

GAME CHANGERS

Looking to the Future



Our Mission

LFS Association provides a wide range of information, advocacy and support services for individuals and families with Li-Fraumeni syndrome. We support a consortium of researchers, medical providers and caregivers to further research and promote optimal care for the LFS community.

2017 IMPACT REPORT



\ PRESIDENT'S LETTER

Dear Friends of LFS Association,

When I look back on the past year and try to think of a way to describe the LFSA's impact, the phrase that comes to mind is "Game Changer." Webster's Dictionary defines game changer as "a newly introduced element or factor that changes an existing situation or activity in a significant way." The LFSA's 2017 efforts to support LFS patients and their families, further LFS research, and raise awareness of LFS, have not only significantly changed the lives and futures of LFS patients and families, but also the future of LFS research as we know it.

We hope to show you in this Impact Report just some of the many different ways we've worked to inspire change for the LFS community, but I'd like to highlight a couple of achievements I'm quite proud of here:

- The LFSA held our inaugural Youth Workshop which brought together 21 teens with LFS from around the world to participate in a weekend of fun and educational activities, and develop lifelong treasured friendships and bonds.
- The LFSA became a recognized member organization of the esteemed National Organization for Rare Disorders, Inc. (NORD) resulting in NORD now having a report on LFS in their searchable rare disease database!

In 2018, the LFSA will work toward further establishing our global presence. We look forward to holding the 4th International LFS Association Symposium, the only conference of its kind that connects LFS patients and family members, researchers, scientists, and medical professionals from across the globe. We are also excited to have welcomed five new international chapters in Canada, Brazil, New Zealand, Germany and the Netherlands in 2017!



On behalf of the LFSA, I want to extend my sincerest gratitude to everyone for their support. The LFSA knows that our accomplishments are all just a testament to the remarkable efforts and generous contributions made by our supporters. Together, in 2018 we will continue to build a brighter future for LFS families.

Jenn Perry

Handwritten signature of Jennifer Perry in black ink.

LFSA Association President

\ MEDICAL DIRECTOR'S MESSAGE

The march of progress has continued in 2017 toward a better tomorrow for those with LFS. Multiple publications in 2017 by LiFE Consortium researchers have highlighted the role of whole-body MRI screening for early detection of cancer in individuals with LFS. Additional exciting work is being done in augmenting this strategy utilizing circulating tumor DNA to detect early genetic signatures of cancer in the blood.

In 2017 there has also been unprecedented international collaboration on the development and expansion of the Li-Fraumeni patient database by The City of Hope and LiFE

Consortium. This promises to be one of the most important projects to date in promoting LFS related research and advancing our understanding of the unique risks for each person and family affected with LFS. This LFSA supported research, coupled with the rapid pace of new cancer discoveries in the last year, fills me with optimism for the future.

— **Robert Lufkin, D.O.**
LFSA Scientific and Medical Advisor

\ BY THE NUMBERS

LFS FACTS

1969

THE YEAR LFS WAS FIRST RECOGNIZED BY
DRS. FREDERICK LI AND JOSEPH FRAUMENI, JR.

1990

THE TP53 GERMLINE MUTATION WAS
DISCOVERED TO BE THE CAUSE OF LFS

TP53 MUTATIONS HAVE BEEN IDENTIFIED
IN THE TUMOR TISSUE OF

>50%
OF ALL CANCER PATIENTS

50%  **90%**
BY AGE 40 BY AGE 60

CHANCES OF DEVELOPING CANCER WITH LFS

THERE ARE LIKELY

OVER 1,000

MULTIGENERATIONAL FAMILIES WORLDWIDE WITH LFS

LFSA 2017 IMPACT

21 TEENS

FROM

6 COUNTRIES

ATTENDED OUR INAUGURAL LFSA
YOUTH WORKSHOP IN SALT LAKE CITY

8 COMMUNITY EVENTS

HELD BY FRIENDS OF THE LFSA TO
RAISE AWARENESS & FUNDS FOR LFS

LFSA ATTENDED

6 CONFERENCES
ACROSS THE US & BRAZIL

TO RAISE AWARENESS AND ADVOCATE FOR
LFS PATIENTS AND FAMILIES

LFSA SPONSORED

19 WHOLE-BODY MRIs
FOR CHILDREN

LFSA GLOBAL OUTREACH

280,000+

UNIQUE VISITORS TO THE LFSA WEBSITE

172 COUNTRIES
HAVE INQUIRED ON LFSASSOCIATION.COM

LFSA INTERNATIONAL CHAPTERS NOW IN

5 COUNTRIES

BRAZIL, CANADA, GERMANY, NEW ZEALAND & THE NETHERLANDS

2017 LFSA YOUTH WORKSHOP

In August, the LFSA held their inaugural Youth Workshop in Salt Lake City, treating 21 teens with LFS from around the world to a weekend of fun and educational activities, and a lifetime of friendships. During the workshop, youth attended Dr. Yelena Wu's and Dr. Christian Kratz's presentations on Living with LFS. The weekend also included an educational tour with the elephants at Utah's Hogle Zoo and hands-on lab work in the same laboratory where groundbreaking LFSA-funded research is conducted.

The LFSA would like to thank Dr. Joshua Schiffman, Dr. Lisa Abegglen, the Huntsman Cancer Institute researchers and staff, and the staff at Utah's Hogle Zoo for their assistance in making this once-in-a-lifetime opportunity a reality for the LFSA.



"The Youth Workshop was an amazing experience! I was overjoyed to be able to meet and bond with other kids and families who have the same struggles as my family and me. We all could **lift each other up in hope and strength!** I made MANY new lifelong friends at that conference. Because of our shared experiences, I immediately felt a connection with everyone there. It's as if **we are one big family.** And it is a family I am **BLESSED** to have in my life!" - Anna Joy Ryan

"The **LFSA Youth Workshop was a complete game changer** for both the caregivers and teenagers with LFS. It created new relationships, understanding, motivation, and above all else, the inspiration to continue to focus on adolescents with LFS and to meet their specific needs. An amazing time was had by all!"
- Dr. Joshua Schiffman, MD, LFS Doctor & Researcher

"The best part of the youth workshop was meeting people who had gone through the same things. **We could all connect** just by telling our stories." - Mona Heuer

"The Youth Workshop taught me about LFS, and how it affects us, but it also showed me that there are many children just like me who live with LFS, too. It taught me that there are others like me, and **it helped me create friendships through the process.**"
- Ryann Zimmerman

"I did not expect that by attending the Youth Workshop I would be blessed with **new, inspiring, and understanding friends, an amazing support group, and the motivation to live life to the fullest**, no matter what is thrown my way! The doctors who attended taught me so much, and I can't wait to see what the future holds for those with LFS." - Cameron Block

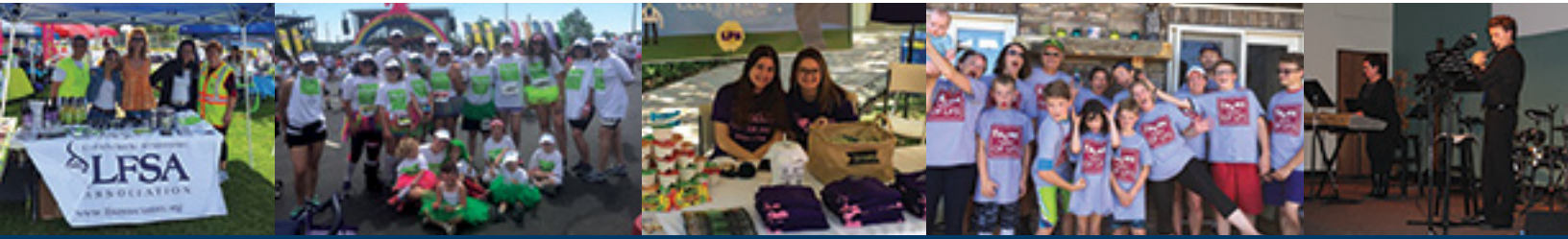


"**Being able to see how powerful** it was for the teens and parents **to meet each other and share experiences, fears, hope, and companionship was life-changing** for me. I believe that the parents, as well as the teens, left the weekend feeling like they were not alone and gained lifelong friends. **The weekend strengthened my commitment** to LFSA and its goal of being a source of support for families with LFS."
- Kathy Higgins, LFSA Education and Outreach Liaison



COMMUNITY EVENTS

LFSA Community Events not only raise funds, but also raise awareness of LFS, garner support for the LFSA mission and bring LFS community members together to support one another. In 2017, the LFSA and our supporters held a variety of engaging events – a sampling of them are featured below. We would like to thank all those who held events to support the LFSA, as well as all event attendees, sponsors and donors!



'MO SONGS FOR KERRY'

On July 29th, Kathy and Jaime Higgins held the 4th Annual Mo Songs for Kerry Fundraiser, a celebration of life in memory of their two daughters, Maureen and Kerry. The event was bigger than ever, and featured local bands, a craft show, carnival games for kids, BBQ and other fun activities for families! Event proceeds were used to pay for life-saving MRIs for children with LFS and to send children with LFS to summer camp.

Noelle's Triathlon

LFS fighter Noelle Johnson and her inspirational LFS Fight Club of family and friends returned to complete their 3rd consecutive triathlon to fundraise for the LFSA.

Fran-tastic Baths and Barks

In April, with help from Tag Nutrition and in collaboration with Kids Boost, young LFSA supporters, Jordan and Mackenzi, washed dogs to raise funds for the LFSA.

Carly's Marathon

When Carly isn't working as a genetic counselor at Mass General she is raising awareness and funds for the LFSA! On October 8th, Carly Grant completed the Mohawk Hudson River Marathon to raise money for the LFSA.

Kathy and Stephanie's Color Run

Kathy Demko, Stephanie Kudriashova and more than 20 of their family members and friends represented the LFS community as Team Faces of LFS in the Color Run, a festive paint race that celebrates health, happiness and individuality.

Layna and Rebecca's Bake Sale

In August, two shining stars of the "Team Sea of Hope" raised funds for the LFSA with a bake sale! Layna and Rebecca, the sweet grandchildren of Kathy Demko, donated the proceeds to the LFSA in honor of Kathy's niece, Sarah, who is thriving, in spite of her LFS and past cancer.

Palmer Trinity School's International Festival!

Before attending the Youth Workshop, friend of the LFSA, Chiky Fernandez, promoted LFS awareness at Palmer Trinity School's International Festival! The school's signature event celebrates Miami's multicultural community and student initiatives, such as Chiky's "Cancer Club!"

Elijah's Concert

One of LFSA's young heroes, Elijah Johnson, jumped right in to fundraise for Salute! and raise LFS awareness by holding a concert at his church where he performed. During intermission, his parents engaged in conversations about LFS, the LFSA, and the research we fund!

LFSA Salute! GALA FUNDRAISERS

Salute! Hartford 2017 Gala

Friends of the LFSA gathered to support patients and families living with LFS on September 28, 2017, at The Society Room in Hartford, CT, for LFSA's Salute! Hartford 2017 Gala, a Gatsby-inspired evening of cocktails, appetizers, a raffle and more! Proceeds from the event were used to fund research initiatives dedicated to improving and prolonging the lives of LFS patients worldwide.

Salute! Boston 2017 Gala

On June 13, 2017, LFSA supporters gathered at The Brahmin in Boston, MA, for the Salute! Boston 2017 Gala. Event attendees were treated to Brahmin's Signature 1920s Cocktail Samplers, appetizers, a raffle and an optional wine tasting. Event proceeds were used to fund LFSA's Youth Workshop.



\ LFSA's GLOBAL MOVEMENT

Raising awareness of LFS and advocating for the remarkable families and individuals affected by LFS are vital to the LFSA's mission of furthering research and promoting optimal care for the LFS community. In 2017, the LFSA established five new international offices and attended numerous events to make meaningful connections and spread the word about LFS around the world.

CANADA

"Our country includes ten provinces and three territories whose health care system is administered through Canada's Health Act which provides funding for each territory and province. I have a vested interest in ensuring we have the financial backing and a care protocol in place to care for those I love and the other families affected by LFS."

—Chiquita R. Hessels,
Branch Chair, LFSA Canada

THE NETHERLANDS

"In the Netherlands, we have worked hard to produce a brochure for general practitioners and a standard of care with different stakeholders, and we strive to inform patients and their families about all corresponding subjects surrounding LFS."

—Tom van der Wal, Branch Co-chair, LFSA Netherlands

GERMANY

"Germany has a relatively large population (82 Mio people). Assuming a TP53 carrier frequency of 1:5000, one would expect that over 16,000 people in Germany are carriers of a TP53 germline mutation. Where are they? The answer is probably simple: LFS is not sufficiently diagnosed in Germany due to lack of awareness!"

—Christian Kratz, MD, Branch Chair, LFSA Germany

BRAZIL

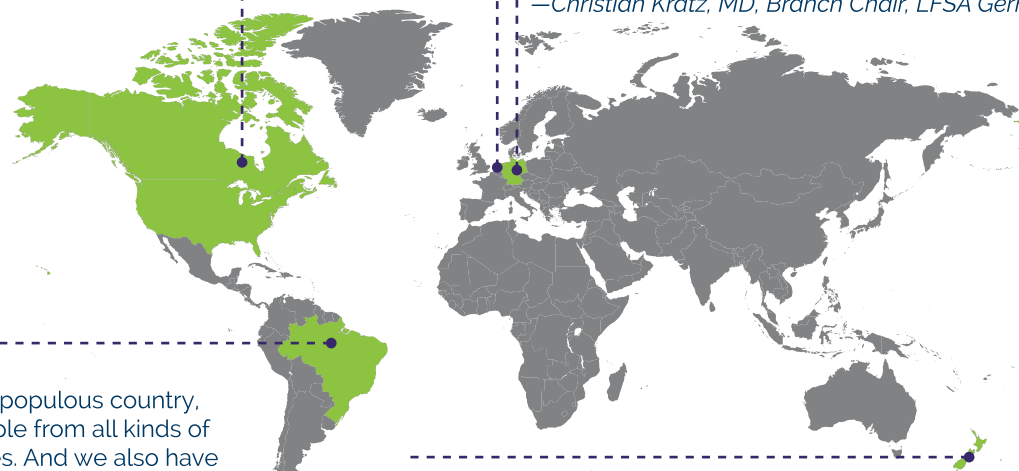
"Brazil is a wide and populous country, where we have people from all kinds of ancestry and cultures. And we also have one of the biggest populations diagnosed with LFS in the world. Unfortunately, many don't even know this syndrome exists or that some of them might carry this mutation and all the risks that come along with it."

—Yasmin Abdalla Shaaban,
Branch Chair, LFSA Brazil

NEW ZEALAND

"We are a small country with a small population. To date there are very few diagnosed with LFS here – I believe this is more to do with awareness than genetics. Medical professionals need to know about LFS before they can start to look for it and diagnose it."

—Samantha Arthur, Branch Chair, LFSA New Zealand



\ WHERE WE'VE BEEN

In February, the LFSA exhibited at Rare Disease Day at the National Institutes of Health in Bethesda, MD, and attended Rare Disease Week on US Capitol Hill with Rare Disease Legislative Action. During the week, LFSA Board Members, Holly and Kathy, attended the Rare Disease Congressional Caucus meeting with US Senators and Representatives to discuss LFS patients' legislative needs.

In April, LFSA Volunteer Margie Fernandez and Holly Fraumeni attended the American Association of Cancer Research Annual Meeting in Washington D.C. and spoke with LFS researchers attending the conference about the significance of the discovery of LFS, and its role throughout p53 and cancer research.

In May, the LFSA took part in A.C. Camargo Cancer Center's 5th LFS meeting in Sao Paulo, Brazil, with Drs. Alexandre da Costa, Maria Nirvana and NCI's Maria Isabel Achatz.

In September, LFSA volunteer board member, Kathy Higgins, exhibited on behalf of the LFSA at The National Society of Genetic Counselors Annual Conference in Columbus, Ohio. During the event, she spoke to genetic counselors and other professionals about the needs of LFS patients.

In September, LFSA Canadian Chapter Chair Chiquita Hessels exhibited on behalf of the LFSA and presented at a special session at The Canadian Association of Genetic Counsellors Annual Education Conference in Victoria, BC.

In November, Medical Director Rob Lufkin and Holly Fraumeni attended The Society of Neuro-Oncology's Annual Meeting in San Francisco, CA, and exhibited on behalf of the LFSA.