



LFS ASSOCIATION

The Power of Purpose

2023 IMPACT REPORT



LI-FRAUMENI SYNDROME
 **LFSA**
ASSOCIATION

Devoted to a World Without Inherited Cancer

A Message from the LFSA President

Dear Friends of LFS Association,



The LFS Association embodies Power of Purpose.

Thirteen years ago, LFSA was formed to fulfill a powerful purpose: to advocate, support, and inform families and individuals with LFS. As a founder of LFSA, I am delighted to share with you that we have expanded our purpose to also champion youth and young adults with LFS, advance lifesaving LFS research, and bolster awareness of the critical benefits of genetic testing and early detection cancer screening.

At the heart of our expanded efforts is the LFSA International Youth Workshop, which brings together young adults to ensure they know they are not alone. This year's Youth Workshop inspired beyond all expectations! It was our fourth Youth Workshop—and our third in-person event—since the inaugural 2017 workshop at The Huntsman Cancer Institute. This August, 23 young people gathered at the renowned Memorial Sloan Kettering Cancer Center in New York City for the largest and most diverse Youth Workshop to date. About half of our young people had not attended an LFSA Youth Workshop in the past. We were deeply moved to witness their eagerness to learn, and we were profoundly inspired by their spirit of hope. Our veteran attendees rekindled old friendships, and all participants were engaged in sharing their LFS experiences with new friends.

The relationships forged at the Youth Workshop are indispensable. They are essential not only for young people but also for their parents and other members of their family. When we conceived of the Youth Workshop, it was our hope to spur connections that were kindred and meaningful, but we had not anticipated that the Youth Workshop would lead so many of our young people into professions that directly address LFS and benefit the community. Our LFSA young adults are studying to be biologists, physicians, genetic counselors, and even cancer researchers. It is simply awesome!

Scientific research is fast advancing. You will read more here explained by Robert Lufkin, DO, LFSA's Scientific and Medical Director, and Sean Downing, PhD, LFSA's Scientific Advisor.

We're currently learning the outcome of a breast cancer study that was made possible in part by an LFSA Research Grant. We're also involved with another study to establish a *TP53* biobank to study LFS through the Abramson Cancer Center at Penn Medicine. Science, especially research related to p53, is moving fast, but I know you will agree there is much more to be done. For those of us who have LFS, the science and clinical applications can't come fast enough.

As the research progresses, we are also working to advance early detection screening and genetic testing. You may have noticed we recently tweaked our awareness campaign to include the word "hereditary" — Put Hereditary Cancer To The Test. We also refined our descriptor to reflect this: "Dedicated to a world without inherited cancer." In part, this is to emphasize that the work we are joining together to do is benefiting the field of cancer beyond LFS and in particular, it is advancing knowledge about the many other forms of inherited cancer.

Our purpose remains powerful. I know you, like me, are determined to put an end to our kids and our family members being diagnosed with cancer. My most fervent desire is that one day LFS will be treated as a chronic condition.

What gives me HOPE is that you join us in this shared purpose. You are the driver of our purpose. You are the heart of our purpose. You are the engine of our purpose. Your volunteer contributions, fundraising, donations, research, and even your tears, are the power behind what we do every day. They are our purpose.

Thank you for helping advance LFSA's work and for your fierce support of our families. You are our power!

With my deepest gratitude,

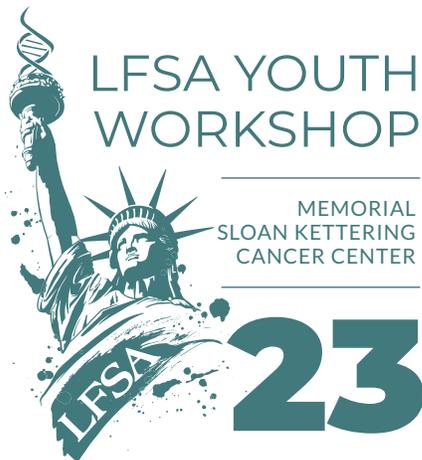
Jenn Perry
LFSA President, LFS patient and LFS mom



ON THE COVER

Lakita, a vibrant and resilient young girl from Kenya, was born in 2006 with a love for dancing and art. In 2017, at the age of 10, she was diagnosed with Osteosarcoma due to LFS. After a year of challenging treatment, she triumphed. In 2020, the cancer recurred, leading to the amputation of her leg. Lakita shared her inspiring story of perseverance during International LFS Awareness Month in May. Last August, she attended the LFSA Youth Workshop at Memorial Sloan Kettering Cancer Center in New York, making life-long friends with other LFS youth and demonstrating her incredible determination. Lakita's remarkable story serves as a beacon of hope and resilience for all those affected by LFS. She is the beloved daughter of Joyce Mwangi, the Communications Director of the LFSA African Chapter.

LFSA Youth Connect For a Better Future



The LFSA Youth Workshop brought together 23 young people and their families at the prestigious Memorial Sloan Kettering Cancer Center in New York City for a two-day event. Friendships were rekindled and new friendships formed during a weekend of seminars and a variety of engaging activities. LFS clinical, scientific, and psychosocial experts shared the most current studies and advances designed to help LFS youth better navigate their transition to adulthood.

Youth participated in a hands-on genetics lab, interactive panel discussions led by LFS experts, and educational sessions on topics ranging from healthy lifestyles to LFS breast cancer implications and options, and whole-body MRI benefits. Attendees forged meaningful and kindred connections with others who share the LFS journey. Needless to say, fun was had by all, particularly during the ice cream breaks, penthouse party, and sunset dinner cruise.



After a night of introductions at the hospitality suite, youth attendees meet MJ, a new K9 recruit to the NYPD.



Dr. Michael Walsh opens the workshop with the latest advances in LFS research.



Attendees learn the science behind LFS research with a genetics lab activity.



Heather Hightower, RN, and Alexandra Russo, LCSW discuss transitions to adulthood.



Dr. Christian Kratz weighs the benefits of healthy lifestyles with LFS.



Youth attendees showcase their work during an interactive session building DNA strands with candy.



Dr. Natalia Polidorio discusses breast cancer and options for youth with LFS.



Dr. Maria Isabel Achatz advises on the tough decisions and good choices for healthier outcomes with LFS.



Interactive panel discussion with Dr. Michael Walsh, GC Jennifer Kennedy, Dr. Christian Kratz, Dr. Marie Barnett, Dr. Natalia Polidorio, Dr. Maria Isabel Achatz, Prof. Arnold Levine, and Dr. Gerald Behr.



LFS youth and family members enjoy a New York skyline dinner and dance cruise with unique perspectives of Manhattan and the Statue of Liberty.



LFSA CLIMB FOR A CURE

WALK • RUN • HIKE • BIKE

LFSA Climb For a Cure Kickstarts Annual Fundraiser

LFSA's inaugural Climb For a Cure was a spectacular success. It established a fundraising event that will continue to grow in years to come. During the June 24th weekend, fundraising teams embarked on exhilarating hikes across various locations, including Colorado, Pennsylvania, and Brazil. A team in Massachusetts undertook a 26-mile bike ride to honor their loved ones diagnosed with LFS.

As LFSA families, friends, and supporters came together over the weekend, they built community and expanded awareness about LFS. LFSA hosted fundraising websites for each team, enabling them to create unique events, share their stories, and ask for donations. This year's Climb For a Cure raised more than \$6,000 for the LFSA Youth Workshop.



Weiss Family



Johnson Family LFS Fight Club



Team PATT

Inspiring Awareness

Spreading the word on LFS, one story at a time!

James and Kathy Higgins, who have long been champions of LFS, raised awareness and advocated for genetic testing by promoting Jamie's new book, *Since You Asked: My Anecdotal Life*. Jamie, who was diagnosed

with LFS, published an autobiographical collection of stories in his book, and a portion of the proceeds supported LFSA's Youth Workshop. Jamie and Kathy represented LFSA at book events in Pennsylvania, New York, and Texas for the American Society of Pediatric Hematology/Oncology Conference.



LFSA joined 40,000 oncologists and other cancer experts in Chicago at the largest international cancer conference in the world, ASCO (American Society of Clinical Oncology). A booth that provided information on LFS and the need to strengthen genetic testing attracted cancer professionals from around the world.

LFSA Medical and Scientific Advisory Boards Advance Science with Hard Questions

LFSA's Medical and Scientific Advisory Boards continue to probe for answers to the most pressing questions about Li-Fraumeni syndrome. Our exploration of new areas of research is directly improving the lives of those with LFS as well as advancing knowledge about cancer in general. At this year's LFSA Youth Conference in New York City, many of our researchers and clinical experts presented updates on the latest LFS scientific findings related to treatments, cancer screening, and surveillance strategies offering perspective and new revelations.

Below are early findings from two ongoing research studies funded by LFSA Research Grants.

Characterization of the Adaptive Immune Responses to Inherited TP53 Breast Cancers



Prof. Arnold Levine

While we know that immunotherapy is powerful in treating spontaneous cancers, little is known about the role our immune system plays in the onset of LFS cancers.

The study, led by Prof. Arnold Levine, Institute for Advanced Study, Princeton, reflects a collaborative effort among researchers, multiple institutions, and 70 LFS patients who participated by donating tissue samples. The collaboration exemplifies how LFSA is advancing science and offering hope.

Prof. Levine and his collaborators are seeking to determine the immune system response to breast cancer in Li-Fraumeni syndrome patients and what type of immune cells may be responding. Understanding the immune response in TP53-driven LFS breast cancers may lead to a better application of immunotherapies to treat patients, potentially leading to new and more effective therapies. Initial findings of this ongoing study indicate that the immune system does recognize early stages of tumor growth in LFS breast cancers.

Refolding Mutant p53 as a Cancer Prevention Strategy in Li-Fraumeni Syndrome



Dr. John Karanicolos

Mounting evidence suggests that precancerous lesions are driven by alternative activities of the mutated p53 gene in LFS beyond what is currently known. This study, led by Dr. John Karanicolos, Fox Chase Cancer Center, Philadelphia, focuses on developing drugs to reshape the mutated p53, thus, better controlling future activities of this rogue gene.

The potential benefit is significant. First, this would shed greater understanding on issues related to toxicity in healthy cells of LFS patients. Second, we hope to better understand the cancer-promoting activities of the mutated p53. If successful, this study may prompt an entirely new class of drugs.

Spurred by LFSA funding and early support of this project, the study has been awarded an additional grant from the National Cancer Institute (NCI) to promote further research. The work has been presented at several scientific conferences, and this LFSA grant is funding a young scientist early in his career.

So where do we go from here?

Our work continues. It is our fervent belief that each study funded by LFSA will bring us closer to a world without LFS and to a better understanding of how to diagnose, treat, and prevent all cancers. We hope the LFSA-funded studies will incent other researchers to work on Li-Fraumeni syndrome thereby helping LFS patients as well all who currently or will one day have a cancer diagnosis.

We think big and bold, and we ask daring questions: Can there be a vaccine to prevent and treat breast cancer? Is it possible to develop a drug that will reshape the mutated p53 and prevent cancer in LFS patients? We're obviously far from answering these questions, but asking hard questions is creating new possibilities in cancer prevention, detection, and therapies.

LFSA's Medical and Scientific Advisory Boards will continue to collaborate with other great scientific minds around the world to grow our understanding of LFS, p53, and cancer in general. The more we know, the more we can help LFS families. We are fiercely dedicated to finding the answers to the unique challenges of living with LFS.

With gratitude for your support that makes this possible,

Robert Lufkin, DO - LFSA Scientific and Medical Director
Sean Downing, PhD - LFSA Scientific Advisor

Supporting LFS Families Around the World

LFSA's 12 international chapters take great strides to reach those with LFS in their communities and provide the support they most need. LFSA chapters are led by local medical professionals and individuals with LFS in Africa, Australia/New Zealand, Canada, France, Germany, India, Italy, Japan, Latin America, Netherlands, Saudi Arabia, and Singapore. While medical systems and customs vary, these chapters are united by a mission to solve the puzzle of LFS and improve life for all with LFS around the world.



Here's a sampling of our international happenings in 2023:

Africa: LFSA Africa Chapter Chair Samuel Omolo shared the importance of LFS education, awareness, and training on the morning news program, *Good Morning Kenya*. Omolo also co-chaired a webinar where medical students discussed opportunities to become involved in LFS clinical and scientific work.

Canada: The leadership of LFSA Canada connected with genetic counselors from across the country at the CAGC conference in Edmonton, Alberta. They represented LFSA at the Canadian Organization of Rare Disease (CORD) conference in Calgary, Alberta, and the Canadian Pediatric Cancer Consortium (CPCC) conference in Toronto. They also will be attending the CHUM-Medical Genetics Symposium in Montreal this December.

The Newfoundland and Labrador House of Assembly was lit in our LFSA colors this year highlighting p53/LFS Awareness Month. The lighting will occur again this coming May. Also, those Canadians with LFS will be included in the country's first in the world cell-free DNA study.

Latin America and France: LFSA Latin America and France hosted a networking and patient support event in Paris for Brazilians with Li-Fraumeni syndrome. These chapter events integrate the LFS community and bring together families from

around the world, creating a sense of belonging and friendship. The chapters' goal is to ensure those with LFS have greater knowledge about exams and screening protocols in order to have improved self-care and also educate others.

Germany: LFSA Germany hosted 80 participants at the LFS Infoday at the renowned Cancer Institute in Heidelberg. The event is officially accredited for continuous education credit for physicians. The organization was one of only three patient organizations to receive the Yescon Shine-A-Light Award, Germany's largest Cancer Conference recognition. Chapter representatives also participated in a variety of university lectures and local cancer events.

Singapore: Together with genetic counselors and medical social workers, the National Cancer Centre Singapore hosted a Living with LFS event on May 6. Participants were inspired and empowered by listening to the journeys of others, and, as a result, officially launched the LFS Support Group that will be led by their medical social workers. LFS Support Group members actively share updates on their lives and provide encouragement and support to one another and their family members. The members intend to expand efforts on behalf of the LFS community and are actively engaged in planning our 2024 LFS Awareness Month.

SAVE THE DATE

7TH International LFS Association Symposium

Hosted by Penn Medicine/CHOP and in partnership with the LiFE Consortium

REACH24
research • education • advocacy • community • hope

October 19-22, 2024

Anticipated Attendance:

500+ LFS patients, family members and medical professionals from across the globe

REACH24, our 7th International LFS Association Symposium, will be a hybrid live and virtual experience enabling scientists, doctors, geneticists, and LFS families to make meaningful connections from around the world.