LFSA Medical and Scientific Advisory Boards Join to Accelerate Progress

Among the issues discussed:

- Surveillance strategies. The increased availability and use of genomic testing has led to earlier detection and improved survival among LFS patients. LFSA continues to collaborate with its scientific advisory boards to refine surveillance strategies and immunotherapeutic paradigms are being used as an emerging surveillance modality.
- Novel therapies. We are entering into areas of transitioning from small-molecule drugs to biologics, with the advancement of immunotherapies and the use of checkpoint inhibitors in association with certain germline mutations to reactivate the TP53 pathway. In addition, there has been an escalation of novel agents that can decrease immune system responses in LFS patients that will promote LFS patient care. We must continue to pursue novel agents with synergies that will benefit LFS patients.
- By working together: our LFS research and clinical experts can leverage the unique challenges of LFS to drive innovations and new insights. The LFSA is fiercely committed to continuing to drive research and advance the understanding of LFS.

LFSA Medical and Scientific Advisory Boards have come together in a joint effort to discuss patient care and treatment strategies. The LFSA is committed to fostering new connections and strong partnerships that will expand treatment options and improve quality of life for those with LFS-related cancer.

Here’s just a sampling of our international efforts:

- **Africa:** Our recently formed Africa chapter is led by Samwel Chikomba, a healthcare worker from Kenya, who hosted their first board meeting at the African Society for Clinical Oncology, ASCO. In addition, there has been an expansion of newer therapies that will offer improving outcomes for LFS patients.
- **Australia/New Zealand:** This LFSA chapter was one of several chapters that convened to improve the living standards of the citizens, where LFS is more prevalent. Australia and New Zealand are leading in the area of genetic counseling and intervention. This is recognized for being one of the largest case series in LFS.
- **Japan:** In Japan, chair Chieko Tamura also serves on LFSA’s Genetic Counseling Advisory Group. Certified as a genetic counselor, she engages the 10,000 people who attended the event. Samnow has family members who survived LFS and volunteers to be a youth program volunteer.
- **Latin America:** LFSA - Latin America is hosting a new awareness campaign expanding its reach to countries such as Brazil, led by Dr. Marielussi, Waddington Achatz. LFSA - Latin America works closely with the George Puntland Trust in September, and Saranda Arturo continues to support families with LFS in Australia and New Zealand.
- **Canada:** LFSA - Canada is co-chaired by Chi-Hwa Hee and Dr. David Malkin, along with an African Rusty, passionate and dedicated to the mission. They convene to improve the quality of life for LFS patients.
- **Germany:** The LFS Global Reach of LFSA

**The Global Reach of LFSA**

LFSA now has 12 chapters around the world as Italy joins Africa, Latin America, Canada, France, Germany, India, Japan, Netherlands, Australia/New Zealand, Saudi Arabia, and Singapore to support families with LFS around the world.

Each international chapter is chaired by a local medical professional who connects LFS families with vital local resources. The newly formed Italian chapter is led by Dr. Valentina Pigagiao and collaborators Matteo Passo and Marzia Locatelli.

“However, we are in the world, we can collaborate and challenge each other to solve this puzzle that is LFS,” says Jenny Perry, LFSA President. “We are profoundly grateful for the vast network that shares information and supports our LFS families.”

For the first time, LFSA participated in the largest cancer conference in the world, the American Society of Clinical Oncology, ASCO. This annual meeting in Chicago each year attracts world leaders in oncology. Through a prominent presence in the ASCO exhibition hall, LFSA leadership Kathy Higgins, Debbie Soprano, and Gina Vild, with a strong display of LFS-related resources, will bring attention to individuals who were present. They came away with deeper knowledge of how physicians from around the world view and manage LFS patients and with robust strategies to strategize, and create synergies that will benefit treatment of LFS-related cancer.

LFSA leadership Kathy Higgins, Debbie Soprano, and Gina Vild, met with many of the 40,000 attendees, including Dr. David Malkin, along with Anna Joy Ryan, all passionate and dedicated to the mission. They convene to improve the quality of life for LFS patients.

**Booster LFS Awareness Among Medical Professionals**

As COVID restrictions eased during 2022 in many parts of the world, LFSA was eager to participate in events to promote engagement with physicians, scientists, and genetic counselors as a partner to foster vital collaborations and partnerships.

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Dear Friends of LFSA Associates,

This year’s LFS Association has accomplished so much as a result of your generous and essential support. Your contributions make our progress possible. Your gifts, volunteer efforts, and expressions of support enable us to advance the work of LFSA.

We are aching of something as known as the butterfly effect.

The butterfly effect explains how the single flutter of a butterfly’s wings can have a significant effect on weather patterns, and even affect the course of a hurricane.

The gift was synonymous to a butterfly flapping its wings. As it flutters in the heart of our success, it is symbolic of how a seemingly small act can result in a significant impact.

The butterfly effect helps us understand the interconnectedness of our actions and how they can influence the future.

Your support has helped us take on the challenge of eradicating LFS and made a meaningful impact.

A Message from the LFSA President

Leading the Charge

Insurance Resources for LFS Families

Navigating insurance and medical bills can be a complex and daunting task for families. The LFSA’s latest insurance information includes updates that will serve as a vital resource.

Frequently Asked Questions

Will my health insurance pay for my LFS-related treatment?

Can my health insurance raise the premium or deny me coverage because of my LFS?

Why is it difficult to get coverage for my LFS-related treatment?

What does my insurance cover?

Insurance Basics for Individuals with Li-Fraumeni Syndrome

Individuals with Li-Fraumeni Syndrome (LFS) are at risk for a range of cancers, including:

- Breast cancer
- Colon cancer
- Endometrial cancer
- Gastrointestinal stromal tumor (GIST)
- Kidney cancer
- Melanoma
- Lung adenocarcinoma
- Melanoma
- Neural crest-related tumors (such as glioma, neuroblastoma, and schwannomas)
- Osteosarcoma
- Soft tissue sarcoma
- Thyroid cancer
- Uterine cancer
- Wilms tumor

Genetic matters:

Understanding the genetics and family history of LFS is crucial.

The genetic profile can help predict the types of cancer likely to occur in an individual.

Understanding the genetic aspects can lead to early detection and effective treatment strategies.

Learning your family history is a key resource in understanding LFS. LFSA wants the public to know that many cancers are associated with LFS with these living conditions:

- Soft tissue sarcomas
- Asbestos-related diseases
- Breast cancer (in females)
- Central nervous system (CNS) tumors (such as glioma, neuroblastomas, and schwannomas)
- Osteosarcoma
- Soft tissue sarcoma
- Thyroid cancer
- Wilms tumor

The LFSA Youth Workshop 2023

LFSA has announced that its 4th LFSA Youth Workshop will be held in 2023.

Kidney cancer

Lung adenocarcinoma

Melanoma

Osteosarcoma

Survival rates for LFS

The study aims to provide a comprehensive overview of insurance costs and insurance plan information. It will also answer frequently asked questions by those with LFS.

PUT CANCER TO THE TEST

Learn how genetic testing saves lives through early detection.

LFSAssociation.org/getAeSted

Coming Soon!

The LFSA Youth Workshop 2023

Deep friendships have been forged among LFS teens and young LFS parents since the LFSA held its first Youth Workshop in 2017 at the Huntsman Cancer Institute. The relationships, support, deep connections, and affection that evolved from the first Workshop continue to enrich families to this day.

Our Youth Program helps young people with LFS live their lives to the fullest and make connections with others who have shared experiences. This program, which consists of an open-panel session with experts and breaks with the LFSA’s youth newsletter.

Raising Awareness

For the latest details and for access to past webinars, visit the Youth Program page here.

Sign up for regular updates on youth news and please help share the information.
Dear Friends of LFS Association,

You can find the Health Insurance Resources, including the Pediatric and Adult Appeal programs, at [bit.ly/3VDdcv0].

Enrolling LFS into a global imperative as demonstrated at REACH22, event experts and families representing 14 countries gathered to collaborate, share, and learn. In our first post-COVID hybrid event, more than 400 people and 237 families gathered at the National Cancer Institute (NCI) in Bethesda, Maryland to both virtually and in person.

Hosted by the NCI – part of the National Institutes of Health and the major federal government principal agency responsible for conducting and supporting cancer research – and in partnership with the LFS Consortium, the 6th International LFSA Symposium attracted some of the greatest minds in cancer research, treatment, and care, along with those who have unique expertise in LFS.

Some of the most promising research was discussed in sessions that included understanding the LFS spectrum of TP53 variants, emerging research on TP53 biology and the connection between elephants, evolutionary medicine and Li-Fraumeni syndrome. Other sessions focused on a range of issues including the implications of testing children for LFS and implementing screening strategies. This year, LFS Association launched, Put Cancer To The Test, an awareness campaign that educates the public about LFS, and the importance of genetic testing in families where there has been a prevalence of cancer diagnoses. Determining whether a LFS familial concern is a first step to early diagnosis and access to vital resources.

In acts both large and small, together, we are furthering our understanding of this disease and advancing scientific research, but it was huge for the LFSA.

Following his presentation on the early days at the NCI, Dr. Fraumeni reconnects with the team at NCI.

The butterfly effect explains how the single flutter of a butterfly’s wings can have a significant impact on weather patterns thousands of miles away. This, in turn, sparked interest and additional funding from several large cancer research organizations.

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You can find the Health Insurance Resources, including the Pediatric and Adult Appeal listing for several large cancer research organizations. I am thrilled to share stories of the impact these gifts have made.

The gift was synonymous to a butterfly flapping its wings. As a donation to LFSA’s Genetic Counseling Advisory Board, it fund a first-of-its-kind breast cancer study in LFS patients. This study was the result of LFSA’s commitment to cancer research, but it was huge for the LFSA. In acts both large and small, together, we are furthering our research – and in partnership with the LiFE Consortium, the 6th REACH Symposium.

Each member of the LFSA community of families, researchers, medical providers, and caregivers. It is our passion to make a difference. Together, with your help, we are the building blocks of a future where LFS is eradicated.

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Recently, Li-Fraumenis Syndrome was recognized by the World Health Organization as a genetic disorder. The butterfly effect explains how the single flutter of a butterfly’s wings can have a significant effect on weather on the other side of the world. The butterfly effect is a metaphor for a cause-and-effect relationship where small actions can have large consequences.

One of the most inspirational sessions was a discussion among patients and their families who have unique expertise in LFS. One of the most inspirational sessions was a discussion among patients and their families who have unique expertise in LFS. They shared their experiences, their stories, and their hopes for a cure. T o a rapt audience, they shared their experiences, their stories, and their hopes for a cure. They shared their experiences, their stories, and their hopes for a cure.

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The Global Reach of LFSA

LFSA now has 12 chapters around the world as it joins forces with Latin America, Canada, France, Germany, India, Japan, Netherlands, Australia/New Zealand, Saudi Arabia, and Singapore to support families with LFS around the world.

Each international chapter is chaired by a local medical professional who connects LFS families with vital local resources. The newly formed Indian chapter is led by Dr. Samir Bajpai and includes Drs. Debabrata Sen and Pradeep Arora.

“Not everyone who is in the world, we can collaborate and challenge each other to solve this puzzle that is LFS,” says Jenny Perry, LFSA President. “We are profoundly grateful for this vast network that shares information and supports our LFS families.”

Here’s just a sampling of our international efforts:

- **Africa:**
  - LFSA - South Africa is led by Ian influence, who chairs the LFSA’s South African Advisory Board. This year, LFSA hosted its first international meeting in Cape Town, South Africa, LFS conference was well-received and involved with passionate discussions on immunotherapy approaches for LFS. The conference highlighted the need for greater collaboration and advancements in LFS research.
  - LFSA - Kenya actively participated in the 6th International LFS Association Symposium in Berlin, Germany.

- **Canada:**
  - LFSA - Canada is co-chaired by Chiquita Hessels and David Malkin. This year, LFSA - Canada hosted a booth at the Africities Summit, a Pan African conference with participants from Kenya to attend LFSA's Symposium. LFSA - Africa recently published a report on the Global LFS landscape.

- **Germany:**
  - LFSA - Germany is led by Dr. Pierre Hainaut and Frébourg, founder of LFSA - France, Drs. Pierre Hainaut and Sablowski, under the guardianship of Dr. Christian Kratz, held many family meetings and youth outings this year.

- **India:**
  - LFSA - India is co-chaired by Dr. Sameer Rastogi and the National Cancer Institute’s Dr. Payal Khincha, who are spearheading a comprehensive LFS program in India. This is recognized for being the largest cancer conference in India.

- **Japan:**
  - LFSA - Japan is chaired by Chieko Tamura also serves on LFSA’s Genetic Counseling Advisory Group. The chapter hosted a booth at the Japanese Cancer Society’s annual meeting.

- **Latin America:**
  - LFSA - Latin America is led by Daniela Cerrato in Brazil. This chapter is active in many arenas.  A highlight this year for our May Day and hosted webinars on LFS.

- **Netherlands:**
  - LFSA - Netherlands is led by Dr. David Malkin, along with Anna Joy Ryan, all passionate and active LFS family advocates. A highlight this year for LFSA - Netherlands is their active LFS family advocacy work.

- **Saudi Arabia:**
  - LFSA - Saudi Arabia is co-chaired by Fahad Alsubaie, LFSA - Saudi Arabia, who also participates in the LFSA - GCC. This chapter is addressing the need for greater collaboration and advancements in LFS research.

- **Singapore:**
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- **U.S.:**
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Boosting LFS Awareness Among Medical Professionals

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LFSA Medical and Scientific Advisory Boards Join to Accelerate Progress

Among the issues discussed:

- Surveillance strategies. The increased availability and use of genetic testing facilitated to address Early diagnosis and intervention. Peripherally blood prognostics have proven improved in recent years, and the LFS community is working to standardize and streamline programs as they continue to evolve. This intense focus on Early diagnosis and cancer prevention will continue. There is consensus that the best defense against LFS remains early detection and intervention.

- Novel therapies. We are entering into an arms race of astounding novel therapies. Basic science discoveries in the areas of immunotherapy and immunotherapeutics are being used as an uncharacteristic weapon in the war against LFS. LFSA is working closely with international organizations that are associated with certain p53 mandates to measure the threat. In addition, there has been an explosion of new therapies that promise to deliver more precise LFS-targeted therapies that will promote impact LFS patient care. We must continue to work together to help ensure that all are able to coordinate a coordinated effort to address the unique challenges of LFS.

- The LFSA Medical and Scientific Advisory Boards came together to probe the deeper questions about the Li-Fraumeni syndrome and to discuss how the unique medical insights. The LFSA is fiercely committed to continuing to drive innovative approaches to the unique challenges of LFS. This meeting was launched 12 years ago.

- The LFSA Medical and Scientific Advisory Boards joined together for the first time at the 6th International LFS Association Symposium in Berlin, Germany. This annual meeting held in Chicago each year.

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- This meeting was launched 12 years ago.
The Global Reach of LFSA

LFSA has 12 chapters around the world as it joins Africa, Latin America, Canada, France, Germany, India, Japan, Netherlands, Australia, New Zealand, Saudi Arabia, and Singapore to support families with LFS around the world.

Each international chapter is chaired by a local medical professional who connects LFS families with vital local resources. The newly formed Indian chapter is led by Dr. Savita Rastogi and includes Doctors Weiss and Mario Penruck-Lutz.

“None matter where we are in the world, we can collaborate and challenge each other to solve this puzzle that is LFS,” says Penny, LFSA President. “We are profoundly grateful for this vast network that shares information and supports our LFS families.”

Boosting LFS Awareness Among Medical Professionals

As COVID restrictions eased during 2022 in many parts of the world, LFSA was eager to participate in events to promote engagement with scientists, physicians, and genetic counselors, as a path to forge valuable collaborations and partnerships.

For the first time, LFSA participated in the largest cancer conference in the world, the American Society of Clinical Oncology (ASCO). This annual meeting in Chicago each year attracts world experts in oncology. Through their prominent presence in the ASCO exhibit hall, LFSA leadership, Kathy Higgins, Debbie Soprano, and Gina Vild, met with the more than 40,000 professionals who attended the five-day event. They came away with deeper knowledge of how physicians from around the world view and manage LFS patients and with robust contacts that we hope will spur further sponsorship.

In addition, there has been an explosion of newer antibody therapies that will promise to impact LFS patient care. We must explore how to use these therapies to treat LFS-related cancer. In the 6th anniversary year of the Cancer Medicine Centre) application for annual whole-body surveillance strategies.

By working together, our LFS research and clinical experts continue to collaborate on all the topics that are important to our patients and their families, the research community, and medical experts. That connectivity and by creating partnerships that will prompt new generation of immunotherapies and novel therapies. The LFSA is fiercely committed to continuing to drive meaningful research that will promote innovation in oncology that will benefit patients with LFS.

Here’s just a sampling of our international efforts:

Africa: This chapter has two of its members, Dr. David Malkin, along with Anna Joy Ryan, all passionate and active LFS advocates. Their efforts have been instrumental in raising awareness of LFS in the UK. The chapter has also been working on genetic counseling and education for LFS patients and their families.

Canada: LFSA - Canada is co-chaired by Chiquita Hessels and Dr. David Marcelo, along with Anna Joy Ryan, all passionate and active LFS advocates. Their efforts have been instrumental in raising awareness of LFS in the UK. The chapter has also been working on genetic counseling and education for LFS patients and their families.

Germany: Youth Initiative is a pillar of Germany’s robust efforts. The chapter is co-chaired by Bente Sand and Claudia Schwalbok and works closely with the German Pediatrician for LFS patients and young adults.

India: LFSA - India is co-chaired by Dr. Sanjay Bajaj and the National Cancer Institute Dr. Prayag Kaushik. The chapter is working to increase awareness of LFS in India and to connect families with vital local resources.

Japan: LFSA - Japan chair Chieko Tamura also serves on LFSA’s Genetic Counseling Advisory Group. She is a long-time advocate for and supporter of LFSA’s activities in Japan. She brings to her work a unique perspective that integrates American and Japanese cultures and is actively using it to serve and support LFS patients and their families.

Latin America: LFSA - Latin America is based in Mexico City and is expanding its reach far beyond Brazil. Led by Dr. Maria Isabel Achatz, LFSA - Latin America is a shining example of how cultural connectivity and by creating partnerships that will prompt clinical-genomics and is actively using it to serve and support LFS patients and their families.

Netherlands: LFSA - Netherlands has grown tremendously, expanding its reach far beyond Brazil. Led by Dr. Niels van der Wijngaard, LFSA - Netherlands largely focused on awareness-raising this year and is very active in the educational programs, aiding in support.

South Arabia: LFSA - South Arabia, under the leadership of genetic counselor Lamia Sablowski, is a shining example of how cultural connectivity and by creating partnerships that will prompt clinical-genomics and is actively using it to serve and support LFS patients and their families.

U.S.: LFSA leadership has continued to connect with more and more community-based and hospital-based programs as they continue to evolve. This intense focus on early diagnosis and cancer prevention will continue. There is consensus that the best defense against LFS remains early detection and intervention.

Novel Therapies:

We are entering into an astounding era of medical breakthroughs. In oncology, immunotherapy combinations are being utilized in an increasing number of clinical trials. LFSA has been associated with certain germline mutations to reactivate the TP53 protein. The LFSA is funding research grants in both areas.

In the field of immunotherapy, there has been an explosion of newer antibody therapies that will promise to impact LFS patient care. By working together, our LFS research and clinical experts continue to collaborate on all the topics that are important to our patients and their families, the research community, and medical experts. That connectivity and by creating partnerships that will prompt new generation of immunotherapies and novel therapies. The LFSA is fiercely committed to continuing to drive meaningful research that will promote innovation in oncology that will benefit patients with LFS.

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The increased availability and increased patient participation in research has forced us to address what it really means to have LFS. A new LFS classification system is being created to better encapsulate the risks of the various p53 variants. Our goal is to implement more effective, risk adapted surveillance strategies.

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