In 2020, we celebrated two major milestones in LFS history. This year, the 30th anniversary of the discovery of Tp53 and its involvement with Li-Fraumeni syndrome, and marks the 50th anniversary of the first Familial Syndrome meeting at the National Cancer Institute.

The first family pedigree with LFS was discovered in 1969 by Drs. Bordenat, Luscher, and Andolfo. It was not until 1990 that the LFS connection to Tp53 was realized. Dr. David Malkin, LFSA Medical Advisory Board member, who co-discovered this connection with Dr. Stephen Friend, reflected on the eighth of Family Discoveries during an August 2020 LFSA International Symposium in October.

It started with a question: “What causes Li-Fraumeni syndrome?” Malkin said. “There was no rational reason to suspect that Li-Fraumeni syndrome was hereditary.” However, Tp53 gene mutations are now known to cause Li-Fraumeni syndrome. In 2020, we celebrated two major milestones in LFS history.

The LFS Association was founded in 2000 with the LFS Association Global Pioneer Award. Malkin was the first LFS patient to be awarded this award. In 2019, the Li-Fraumeni Syndrome Syndrome was formed to partner with the Li-Fraumeni Exploitation of LFS (LiFE) Consortium, an international and multidisciplinary alliance of scientists, clinicians, pathologists, and genetic counselors. The LFS Association brought the patient forward, bringing together LFS patients and LFS, and research. As we celebrate our 10th Anniversary of this research. As we celebrate our 10th Anniversary of this...
A Message from the LFSA President

Dear friends of the Li-Fraumeni Syndrome Association,

Without a doubt, 2020 has been an extremely challenging year for individuals with Li-Fraumeni syndrome. The impact of the COVID-19 pandemic on the Li-Fraumeni syndrome community was significant and unavoidable. We are so grateful not only for the timely and accurate information shared and the support for the community but also for the tireless efforts of LFS doctors, genetic counselors, researchers, and scientists in the field. We have worked closely with them during this trying time, and together we have helped to guide LFSA as an organization through this unprecedented and challenging period.

As you know, the COVID-19 pandemic forced us to cancel the International LFS Association Symposium 2020 that had been scheduled to take place in Boston, the 5th International LFS Association Symposium. This move allowed us to reach more people than ever before and connected LFS doctors, scientists, genetic counselors, and patients around the world in a much better place thanks to the REACH 2020 LIVE online event platform and mobile app.

Download the new LFSA mobile app! Get access to all REACH 20 sessions at your fingertips. Connect with hundreds of LFS families, doctors, geneticists, and scientists today!

With the threat of the coronavirus, we’ve had every excuse to slow down or put a hold on starting everything until the crazy year we are having is over. But our goal was to stay focused on our mission.

The foresight ten years ago to bring LFS families together at our first International LFS Association Symposium was to reach more people than any other symposium and prove an unprecedented success.

The LFS Association is thrilled to announce its new Scientific Advisory Board to drive LFS Research.

The mandate to social distance put a damper on in-person events for fundraisers for the first quarter this year. However, friends of the LFSA stepped up with some creative ways to raise awareness about LFS and encourage donations.

LFSA Volunteers Take Fundraising to a New Level

LFSA Fell Gymnastics Invitational, Boston, MA

The annual LFSA Fell Gymnastics Invitational was dedicated to Helene Subkowick, LFSA's first Youth Champ in Canada. After much wait to ensure COVID-19 health and safety precautions, the gymnastics competition and fundraiser brought gymnasts together to compete after months away from the gym and take part in this fun event to support LFS.

 steakhouse gift cards, and more — were auctioned off.

Higgins Family Sock It to Cancer for LFSA, Sayre, PA

What fun and such great support shown in the face of adversity this year when more than 20 members of our community held Facebook fundraisers to benefit the LFSA Higgins Family Sock It to Cancer for LFSA! Higgins Family Sock It to Cancer for LFSA!

With all the craziness of 2020, we had every excuse to slow down or put a hold on starting everything until the crazy year we are having is over. But our goal was to stay focused on our mission.

We are resilient despite adversity. We have the resolve to make a better future for individuals and families with LFS. We are resilient despite adversity. We have the resolve to make a better future for individuals and families with LFS.
Dear Friends of the Li-Fraumeni Syndrome Association,

In this time of change and challenge, we want to start by saying, thank you. Thank you for your support, your commitment, your hope, your passion. We recognize this year has been tough for many. As a community, we have faced incredible stress and uncertainty, and we have continued to push forward with hope and resilience. Yet, despite the challenges and even because of them, the Li-Fraumeni Syndrome Association (LFSA) has continued to grow and make a difference in the lives of those affected by Li-Fraumeni syndrome and related conditions.

A Message from the LFSA President

With the close of 2020, we have every reason to be hopeful that we have turned a page. In this final month of the year, we have celebrated so many milestones. The foresight ten years ago to bring LFS families together in Boston was not lost on us. With the International LFS Association Symposium to an online platform, we were able to connect our LFS medical, scientific, and patient community like never before. The LFSA family has grown, and together we have the resolve to make a better future for individuals and families with LFS.

LFS Association Symposium Proves a Virtual Success

The LFSA President, LFS patient

The theme of the 2021 International LFS Association Symposium was “Positivity and Resilience.” The symposium was held online from February 15-19, and served in leadership for the LFSA. Your efforts have helped us continue to serve you, our mission and vision.

The LFSA’s Scientific Advisory Board will help develop and guide new research areas and initiatives. The LFSA’s Advisory Board and Genetic Counseling Advisory Board, together with the LFSA’s Scientific Advisory Board, will continue to help us achieve these goals.

LFS Volunteers Take Fundraising to a New Level

The mandate to social distance put a damper on in-person events for fundraisers; however, this year, LFSA stepped up with new and innovative ways to raise awareness and funds.

LFSA Fall Gymnastics Invitational, Boston, MA

The third annual LFSA Gymnastics Invitational was dedicated to Henning Sablowski, LFSA’s first LFSA Youth Ambassador. Despite the challenges, the gymnastics competition brought gymnasts together to compete at the highest level of competition.

New Scientific Advisory Board to Drive LFS Research

The LFSA is thrilled to announce its new Scientific Advisory Board. In addition to the association’s Medical Advisory Board and Genetic Counseling Advisory Board, the new board brings together top scientists in the field of Li-Fraumeni syndrome.

Co-chaired by Dr. Maria Isabel Achatz and Prof. Anne Levine, LFSA’s Scientific Advisory Board will help develop and guide new research areas and initiatives.

“Li-Fraumeni Syndrome doesn’t stop. Our goal is to stimulate original Li-Fraumeni syndrome research,” Achatz said. “We’ve only begun to organize, but we have the top international experts in molecular biology, immunology, clinical research and LFS. Our goal is to stimulate original Li-Fraumeni syndrome research. We’re only beginning,” she concluded. “We’ll also be very excited to work with LFSA Medical Advisory Board to bring together LFSA patients, families and scientists in the area of Li-Fraumeni syndrome, and help to find a cure. We have the potential to form an association like LFSA that connects patients with researchers and scientists in the field who they don’t know.”

Download the new LFSA mobile app! Get access to all 2021 REACH 20 sessions at your fingertips. Connect with hundreds of LFS families, doctors, geneticists, and scientists today!

— Robert Lufkin, D.O.

LFSA Scientific and Medical Director

The LFSA has grown significantly in the past year, and we are poised to lead the way in this charge, always keeping in mind the needs of our community. We look forward to the 2021 International LFS Association Symposium and beyond. We are ready to take the next steps with you. As always, our mission is to continue to support screening and early cancer detection.

Medical Director’s Message

As we look at the 10th anniversary of the founding of the LFSA, we recognize how much has been accomplished and how much remains to be done. The last few years have been significant because of the recognition of Li-Fraumeni syndrome. The recognition of Li-Fraumeni syndrome has led to the establishment of the LFSA. The LFSA has been able to support families and provide resources, education, and support for individuals with Li-Fraumeni syndrome. The LFSA has been able to make a difference in the lives of those affected by Li-Fraumeni syndrome.

The LFSA is able to do this because of our dedicated staff, our board members, our volunteers, and our supporters. The LFSA is able to do this because of the support of our community and the dedication of our staff.

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Dear Friends of the Li-Fraumeni Syndrome Association,

A Message from the LFSA President

As we celebrate the 10th anniversary of the founding of the Li-Fraumeni Syndrome Association (LFSA), I am honored to reflect on the challenges and successes we have experienced over the past decade. Our year-long celebration of this milestone year has been an opportunity to reflect on the progress we have made, and to look forward to the future.

The LFSA was established with the mission of serving families with Li-Fraumeni Syndrome (LFS), a rare genetic disorder characterized by an increased risk of cancer. Since its inception, the LFSA has been dedicated to providing support, information, and resources to those affected by LFS.

Over the past decade, the LFSA has grown significantly, with a focus on expanding our reach and impact. We have established a new grant program, expanded our youth program, and increased our presence in India; the LFSA now has chapters in 10 different countries. In the past year, we have seen unprecedented success.

The impact of the 5th International LFS Association Symposium was hosted by Dana-Farber Cancer Institute in partnership with the LiFE Consortium. The LFS Association Symposium was hosted by Dana-Farber Cancer Institute in partnership with the LiFE Consortium. Having an active international presence allows us to support and learn from one another to advance LFS research and funding.

The impact of the 5th International LFS Association Symposium became a virtual platform that reached more families with LFS. The LFSA has served in leadership for the LFSA. Your efforts have helped us grow.

The LFSA research and physician community is incredibly talented, skilled, and dedicated to finding answers for our families. We have the top international experts in molecular biology, as well as others. A huge LFSA thank you goes out to Dr. Judy Garber and her team at Dana-Farber Cancer Institute in partnership with the LiFE Consortium.

We have seen dramatic progress in the last decade, and I look forward to continued growth and success in the years to come.

The past year has been challenging, but we are determined to continue our mission and serve our community.

Robert Lukett, D.O.
LFSA Scientific Lead and Medical Director

Medical Director’s Message

As we celebrate the 10th anniversary of the founding of the LI-FRAUENINI Syndrome Association (LFSA), I am proud to reflect on the challenges and successes we have experienced over the past decade. Our year-long celebration of this milestone year has been an opportunity to reflect on the progress we have made, and to look forward to the future.

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Robert Lukett, D.O.
LFSA Scientific Lead and Medical Director

Download the new LFSA mobile app! Get access to all REACH 20 sessions at your fingertips. Connect with hundreds of LFS families, doctors, geneticists, and researchers today!

The LFSA’s Advisory Board is thrilled to announce its new Scientific Advisory Board. In addition to the association’s Medical Advisory Board and Genetic Counseling Advisory Board, the new board brings together top scientists in the field of Li-Fraumeni syndrome.

Co-chaired by Dr. Maria Isabella Achara and Prof. Amie Levine, LFSA’s Scientific Advisory Board will help develop and guide new research around LFS and Li-Fraumeni syndrome.

“Our goal is to stimulate original Li-Fraumeni syndrome research,” Achara said. “It has only begun to organize, but we have the top international experts in molecular biology, immunology, clinical research and LFS.”

“Li-Fraumeni syndrome represents problems that are ripe for action, pull a team together, find funding to pursue and come up with new solutions,” Levine added. “We’re also keen to work with LFSA’s Medical Advisory Board to bring in people from academia and industry to develop and oversee symposia of medical doctors and research scientists will benefit LFS and childhood cancer patients around the world. We’re grateful to have an associate like LFSA that connects patients with researchers and scientists in the field.”

The mandate to social distance put a damper on in-person events for fundraisers for the first quarter of this year. However, friends of the LFSA stepped up with some creative ways to take awareness about LFS and encourage donations.

Philpot Memorial Bowling Tournament, Sacramento, CA

The Higgins Family Sock it to Cancer for LFSA, Sayre, PA

The Higgins Patrick raised over $1,300 in cupcake sales for the LFSA Fall Gymnastics Invitational was held in Germany. After much work to ensure COVID-19 health and safety precautions, the gymnastics competition took place over the summer months away from the gym and raised more than $8,500 for the LFSA Foundation.

Facebook Fundraisers & Company Matching Gift Programs

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Celebrating Collaboration & The Power of Us

In 2020, we celebrated two major milestones in LFS history. This year is the 30th anniversary of the discovery of Tp53 and its involvement with Li-Fraumeni syndrome, and marks the 30th anniversary of the first Li-Fraumeni Syndrome Association meeting at the National Cancer Institute. The first family pedigreed with LFS was discovered in 1969 by Dr. Barnard Look and Dr. Joseph Lyon. It was only until 1990 that the LFS condition was finally recognized. Dr. David Malkin, LFSA Medical Advisory Board member, who co-discovered this connection with Dr. Stephen Friend, reflected on the eight-to-10-fold increased disorder during the 30th International LFS Association Symposium in October.

It started with a question: “What causes Li-Fraumeni syndrome?” Malkin said. “There was no rational reason to come up with such a low number when we decided to do the research. The next to unraveling the question was smooth, in fact, their first theory proved altogether wrong. But, such is the beauty of science. The correct, useful and flat out wrong stories lead us to the right direction.”

Malkin and Friend, picked the Tp53 gene. The Tp53 protein was initially thought to drive cancer, but later errors and flat out wrongs lead us to discover the right.

The priorities of the LFS Association are patient-centered:
- How do we prevent cancers in LFS patients?
- How do we manage the psychological consequences of LFS?

The LFS Association was formed in 2000 with the LFS community in mind. Today, the Annual Meeting of the National Cancer Institute brings together LFS researchers and community members. In the first time, LFS patients and their families and researchers were asked to describe LFS and present their research. This year, the Li-Fraumeni Syndrome Association was formed to pair geneticists with LFS patients to identify cancer risks and treatments for people living with the syndrome.

The LFS Association brought the patient forward, bringing LFS issues to the forefront of the research. As we celebrate our 30th Anniversary of this wonderful journey, we are now sharing stories and patients we recognize are the most progressive and are grateful for the medical, ethical, and psychological advances. As we carry out our mission to support and advocate for individuals and families with LFS, we also look to our future. We look to the future of a future, a future that is looking to bringing questions about LFS and, ultimately, a future we will want to bring the cure.

LFSA’s MISSION

The LFS Association provides a wide range of information, resources, and support services for individuals and families with Li-Fraumeni Syndrome. We support a consortium of LFS researchers to conduct research and promote optimal care for the LFS community.

Making Connections During Pandemic

In a year that kept many people apart because of the COVID-19 pandemic, LFSA was extremely active bringing the LFS community together. Through virtual meetings and virtual events, LFSA connected LFS patients with one another and with medical, scientific, genetic, and even mental health experts. There are some of the events and initiatives LFSA put forth this year to connect our communities.

The first step in the process is to submit a letter of intent through a form available on the LFS Association’s website, www.lfsassociation.org. After the first letter of intent is submitted, the LFSA Scientific Advisory Board will review the letters of intent to narrow down and invite the best candidates to submit a full proposal for funding. Once a grant is awarded, the board intends to stay closely engaged with the grantee to help ensure that the research is being conducted as outlined in the grant. After the meeting, LFSA will publish and seek out larger grants to further the research.

Our hope is to continue offering grants for LFSA research on a consistent, regular basis, but that is highly dependent on continued funding by the LFSA. Donating, as always, is critical.

Celebrating Resilience, Resolve & Results!

2020 LFSA IMPACT REPORT

Making Connections During Pandemic

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Recordings of the webinars can be viewed on our websites, www.lfsassociation.org.

Expansion of Youth Program to Young Adults

The LFS Association has established a new grant program to help fund more scientific research focusing on Li-Fraumeni Syndrome. The inaugural grant of up to $45,000 is on track to be awarded in the U.S. in the coming weeks.

LFSA Scientific Advisory Board Member Sean Downing, PhD, Yalei School, will oversee the grant process. Because LFS is so rare, it does not get a lot of attention,” Downing said. “If we’re going to make a difference, LFSA needs to raise awareness to the disease and drive more research to help us better understand Li-Fraumeni Syndrome.”

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Celebrating Collaboration & The Power of Us Making Connections During Pandemic

In 1990, Dr. David Kim and a team of scientists at the research proved it actually suppressed the growth of errors and flat out wrongs lead us to discover the right. Malkin and Friend pivoted to the syndrome? Malkin said. “There was no rational reason to time,” Malkin said.

This year is the 30th anniversary of the discovery of this discovery that inherited (germline) mutations of gene. The are the primary cause of LFS opened the door for predictive psychosocial advances.

As we carry out our mission to support and advocate for individuals and families with LFS, we also look to our future. We will focus on a future of hope, a future with a vision for bringing questions about LFS and, ultimately, a future with hope.

LFS’s MISSION

The LFS Association provides a wide range of information, advice and support services for individuals and families with Li-Fraumeni Syndrome. It’s a non-profit and 501 (c)(3) organization. If you’re interested in volunteering, donating, or other forms of support, please visit the website, www.lfsassociation.org.

2020 LFSA Youth Workshop Virtual Meeting

LFSA Youth Workshop 2020 was held virtually for the first time since its inception four years ago. Aligned to access the virtual meeting brought together LFS youth from all over the world to connect in person and learn from expert speakers in the field, including Dr. Kari Malkin, Jacobsen, and Jeneen Prewer, LLC, of Penn Medicine; Dr. Joseph Fraumeni, MD, of the University of California, San Francisco; and Dr. Daniel Tarrant, FACM, of the University of California, Los Angeles. The workshop featured sessions focused on topics that impacted children and young adults who live with LFS.

Expansion of Youth Program to Young Adults

LFSA has announced a new grant program to support Li-Fraumeni syndrome research funding and awareness. “We need more research to find effective treatments and a cure for Li-Fraumeni syndrome. The inaugural grant of up to $45,000 is on track to be awarded in the first quarter next year.”

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LFSA’s Advisory Board Member Sean Downing, PhD, Tekeda, will oversee the new grant process. "Because Li-Fraumeni Syndrome is so rare, it doesn’t get a lot of attention," Downing said. "But with this grant program, we hope to support and encourage research that will help us better understand and manage this rare disease."