LFS Empowered By Friendship

The LFS Association continued to connect and empower LFS teens and young adults this year through quarterly virtual meetings and digital newsletters. Designed to bring young people with LFS into their lives, the LFS Youth Program debuted to Youth Connect virtual workshops, which invite medical professionals to speak on topics specific to youth concerns. The virtual workshops also set aside time for attendees to ask questions and simply get to know one another.

“When a teen gets diagnosed with cancer like I did when I was 14, you don’t meet a lot of other people like you,” said Cameron Block, LFSA Youth Program Chair. Having a rare syndrome like LFS can compound feelings of loneliness and isolation.

“We want to provide LFS youth and young adults with a positive environment where they can learn more about LFS, feel encouraged and supported,” she said.

The first Youth Connect topic focused on stress and coping with the support they need locally and share LFS resource reactions for those with LFS and studies supporting whether to use for LFS patients and continue testing or treatment.

A recording of the webinar is available to on lfsassociation.org.

Making Connections During Pandemic

The LFSA is committed to raising awareness of LFS from its onset because it literally saves lives. An improved understanding and recognition of LFS decreases the need for diagnostic, early cancer detection, and better informed cancer treatment decisions. Encouraging LFS awareness, LFSA offered its inaugural International LFS Awareness Day on May 3. The day, 5/3, was chosen for its connection to p53, the tumor-suppressing protein that is damaged in LFS patients.

Throughout the month of May, the LFSA community hosted several virtual conferences for LFS worldwide. LFS families shared their stories and LFSA informational products. The LFSA President Jen Perry appeared in a video explaining the background of Li-Fraumeni syndrome and talked about the founders of the syndrome, Drs. Frederick Li and Joseph Fraumeni, Jr.

One week of the month was dedicated to recognizing the LFSA International Chapters and all they do for the global LFS community. Another week focused on the LFSA Youth Program for LFS children and young adults, and the importance of empowering young people with LFS to share their key aspects of their health with their communities.

Intended to be an annual event, the first International LFS Awareness Day proved a big success and answered a much-needed call for LFS awareness. Look to May 2023 for more eyes on May 3, LFS, and the cancer connection that can save lives.

The LFSA would like to express its deepest appreciation to the National Cancer Institute, Division of Cancer Epidemiology and Genetics for their ongoing support and dedication to the LFSA, our mission, and our inaugural International LFS Awareness event.

LFS Awareness Saves Lives

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In the first study, the LFSA Scientific Advisory Board has established a grant program and awarded its first grant to Professor Arnold Levine, PhD, Institute for Advanced Study, Princeton, N.J. Levine and his colleagues are collaborating with the Memorial Sloan Kettering Cancer Center in a study on breast cancer in LFS patients.

**LFSA Scientific Advisory Board goal:**

To bring together basic scientists to collaborate with clinicians in order to initiate research with Li-Fraumeni syndrome patients in the areas of research and more in-person connection, so get ready to see MORE face-to-face education, including our 6th International LFS conference that takes place in person, so we are a full green light on more in-person events with improved technology to allow more people to participate from around the world. These will be in-person events with improved technology to allow more people to participate from around the world. They are funding active research at the interface of the clinic and LFS research efforts by sharing the knowledge base of people with LFS. We're able to reach people that may otherwise not be able to participate. We've also added an LFS Association - Africa chapter, connected disparate groups with one common friendship, leadership, and warm affection were deeply treasured and will be missed.

An inspiring example of these collaborative efforts is a recent project called the Genetic Counseling Awareness Grants (GCAG), established by the LFS Association. "This is among the first of many projects specific to LFS." GCAG promotes cancer genetic awareness and provides resources to encourage collaboration aimed at increasing funding and awareness of cancer genetic counseling. "When you have a rare genetic syndrome like LFS, it is important to have the right people doing your research and the right people doing your education," Prof. Arnold Levine, PhD, Institute for Advanced Study, Princeton, N.J. said. "If you have the Memorial Sloan Kettering Cancer Center in a study on breast cancer in LFS patients, we have a group dedicated to increasing the level of fundamental research in the Li-Fraumeni syndrome area."

"There has been a good deal of research on LFS but much less than on other cancers because it is a fairly rare cancer. Now we're beginning to develop a deeper understanding of the genetics of breast cancer. LFS predisposes to breast cancer. And, 90% of women with LFS and the inherited TP53 gene alteration develop breast cancers. And, 90% of women with LFS will get cancer in their lifetime because of the proximity to develop breast cancer in LFS.

In this study, Levine and his collaborators seek to determine if the immune system is responding to breast cancer in women with LFS. Levine and his colleagues are collaborating with the Memorial Sloan Kettering Cancer Center in a study on breast cancer in LFS patients.

"So much information is out there on other cancers, we now have a database to bring together basic scientists to collaborate with clinicians in order to initiate research with Li-Fraumeni syndrome patients in the areas of research and more in-person connection, so get ready to see MORE face-to-face education, including our 6th International LFS conference that takes place in person, so we are a full green light on more in-person events with improved technology to allow more people to participate from around the world."
Medical Director’s Message

Since the inception and formation of the LFSA, it has been our intention to form a large coalition of patients, caregivers, and researchers worldwide to serve those living with Li-Fraumeni Syndrome. We have chosen to do this because it is a fairly rare syndrome. Now, 25 years into the research with Li-Fraumeni syndrome, it is the mission of the LFSA to identify new areas for research with Li-Fraumeni syndrome.

An example of these collaborative efforts is a recent publication entitled “LFS and Living My Best!” (2020) which included work from the LFSA’s Medical Advisory Board, LFS patient, and genetic counselor. It is hoped that this book serves as a starting point for helping patients and providers understand what Li-Fraumeni Syndrome is and how it can be managed.

In its first year, the LFSA Scientific Advisory Board has established a grant program and awarded its first grant to Professor Levine, PMH, INO, Department of Medicine, Division of Hematology, University of Texas, MD Anderson Cancer Center in a study on breast cancer in LFS patients.

LFS Scientific Advisory Board goal: to bring together basic scientists to collaborate with clinicians in order to initiate research with Li-Fraumeni syndrome patients in the areas of genomics and other possible novel treatment strategies.

“LFS and Living My Best!” is a book dedicated to increasing the level of fundamental research in the Li-Fraumeni syndrome area. - Prof. Arnold Levine

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“LFS and Living My Best!” is a book dedicated to increasing the level of fundamental research in the Li-Fraumeni syndrome area. - Prof. Arnold Levine

LFS Scientific Advisory Board grant: to study patients with severe disease compared to those with less severe disease.

“While we plan to go closer and through more outreach and more in-person connection, we are ready to see HOMER in action! We will continue to provide hope for individuals and resources for individuals with LFS and ultimately LFSA’s ultimate goal, the process of announcing at least another grant, and more is planned for next year.

We’ve also added an LFS Association - Africa chapter, bringing our international chapter number to 11, covering countries such as France, Germany, and Japan.

One of our goals has been to increase the awareness of Li-Fraumeni Syndrome and in the last three decades, it became clear that the development of more tailored approaches for cancer surveillance testing criteria can accelerate future research toward the Li-Fraumeni syndrome.

In 2020, the concept of analyzing tumor patterns and genetic variants and identified differences between variants in TP53-related cancer study. The LFSA’s Scientific Advisory Board is thrilled to be facilitating this collaborative research project, which is funded in part by the LFSA Foundation.

“Gratefully yours,
Jean-Pierre LFSA President, LFS patient, and LFS-More

A Message from the LFSA President

Dear Friends of the Li-Fraumeni Syndrome Association,

I’m honored to tell you that we have a new website and new mobile app! We’ve also launched a new initiative to bring together like-minded patients and caregivers worldwide to support our mission. This new website is designed to offer a more comprehensive and user-friendly experience for our members and potential members. It’s a great resource for those who are interested in learning more about Li-Fraumeni Syndrome and staying informed about the latest news and developments in the field.

The LFSA is excited to announce the launch of a new book, “LFS and Living My Best!” This book is a collaborative effort between the LFSA and leading experts in the Li-Fraumeni syndrome field.

“LFS and Living My Best!” book is available now! Please visit LFSA’s website at lfsassociation.org to see the latest updates and information.

LFS Resources Available Now!

Please visit LFS’s website at lfsassociation.org to view and download the latest resources, newsletters, and more.

LFS Scientific Counseling Group Bridge for LFS Families

Genetic Counseling

LFS Scientific Counseling Group is a non-profit organization that provides education and resources to patients and caregivers of Li-Fraumeni Syndrome. LFS Scientific Counseling Group is dedicated to increasing awareness of Li-Fraumeni Syndrome and providing education and support to those affected by the condition. For more information, please visit lfsassociation.org/scientificcounselinggroup/

Quick Reference Access for Mental Health Providers

This pocket guide, designed for mental health providers, offers a place to start for helping patients who have Li-Fraumeni Syndrome. It includes key points on LFS, important talking points, and helpful resources.

LFS Fact Sheet for Medical Providers

This resource is intended for medical providers who have limited knowledge about Li-Fraumeni Syndrome. It provides a quick overview of the condition, including symptoms, risk factors, and treatment options.

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LFS Awareness Brochure for Teens and Young Adults

This brochure is designed for teenagers and young adults who may have limited knowledge about Li-Fraumeni Syndrome or who may be newly diagnosed. It provides important information on the condition, including symptoms, risk factors, and treatment options.

LFS Awareness Brochure for Family and Friends

This brochure is designed for family and friends of patients with Li-Fraumeni Syndrome. It provides important information on the condition, including symptoms, risk factors, and treatment options.

LFS and Living My Best! Children’s Book

This book is designed for children and is a great resource for helping children understand Li-Fraumeni Syndrome in a way that is age-appropriate and easy to understand.

I’m proud to inform you that we have a new website and mobile app! We’ve also launched a new initiative to bring together like-minded patients and caregivers worldwide to support our mission.

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Medical Director’s Message

The International Agency for Research on Cancer database, which contains information on over 10,000 patients with Li-Fraumeni Syndrome, is expanding with new data. This database is a valuable resource for researchers and practitioners, but it is only as useful as the data entered into it. To ensure that the database contains accurate and up-to-date information, we encourage all patients and healthcare providers to participate in the database.

Using the International Agency for Research on Cancer database, the LFSA has partnered with the Li-Fraumeni Syndrome Association to conduct a new study on the genetic basis of cancer in patients with Li-Fraumeni Syndrome. This study will help to identify new genetic factors that contribute to the development of cancer in patients with Li-Fraumeni Syndrome, which will ultimately lead to better targeted therapies.

In closing, we would like to thank all of our donors for their continued support. Without your generosity, we would not be able to continue our mission of helping individuals and families affected by Li-Fraumeni Syndrome. We look forward to the continued success of our organization and to bringing hope to those affected by this disease.
LFS Youth Empowered By Friendship

The LFSA Youth Program continued to connect and empower LFS teens and young adults this year through quarterly virtual workshops and digital newsletters. Designed to support young people with LFS in their lives, the LFSA Youth Program debuts to Youth Connect sessions which invite medical professionals to speak on topics specific to youth concerns. The virtual workshops also set aside time for attendees to ask questions and simply get to know one another.

“When a teen gets diagnosed with cancer, like I did when I was 14, you don’t meet a lot of other people like you,” said Cameron Block, LFSA Youth Program Chair. Having a rare syndrome like LFS can be very challenging feelings of loneliness and isolation. We want to provide LFS youth and young adults with a support,” Block said.

Connect sessions and Youth Newsletters:

LFS youth. Visit the LFSA website to view the latest Youth Newsletters with LFS and another addressed nutrition. Each Youth Newsletter informs and connects young people with LFS to feel encouraged and supported. Block said.

“Stress and Coping with LFS”

Panelists Rowan Forbes-Shepherd, PhD, Peter Block says making friends living with LFS in other countries is an important focus. To help do this, he said, there is an online program for attendees to ask questions and simply get to know one another.

WFY workshop was incredible! Seeing them and not feeling alone actually brought me to tears.”

WFY has remained in contact with many of them through a group chat on WhatsApp. “Being able to meet those youth at the workshop was incredible! Seeing them and not feeling alone actually brought me to tears.”

Block organized the first International Youth Workshop held in Salt Lake City in 2017. There, she connected with LFS youth from around the world and has remained in contact with many of them through a group chat on WhatsApp. “Being able to meet those youth at the workshop was incredible!”

Block said, “W...
LFS Youth Empowered By Friendship

The LFS Association continues to invest in and connect LFS teens and young adults this year through quarterly virtual workshops and digital newsletters. Dedicated to youth, LFS youth with LFS to their lives to the fullest, LFS’s Youth Program launched during the pandemic, which invite medical professionals to speak on topics specific to youth concerns. The online workshops also set aside time for attendees to ask questions and simply get to know one another.

“When a teen gets diagnosed with cancer, like I did when I was 14, you don’t meet a lot of other people like you,” said Cameron Block, LFSA Youth Program Chair. "We want to provide LFS youth and young adults with a positive environment where they can learn more about LFS, feel encouraged and supported," she said.

Block got involved with the LFSA Youth Program at the first International Youth Workshop held in Salt Lake City in 2017. There, she connected with LFS youth from around the world and has remained in contact with many of them through a group chat on WhatsApp. “Being able to meet those kids at the youth workshop was incredible” seeing them and not having alone time to just be friends.

Today, Block works closely with fellow youth chairs Anna Joy Ryan, Canada, and Isabel Costa and Olivia Naves de Andrade, Brazil, to plan Youth Connect meetings, Isabel and Olivia even translate the newsletters into Portuguese and Spanish.

“Want to support people with LFS and reach them no matter where they are,” said John Lutz. “It is especially difficult for someone with a rare disease like LFS, you need to find ways to fight for LFSA research and care in every corner of the world.”

Each international chapter is chaired by a medical professional who lives in that region. They can convene virtual meetings with the support they need locally and share LFSA information in their native languages. They also respond to local demands and medical systems unique to each country.

When LFS spreads awareness and awareness matters where they are,” said Jenn Perry. “It is especially difficult for someone with a rare disease like LFS.”

LFS Awareness Saves Lives

The LFSA is committed to making awareness of LFS a priority and taking action on this. In 2020, the LFSA was able to answer a much-needed call for LFS awareness, in part through its inaugural International LFS Awareness Day on May 3. The day, 5/3, was chosen for its connection to p53, the cancer-fighting protein that is damaged in LFS patients.

All throughout May, the LFSA and its international chapters planned events and initiatives to help people learn more about LFS. The LFSA community shared stories and LFSA International products. The LFSA President, Joan Flyer appeared in a video explaining the background of LFS Awareness Day and talked about the founders of the syndrome, Dr. Fredric Li and Joseph Fraumeni, Jr.

One week of the month was dedicated to recognizing the LFSA International Chapters and all their efforts for the global LFS community. Another week focused on the LFSA Youth Program’s impact on LFS, and the importance of empowering young people with LFS to share their key assets of health promotion and peer-to-peer support decisions.

Throughout the month of May, the LFSA community held special mentions at LFS awareness events, the LFS families shared their stories and LFSA International products.

The LFSA held its annual LFS Awareness Day webinar, LFS and COVID-19 Webinar Answers Questions that discussed COVID-19 vaccines and concerns within the LFSA community; guest panelists emphasized audience questions about vaccine reactions for those with LFS and studies supporting whether to use the LFS patients and cancer patients undergoing treatment. A recording of the webinar is available on the LFSA website.

The LFSA is proud of the work LFS Aids has done to help us continue critical patient programs and boost LFS awareness. Here are a few ways LFSA supporters rallied their communities.

Community Fundraisers Get Creative

Friends of LFSA found creative ways to fundraise for the association throughout the year. Thousands of dollars were raised to help continue critical patient programs and boost LFS awareness.

Robust Event

LFSA Australia & New Zealand held a robust event last spring to secure funds for the association and build awareness about LFS and p53 in their region. The group also designed an awareness postcard campaign.

Winning Essay

A THC Black wrote an essay about LFS for her school, Georgia Cumberland Academy, and was awarded $1,000 for LFSA, the non-profit she selected.

Colorado Mountain Hike

The Colorado Chapter hosted its inaugural hike from the Mountain (Fort Collins, CO) in their annual LFS Fight Club event. The 4-mile hike featured a 1,600-ft. elevation gain and a challenging scramble to the summit.

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