LFSA YOUTHNEWSLETTER

Our recent Youth Workshop was full of inspiration, discovery, and connection! From hands-on lab experiments and playful DNA activities to eye-opening talks by Dr. Junne Kamihara, Dr. Judy Garber, and Professor Arnold Levine, young people and their families came together to explore, share, and create lasting memories.

In this newsletter, we want to give you a glimpse of how it feels to live with LFS with curiosity and joy — swapping stories, supporting each other, and finding small moments of happiness along the way.

Even simple things, like a laugh with friends, a creative hobby, or a walk in nature, can brighten your day. Remember, you're part of a caring community that's here to lift you up, celebrate your wins, and face challenges together.

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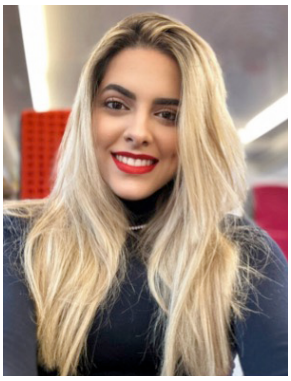

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Let's connect, inspire, and lift each other up!

Youth Workshop Highlights!

From August 15–17, Boston hosted another unforgettable **LFSA Youth Workshop** – a weekend of learning, laughter, and lasting connections. Youth participants enjoyed unique experiences, from a Boston Harbor cruise and hands-on science at Dana-Farber, to cooking classes, team activities, and inspiring conversations with world-renowned experts like Dr. Judy Garber and Professor Arnold Levine, co-discoverer of the *TP53* gene.

The workshop was not just about knowledge – it was about friendship, support, and being part of a community that truly understands. Parents connected in parallel sessions, while youths built memories that will last a lifetime.

If you're a young person living with LFS, don't miss the chance to join future workshops! It's an opportunity to learn, share, and discover that you are never alone on this journey.





TED TALKS DAILY

Entertainment Pick of the Month

Looking for a joyful boost? We've got just the thing!

Check out the TED Talk Daily episode "*Why having fun is the secret to a healthier life*" by science journalist Catherine Price.

She reminds us that fun isn't just about laughs – it's actually essential for our health and happiness. Catherine introduces the idea of "*true fun*" (a mix of playfulness, flow, and connection) and shares simple, science-backed ways to add more of it into your daily life.

Whether it's dancing in your room, cooking something silly with friends, or just letting yourself play, this talk is a reminder that fun is medicine for the soul. So hit play, smile big, and let yourself enjoy the ride!

Scanxiety is real

At the recent Youth Workshop, Dr. Junne Kamihara gave an inspiring talk about cancer screening and research for the future!

One topic that came up often was scanxiety — the anxious feelings before, during, or after scans. It's so common that we wanted to share it in our newsletter, with tips to help you manage those moments with calm and care.

Many people living with cancer experience this nervousness, which can feel overwhelming even though scans are essential for monitoring health. Ways to ease the stress include breathing exercises, mindfulness, gentle movement like walking or biking, counseling, or prayer. Remember, it's normal to feel anxious, and with support, you can find calm and regain a sense of control.

- Feeling anxious around scans? You're not alone.
- Staying proactive with regular screenings can sometimes help reduce stress.
- Lean on friends, family, and support networks — and be gentle with yourself.

Meet Matthew Urquiaga!

Can you tell us a little about yourself — your age, where you're from, and what you enjoy in your free time?

I'm Matthew Urquiaga, I'm 21, from Westchester, New York, and I like climbing in my free time.

When were you diagnosed with Li-Fraumeni syndrome, and how did you find out?

I found out I was diagnosed with LFS when I was 17, as a result of my uncle finding out he was positive.

What has your experience been like living with LFS?

My experience has been all right, knowing that I have a team behind me, and I am very fortunate to have consistent screenings.

How do you take care of your physical and emotional health while managing the syndrome?

Staying active, hitting the gym, while also spending time with friends and family makes it easier to manage with the syndrome. Keeping up a daily routine, maintaining both physicality and staying active along with keeping a reasonably healthy diet also helps.

Are there any resources, routines, or communities that have been especially helpful to you?

I think it's very important for people to just learn more about the syndrome, and there are a ton of resources that the LFSA provides. They allow you to learn more, but also to find a community and see the development within the syndrome, which can provide hope.

What message or advice would you share with someone newly diagnosed?

Find a community, stay active, and remember that there are resources and hope at the end of the day.

In Memory of Dr. Pierre Hainaut

With gratitude and admiration, we honor the life of Dr. Pierre Hainaut, who passed away on July 31, 2025. A brilliant scientist and true friend of LFSA, he dedicated his career to advancing knowledge of the *TP53* gene and Li-Fraumeni syndrome. Beyond his groundbreaking research, he will be remembered for his kindness, humility, and genuine care for families worldwide. His legacy will continue to inspire, and we extend our heartfelt condolences to his loved ones.

Take This With You!

1. **Your LFS journey is unique — celebrate every win, big or small.**
2. **Connect with someone who understands — shared experiences make you stronger.**
3. **Knowledge is power: stay curious about your health and what you can do to protect it.**
4. **It's okay to ask for help — leaning on friends, family, or your community is a superpower.**
5. **You are part of a community that sees you, supports you, and cheers for you.**