask what "procedure code" (also called a CPT code) or codes will be used when your wbMRI is performed.

Person you spoke with: _____ Date: _____

CPT code(s) used: _____

ICD-10 code(s) used: _____
(Note: ICD-10 code Z15.01 - Li Fraumeni Syndrome/Genetic susceptibility to malignant neoplasm should be used in most cases. If this is not being used, discuss with your provider the reason why)

Second step: Call your insurance company and check your coverage for the procedure codes that will be used and have the ICD-10 or diagnosis codes that will be used and see if that information would be helpful for them. Your insurance provider should be able to help you understand your expected coverage for the wbMRI and expenses, if any, are expected to be.

Person you spoke with: _____

CPT code(s) covered at what percent of contracted rate? _____

CPT code(s) covered as a medical benefit at what percentage? _____

Do I have a copay with the visit? How much? _____

Have I met my deductible? If not, how much is left? _____

Have I met my out-of-pocket maximum for the year? If not, how much is left? _____

Can you help me understand how much out-of-pocket cost I can expect? _____


The billing office where you are having your wbMRI should also be able to help you answer these questions. If you do not have financial navigators that can help. Call your center and ask if they have a financial navigator you can speak to. They are usually able to help. Explain that your doctor would like for you to have a procedure (a whole-body MRI) and that you would like to understand more about your insurance coverage and any out-of-pocket costs you may expect/how much you may expect for this procedure.

It is important to check this every year because if your insurance coverage changes your benefits and coverage. Out-of-pocket costs will also be influenced by factors such as if you have met any deductibles or out-of-pocket maximums.

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Insurance Basics for Individuals with Li-Fraumeni Syndrome (LFS)

Note: This resource is primarily intended for individuals navigating insurance within the U.S. healthcare system. This content does not constitute professional medical advice. The information is included for informational purposes only and cannot guarantee coverage for any medical services.

 **LFSA** LI-FRAUMENI SYNDROME ASSOCIATION
GENETIC COUNSELING ADVISORY GROUP

LFSAssociation.org



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- Research
- Where To Get LFS Care
- Treatment Facilities
- Genetic Testing
- Clinical Trials, Studies & Surveillance
- Family & Care Provider Toolkit

CONNECTING THE INTERNATIONAL LFS COMMUNITY

WHAT IS LFS?

Provider Resources

- LFS Fact Sheet for Medical Providers
 - <https://www.lfsassociation.org/wp-content/uploads/2026/05/LFS-Fact-Sheet-for-Medical-Providers-2026.pdf>
- LFS Fact Sheet for Mental Health Providers
 - <https://www.lfsassociation.org/wp-content/uploads/2024/01/Quick-Reference-Resource-for-Mental-Health-Providers.pdf>
- LFS Fact Sheet
 - <https://www.lfsassociation.org/wp-content/uploads/2026/05/LFSA-2-Page-Fact-Sheet-2026.pdf>
- Genetic Testing Fact Sheet
 - <https://www.lfsassociation.org/wp-content/uploads/2026/05/LFSA-Genetic-Testing-Fact-Sheet-2026.pdf>
- “LFS and Living my Best” Childrens’ Book
 - https://www.lfsassociation.org/wp-content/uploads/2024/01/LFS-Living_My_Best_cs.pdf
- Brochures for your clinics, AYA flyers, FAQ documents, and more!

Li-Fraumeni Syndrome (LFS) Fact Sheet for Medical Providers

- LFS is a hereditary cancer predisposition syndrome caused by inherited or de novo pathogenic variants (also called mutations) in one copy of the *TP53* tumor suppressor gene, present in the patient from birth (i.e. germline variant).
- People with LFS only have one fully functional *TP53* gene to protect against accumulation of further cancer-causing genetic mutations.
- Risk for rare and common cancers is significantly elevated for both children and adults with LFS, leading to significant screening recommendations. Below: Approximate percentage of males and females with a first primary cancer by age (PMIDs: [21779515](#), [27496084](#)) and summary of recommended screening modalities by age.

	15 years	30 years	45 years	60 years
Males	15-25%	20-40%	40-60%	>70%
Females	5-15%	40-50%	75-90%	>90%

	Abdominal Ultrasound	Complete Physical +/- Bloodwork	Whole-body MRI	Brain MRI	Dermatology	Endoscopy/Colonoscopy	Breast MRI (Females)	Mammogram (Females)
Age	Pediatric q3-4 mos	All ages; peds: q3-4 mos; adults: annual	All ages annual	All ages annual	18+ years annual	25+ years q2-5 yrs	20-75 years annual	30-75 years annual

- The most common cancers seen in LFS are premenopausal breast cancer, soft tissue sarcoma and osteosarcoma, brain cancer, and adrenocortical carcinoma (especially pediatric). Hematological cancers are also common.
- Not everyone with LFS will develop a cancer; others will develop multiple cancers.
- Medical Providers caring for patients with LFS should...
 - Maintain a high index of suspicion of malignancy during office visits.
 - Be familiar with LFS cancer screening recommendations and coordinate with other specialists as necessary to ensure the patient has access to appropriate screening.
 - Connect the patient with an LFS clinic or a local provider who is willing to coordinate recommended screening scans, including annual whole-body MRI or a suitable alternative if whole-body MRI is unavailable.
 - Avoid ordering scans involving radiation except when medically necessary.
 - Be cognizant of psychological stresses individuals with LFS may experience both chronically and acutely, particularly surrounding periods of



What is Li-Fraumeni syndrome?

Li-Fraumeni syndrome (LFS) is a rare genetic condition caused by inherited pathogenic variants (mutations) in a gene called *TP53*. Individuals with LFS have nearly 100% lifetime risk of cancer of various types that can develop anytime from early infancy to late adulthood. Individuals with LFS have a 50% chance of passing on the condition to their children. Siblings, parents, and other relatives may also have LFS. Individuals with LFS regularly undergo intensive cancer-related screenings and procedures (e.g., whole-body MRI, brain MRI, breast MRI, colonoscopy). There is no cure for LFS or effective ways to reliably detect and treat all possible cancers. Ideally, people with LFS receive care from an interdisciplinary team of health care providers, including a genetic counselor, to ensure comprehensive care. Below are examples of multiple challenges that individuals with LFS and their families may face.



PERSONAL CHALLENGES

- Chronic grief**
 - Concurrent and multiple cancer diagnoses and deaths in the family and LFS community
- Multidimensional loss & PTSD**
 - Trauma from cancers, deaths, and other losses related to uncertainty (e.g., ambiguous loss, unacknowledged loss)
- Scarcity**
 - Anxiety surrounding upcoming screenings and results

COMMUNITY CHALLENGES

- Access to quality healthcare**
 - Invalidating health encounters and role reversal where the person with LFS becomes the educator for providers
- Family communication**
 - Difficulty talking about LFS, risk, genetic testing, reproductive beliefs, and health decisions
- Supportive networks**
 - Difficulty finding support for individuals with LFS and family

STRUCTURAL CHALLENGES

- Health policy**
 - Lack of insurance coverage for affordable care for all individuals
- Health insurance**
 - Private insurance policies screen out individuals with LFS
- Scarcity of resources**
 - Difficulty accessing specialized care for individuals with LFS

FOR ADDITIONAL RESOURCES, PLEASE VISIT
 Li-Fraumeni Syndrome Association – [LFSAssociation.org](https://www.lfsassociation.org)
 National Cancer Institute – [lfs.cancer.gov](https://www.nccih.nih.gov)



Research

Home » Research

DONATE TO LFSA

It is the mission of the LFSA as a patient advocacy organization to promote an increased understanding of Li-Fraumeni Syndrome (LFS) and foster scientific advancement that will improve the lives of those living with LFS. We have been aided in this endeavor by the recent formation of a LFS Research Consortium. This group is made up of dedicated physicians and scientists from all over the world with an interest in LFS. It is the hope of the LFSA that through our collaborative efforts we can make great progress in the battle against LFS.

Current areas of active research in the National Cancer Institute's [Li-Fraumeni Syndrome Study](#) include:

- Developing better LFS cancer [screening](#) protocols for patients living with LFS





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Treatment Facilities

Home » Treatment Facilities

Your location Search radius

National Cancer Institute

6120 Executive Blvd
EPS/7033 MSC 7231
EPS/7033 MSC 7231 MD EPS/7033 MSC 7231
United States

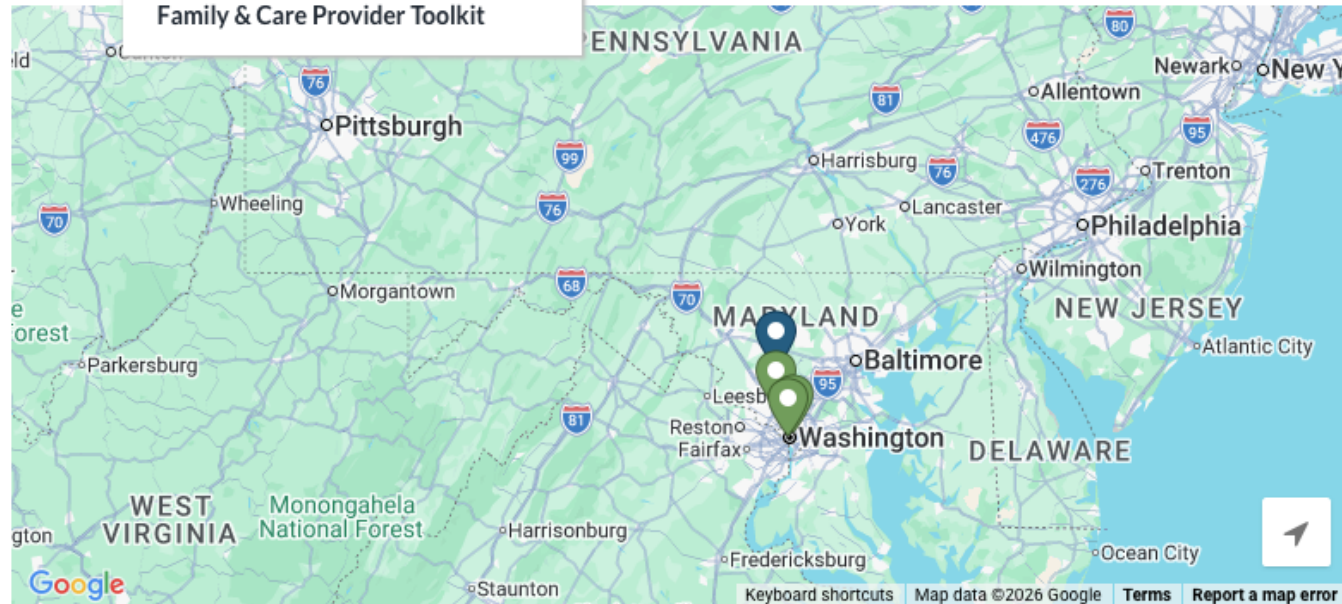
13.6 mi

[Directions](#)

Children's National Medical Center

111 Michigan Ave, NW
Washington DC 20010
United States

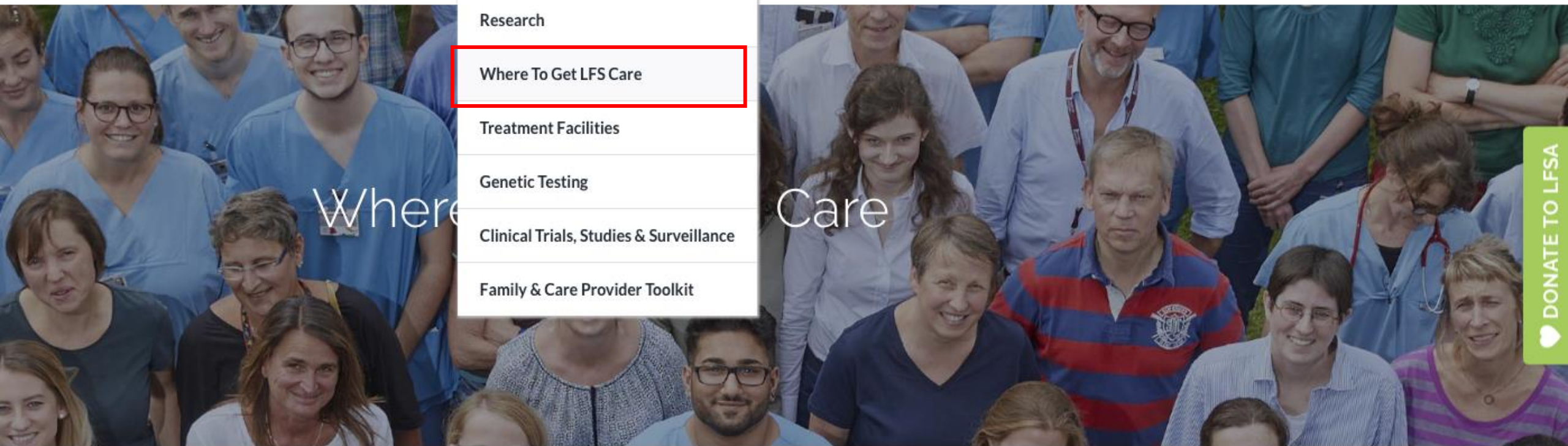
- Research
- Where To Get LFS Care
- Treatment Facilities**
- Genetic Testing
- Clinical Trials, Studies & Surveillance
- Family & Care Provider Toolkit



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- Treatment Facilities
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- Family & Care Provider Toolkit

Centers that Provide Surveillance and Management for Individuals with LFS – These Centers have dedicated clinics and/or providers that follow individuals with LFS.



Webinars

Conferences

7th LFSA International
Symposium
Penn Medicine & CHoP – 2024



REACH 26

research • education • advocacy • community • hope

REACH26

October 2 @ 12:00 am - October 5 @ 12:00 am

8th International LFS Association
Symposium

Details

Start:

[October 2 @ 12:00 am](#)

End:

[October 5 @ 12:00 am](#)

Venue

MD Anderson Cancer Center
Houston, TX 77030 United States



**Hosted by MD Anderson Cancer Center in
partnership with the LiFE Consortium**

Our 8th International Li-Fraumeni Syndrome Association Symposium will be a hybrid event—both in-person and virtual—bringing together scientists, doctors, geneticists, and LFS families to make meaningful connections across borders.

More Details Coming Soon!

ADD TO CALENDAR



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Africa



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Japan



Saudi Arabia



Canada



India



Latin America



Singapore



France



Italy



Netherlands



Sweden

LFS ASSOCIATION

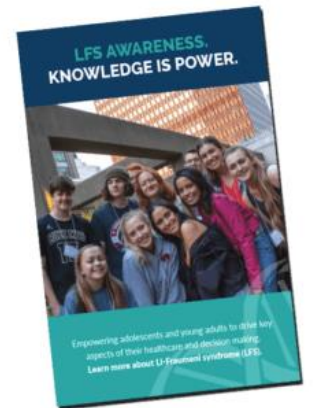


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- LFSA Youth Program**
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The LFSA Youth Program was designed to help young people with LFS live their lives to the fullest and stay connected with one another. We've created this page in hopes that you will find value and help in achieving your own goals to grow and thrive.

a-youth-program/" in a new tab



Download the LFSA Youth & Young Adult Awareness Brochure

Download Portuguese Translated Brochure



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Upcoming Events

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LFS News

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Search for events

FIND EVENTS

List



Today

Upcoming

September 2026

Mon 14

September 14 @ 8:00 am - 5:00 pm

Hunt Fore A Cure Golf Classic

Makefield Highlands Country Club 1418 Woodside Rd, Yardley, PA, United States

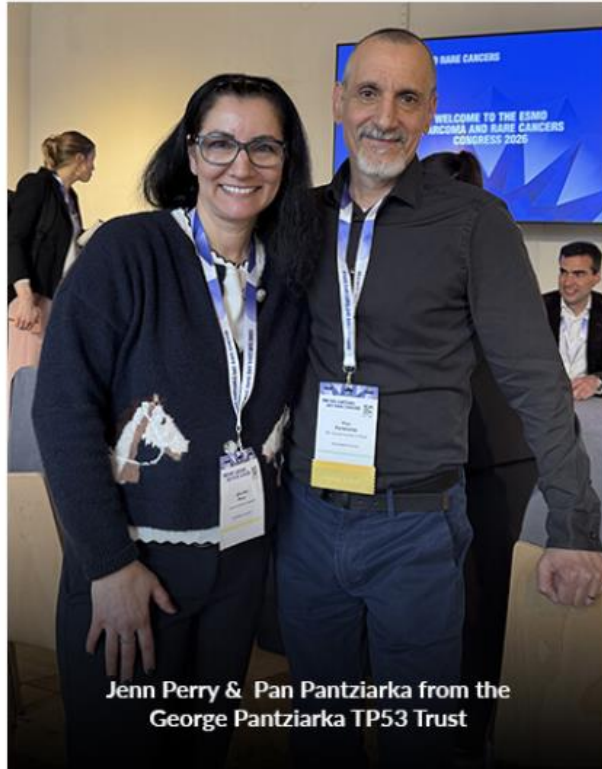
Monday, September 14, 2026 Makefield Highlands Country Club Yardley, PA Tee up for a day that drives real impact. The Hunt Fore a Cure Golf Classic raises vital funds for families living with Li-Fraumeni syndrome (LFS), a condition that causes a

predisposition to cancer affecting both children and adults. The Li-Fraumeni



Hope In Action Blog

A new blog series from Jenn Perry, LFSA President



Jenn Perry & Pan Pantziarka from the George Pantziarka TP53 Trust

Collaboration or Partnership?

I had the opportunity to attend two conferences last month.



(Left to Right) Nobel Laureate, Phillip A. Sharp, Ph.D., Jenn Perry and Arnold Levine, Ph.D.

LFSA at the SU2C Summit: Progress Through Partnership

As I reflect on my recent trip to California



P.O. Box 6458
Holliston, MA 01746, USA
Phone: **1-833-4MYLFSFA** (1-833-469-5372)
Email: info@lfsassociation.org

Li-Fraumeni Syndrome Association
Follow Page 2.6K followers

LEGACY OF HOPE
WEBINAR SERIES

Resources for LFS Families & Providers

**LFSA Genetic Counselor Advisory Group Co-Chair
Megan Frone & LFSA President Jenn Perry**



Take a user-friendly tour of essential resources and explore tools to help families and healthcare providers navigate Li-Fraumeni syndrome. Includes Q&A session.

MAY 12, 11:00 AM ET

Li-Fraumeni Syndrome Association
23 hours ago

FIND SUPPORT

SUBSCRIBE

MORE INFORMATION

REQUEST BROCHURES

MAKE A DONATION

Always at the Heart of What We Do

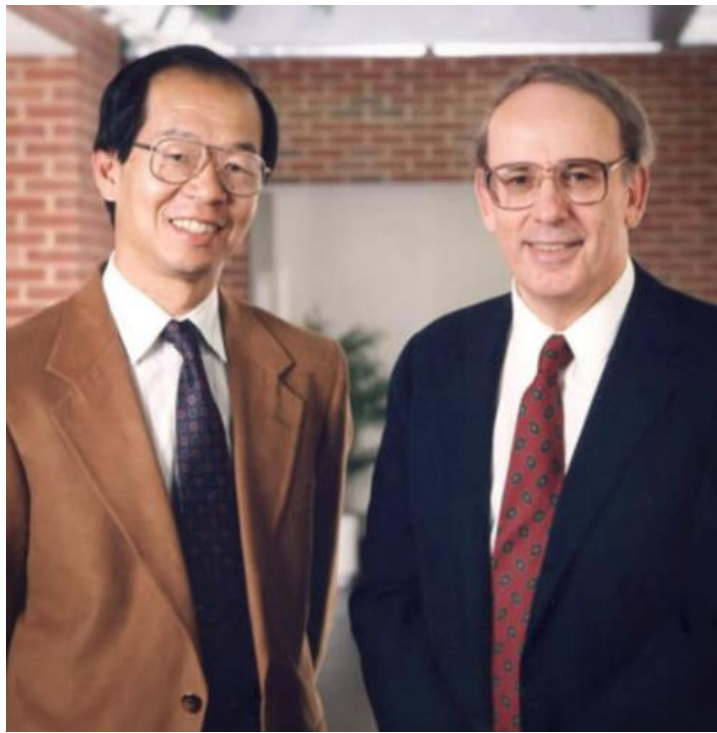
As families who have been affected by LFS, we all know the significant challenges we have faced and overcome. At the LFS Association we want to share hope, resilience and compassion to all of our LFS families. **We are the Faces of LFS...we are LFS Strong.**





My Story...





Frederick Li & Joseph Fraumeni, 1991

November 2010: First Li-Fraumeni Syndrome Conference at the National Institute of Health in Washington DC.

December 2010: Officially formed the LFS Association and selected inaugural Board of Directors.



8th International LFS Association Symposium

Hotel registration to begin sometime this month and then event registration soon after!





Medical Scientific Advisory Board Genetic Counseling Advisory Group

Project driven with key prioritized goals
Team oriented



PsychoSocial Advisory Group – coming soon!





International Chapters...

Critical that we connect our entire community across the globe – we are in different areas in the world, but we are one family with shared goals.

We will reach our goal faster the more effectively we can work together! All of our patients around the world need to know they are not alone and get the education and support they need.


Power in numbers!

**Our newest chapter just formed 2 weeks ago – China!
We now have 14 chapters.**

Li-Fraumeni Syndrome Association
February 24 · 🌐

"You are not just a patient. You are a hero."

Inspiring words to other youth with LFS share by Lakita, Youth Coordinator for LFSA – Africa. Lakita is pursuing advanced studies in psychology, sociology and literature and was recently featured in [The Times of India](#) during International Childhood Cancer Day. [See less](#)



LFSASSOCIATION.ORG
Lakita Frida - the Face of Resilience - LFS Association

Lakita Frida was an energetic dynamo when she attended her first LFSA Youth Workshop in New York City back in 2023. This young Kenyan continues to be an unstoppable force. Lakita, who serves as the Youth Coordinator for LFSA - Africa, is pursuing advanced...

📣 Boost this post to get more reach for Li-Fraumeni Syndrome Association. [Boost post](#)

👍👍👍 You, Becka Bug, Chiquita Hessels and 32 others 3 shares





Youth Program...the next generation

We have hosted 5 Youth Workshops:

2017 – Salt Lake City, Utah, Huntsman Cancer Institute

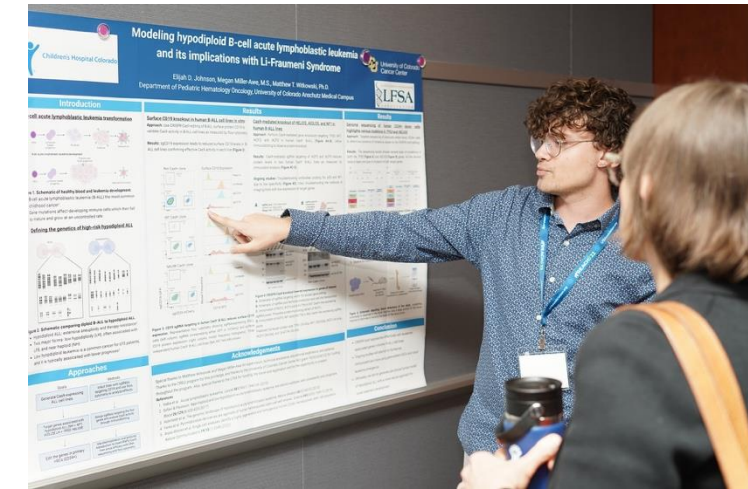
2019 – Boston, Massachusetts, Dana Farber Cancer Institute

2020 – Virtual

2023 – New York City, New York, Memorial Sloan Kettering

2025 – Boston, Massachusetts, Dana Farber Cancer Institute

August 2027 – Location to be announced by the end of the year!





Research...

LFS Association @LFSAssociation · Dec 11, 2025

A promising new study indicates that the immune system actively surveils cancers in individuals with #LiFraumeni syndrome.

Led by the late Pierre Hainaut and members of LFSA's Medical and Scientific Advisory Board, the research shows that the age of cancer onset can be reliably predicted from the immune system's response against tumors. This association to variation in cancer risk could ultimately inform personalized cancer surveillance strategies.

Learn/share more on this exciting development: bit.ly/3KXgWav



Cody Edward Lesko and Edward Fleming, Jr.

Lesko-Fleming Empowerment Grants

Through the tremendous generosity of the Lesko and Fleming

It is critical we support research!
 We fundraise for research and have a research grant program that awards research grants to priorities that are identified by our MSAB.

Katherine M. Howley Endowment Fund for LFS Research

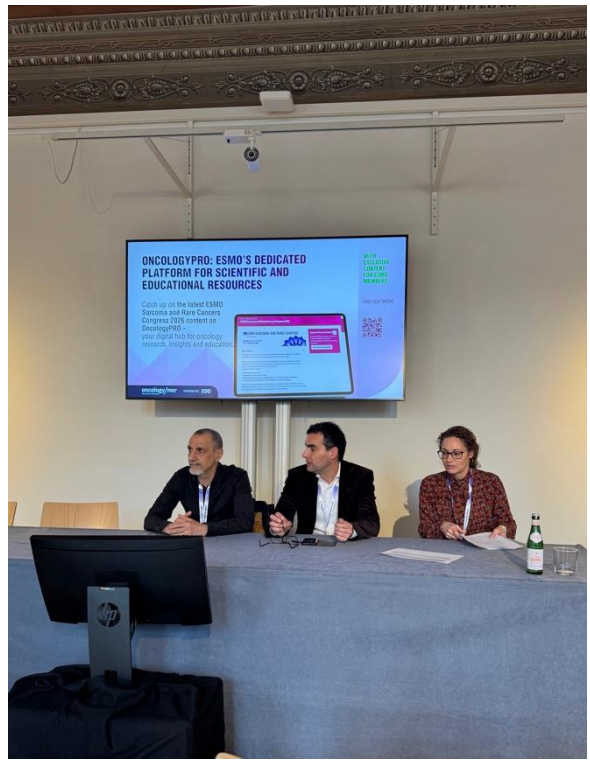


Katherine M. Howley
 (June 30, 1944 – March 22, 2025)





2026 **ESMO SARCOMA AND RARE CANCERS**
Annual Congress
LUGANO SWITZERLAND
12-14 MARCH 2026





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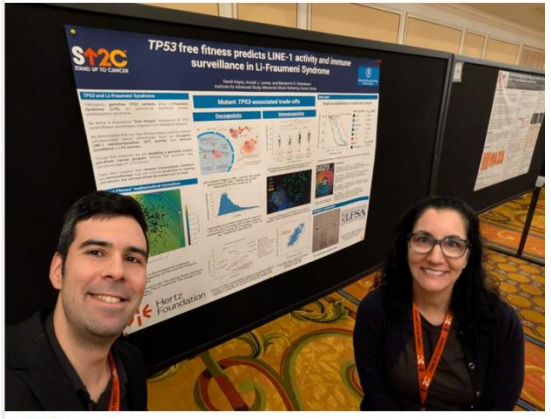
Li-Fraumeni Syndrome Association
 482 followers
 2mo · 🌐

As part of the recent **Stand Up To Cancer** Scientific Summit, **Jennifer Perry** attended an inspiring poster session that included the work of **David Hoyos**, LFSA Medical & Scientific Advisory Board member and computational biologist at Memorial Sloan Kettering Cancer Center.

His research utilizes statistical physics to help predict TP53 associated cancer phenotypes in Li-Fraumeni syndrome cancers. Developments like these are working to enable the use of targeted therapies, such as immunotherapy, against specific cancer mutations.

LFSA is proud to support this incredible work and collaborate with organizations such as SU2C to improve the lives of those impacted by LFS.

#lifraumenisyndrome #lifraumeni #tp53 #inheritedcancer #cancerresearch



50 3 comments · 4 reposts



SU2C INNOVATION SUMMITS 2026

SU2C innovation summits are convened to address areas of strategic scientific and clinical opportunity or areas of urgent and unmet need. These summits help to foster dialogue among key stakeholders and identify priorities for collaborative research projects to be funded by SU2C, often in partnership with other organizations.





AACR ANNUAL MEETING 2026

April 17 - 22, 2026
San Diego Convention Center
San Diego, California





SILVER SPONSOR



Li-Fraumeni Syndrome Association's Post

Li-Fraumeni Syndrome Association
May 1 at 10:44 AM

The 20th Annual p53 Workshop this week at in Toronto brought together leading scientists, clinicians and researchers from around the world to foster collaboration across disciplines and inspire the next wave of p53 research and innovation.

The LFSA team caught up with Arnie Levine, who moderated a panel on p53 and MDM2, Dr. Junne Kamihara from Dana-Farber Cancer Institute and Suzanne Christen - all doing meaningful work to support the Li-Fraumeni syndrome community.

Boost this post to get more reach for Li-Fraumeni Syndrome Association. [Boost post](#)

Chiquita Hessels and 76 others 6 comments 6 shares





Fundraising...



TEAM LFSA
FUEL THE FIGHT
Purpose · Endurance · Hope

Jacob Kubetz will run the Boston Marathon on April 20th to advance hope for families facing LFS.

CLICK TO LEARN MORE ABOUT TEAM LFSA

Education & awareness...



LI-FRAUMENI SYNDROME
LFSA
ASSOCIATION

The AYA-RISE Intervention:
Risk Information & Screening Education for
Adolescents & Young Adults with Cancer Risk

Jennifer W. Mack, MD, MPH

WEBINAR





September 2026

Mon
14

September 14 @ 8:00 am - 5:00 pm

Hunt Fore A Cure Golf Classic

Makefield Highlands Country Club 1418 Woodside Rd, Yardley, PA, United States

Monday, September 14, 2026 Makefield Highlands Country Club Yardley, PA Tee up for a day that drives real impact. The Hunt Fore a Cure Golf Classic raises vital funds for families living with Li-Fraumeni syndrome (LFS), a condition that causes a predisposition to cancer affecting both children and adults. The Li-Fraumeni Syndrome Association (LFSA) provides



DONATE TO LFSA



Events!

We have a *new app* that will be launched in June! This will be the 1st event!

All listed on website:
Current & past events

Coming this fall – register now!





Posts
lfsassociation



View insights

Boost post

53 3 1

Liked by liv.lufkin and others

lfsassociation Join us in congratulating Jacob on his strong finish in today's Chicago Marathon, the first Team LFSA event!

We are proud to have Jacob and his family represent Team LFSA and welcome the community to support their efforts at <https://bit.ly/TeamLFSa>

Every mile Jacob runs and every dollar you give helps



Marathon Team

Jake heading up an incredible run at the 2026 Boston Marathon...the first of many to come with hopefully more to join the team!



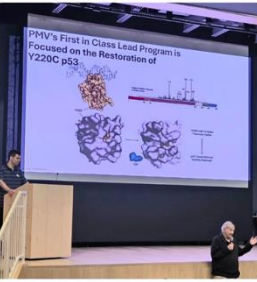




Li-Fraumeni Syndrome Association
 April 19 at 3:44 PM · 🌐

Yesterday's LFS Family Day at [Children's National Hospital](#) included an incredibly informative panel to address patient questions on Li-Fraumeni syndrome and a presentation by LFS Medical & Scientific Advisory Board members David Hoyos, computational biologist at [Memorial Sloan Kettering Cancer Center](#), and Arnold Levine, PhD, Professor Emeritus at the Institute for Advanced Study in Princeton.

Even our youngest participants like Adel enjoyed the interactive session on extracting DNA of a strawberry, led by LFS Genetic Counseling Advisory Group co-chair Megan Frone of the Clinical Genetics Branch at [National Cancer Institute](#). [See less](#)

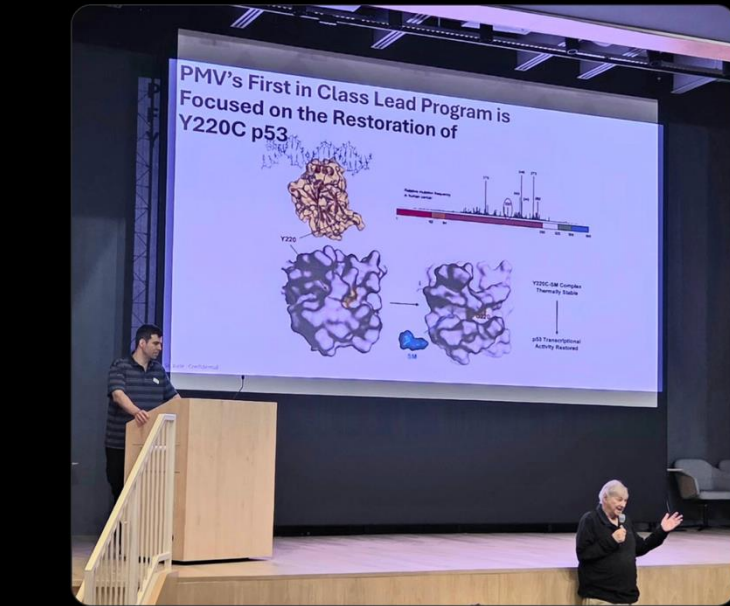




Boost this post to get more reach for Li-Fraumeni Syndrome Association. [Boost post](#)

👍👍👍 Becca Bug, Chiquita Hessels and 38 others 10 comments 3 shares

LFS Association @LFSAssociation · Apr 20

Another @ChildrensNatL LFS Family Day highlight, presentation by LFS Medical & Scientific Advisory Board members David Hoyos, computational biologist @MSKCancerCenter & Arnold Levine, PhD, Prof. Emeritus, Institute for Advanced Study, Princeton. [#lifraumeni #lifraumenisyndrome Show more](#)



Family meetings!

We support centers who care and treat our LFS community.

It is critical to educate and support both the professionals and patients. If you would like to host a family meeting, please email me at:

Jperry@LFSAssociation.org

We can guide, help and cheer you on!





Social Media...

Instagram: <https://www.instagram.com/lfsassociation/>

LinkedIn: <https://www.linkedin.com/company/lfsa-li-fraumeni-syndrome-association/>

Facebook: <https://www.facebook.com/lfsassociation>

X: <https://twitter.com/lfsassociation>

FB voices: <https://www.facebook.com/groups/573233369849062>

Jenn's blog: <https://www.lfsassociation.org/hope-in-action/lfsa-at-the-su2c-summit/>





Silver linings and hope...



Please sign up today as a member!
This is very critical so you can see updates, research, events, and so much more!



