SPRING 2025

LFSA YOUTHNEWSLETTER

Hey there! Let's talk about Li-Fraumeni — our way.

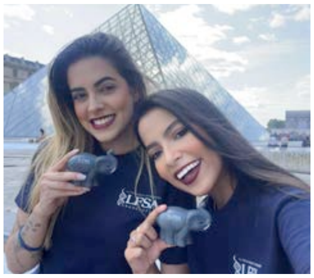
If you're reading this, it means you're part of a rare, strong, and truly unique group: young people living with Li-Fraumeni syndrome (LFS). And yep — we know. It's not something most people hear about every day, and sometimes it can feel like no one *really* gets it.

That's exactly why this newsletter exists.

This is a space where we can talk about health without things getting too heavy, share real stories without filters, laugh at the weird stuff (because let's be honest, there's plenty), and remind each other that life with a rare genetic syndrome is still full of possibilities, surprises, and good moments.

And today's edition is all about that: how to talk about life in a lighter way, even when the topics are serious. Let's explore how we can approach everyday life with more softness, welcome all our emotions, and find ways to live well — even on the tough days.

Welcome! Let's turn this experience into something shared, kind, and yeah, even a little fun.



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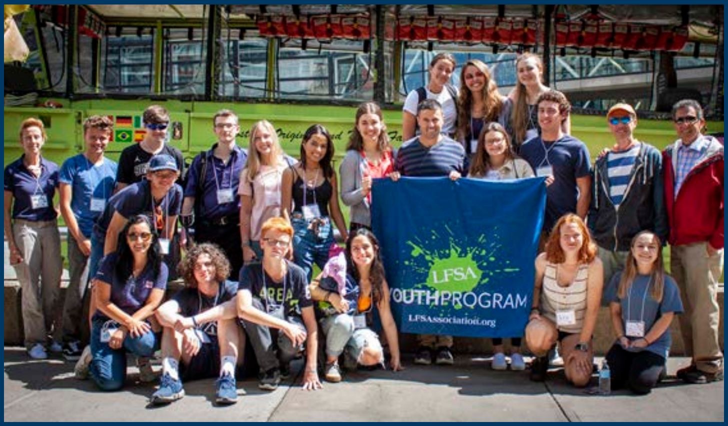
Exciting Event Alert: LFSA Youth & Young Adult Workshop!

We've got some amazing news for young people living with Li-Fraumeni — the **LFSA Youth & Young Adult Workshop** is happening **August 15-17 in Boston**!



This event is a wonderful opportunity for youth and young adults from around the world (ages 13-25) to come together, connect, share experiences, and learn more about navigating life with Li-Fraumeni. It's going to be a fun and impactful few days with workshops, discussions, and new friendships.

Want to join in?
Sign up now to secure your spot! Just fill out the LFSA Youth & Young Adult Workshop Interest Form, and a member of the LFSA team will reach out to provide more details.

This event is truly life-changing — we can't wait to see you there!

Caley Kling: Our Youth Program Coordinator-USA!

Today, we're excited to introduce Caley — she is stepping into a new role as our **Youth Program Coordinator-USA!**

Caley has been such a familiar face in the community, and now she's officially taking on this amazing responsibility of helping to connect, support, and inspire young people living with Li-Fraumeni. She'll be working on even more ways to create new connections for youth with LFS.

"Hello! I am so excited to be stepping into this new role and to be able to support all of you in any way possible! Let's start with a little bit about me. I was diagnosed with LFS at 18 months old, and have been following the Toronto protocol ever since. My dad and little sister also have LFS. I am currently an undergraduate student at Colorado State University studying molecular biology and genetics, with the hope of one day becoming a genetic counselor. Besides school I also enjoy being on the wrestling team, baking and crochet! I hope to get to know you all better, and feel free to reach out to me any time at ckling@lfsassociation.org."

Sharing Experiences Together

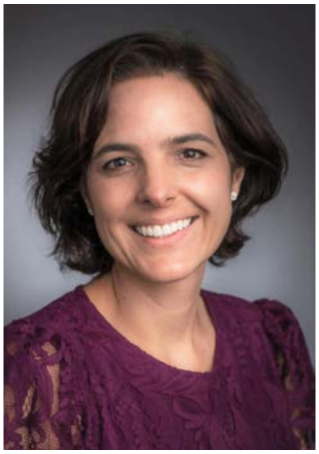
In our last 2024 newsletter, we highlighted how expressing our emotions helps us process what we're going through and feel less alone. But caring for our mental health also means making time for rest, fun, and activities that bring us joy. Whether it's watching movies, reading, painting, or trying something new, these small moments matter.

It would be amazing if more young people around the world could connect and share these experiences together! We invite you to follow our Instagram accounts:

- **@lfsayouth** — for young people worldwide!
- **@lfsaamericalatina** — focused on the Spanish and Portuguese-speaking community in Latin America.

Together, we can build a supportive, inspiring network!

Girls, Young Adults & Families—This One's for You!



We had an awesome webinar with Dr. Renata Sandoval, who talked all about breast cancer and answered tons of questions. It's super relevant for girls, young adults, and their families. If you missed it, no worries—the recording is available now!

Watch the Breast Screening & LFS Webinar >>

LIGHT TIP - TAKE A MOMENT JUST FOR YOU

It could be listening to your favorite song, journaling your thoughts, watching funny videos, or making something yummy.

Be Mindful NOW
(Yes — even just for a few seconds!)

Breathe In, Breathe Out
Feel the gentle rhythm of your breath.

Pay Attention to Your Senses
Notice the taste, smell, and texture of food. Be curious!

Empty the Mind
Take a moment to simply *be still*.

Mind Wandering?
No stress — just gently bring it back to your breath.

Listen Without Judgment
Really listen. Let the words come and go without labeling.

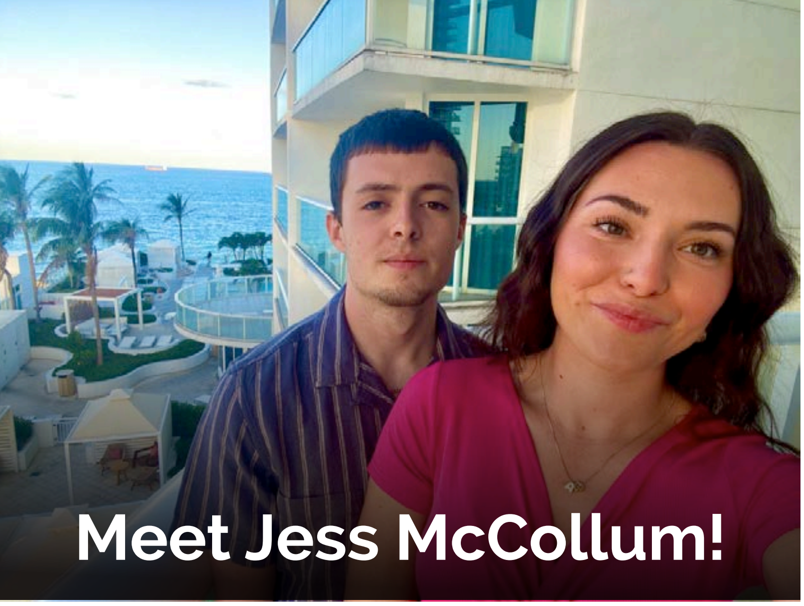
Be Present in the Everyday
Washing dishes? Walking? Texting? Notice what's happening.

Get Outside
Even a short walk in nature can be a full reset.

Forgive Yourself
Negative thoughts happen — you're human. Be kind to you.

Be Grateful
Say "thank you" to people, the trees, your coffee… everything.

Go Easy on Yourself
Progress takes time. You're doing better than you think. Tiny breaks like these can become gentle reminders that **you are more than any diagnosis**.



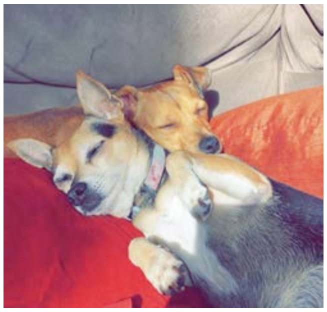
Meet Jess McCollum!

Today, we're super excited to introduce someone amazing to you: Jess McCollum!

Jess is a young adult living with Li-Fraumeni syndrome — in this edition, you'll get to know a bit more about her journey, what helps her stay grounded, and how she finds lightness even in heavy moments.

Can you tell us a little about yourself — how old you are, where you're from, what you do, and what you enjoy doing in your free time? We'd love to get to know the person behind the story.

I am 24 years old and I'm from Hammonton, New Jersey. I have always been interested in healthcare and am currently in nursing school. In my free time I love being outdoors whether that's going to the beach, kayaking, fishing, walking my dogs, and exploring new places I haven't been before. I also love to exercise and spend time with family and friends!



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

I was diagnosed with LFS when I was 22. I went to my annual gynecologist appointment where she felt a lump in my breast. She thought it was just a cyst, but she recommended that I get an ultrasound just to be safe. After I got the ultrasound, the doctor wanted me to get a mammogram which still showed suspicious findings. I then got a biopsy and the next day I was informed that I had Her2+ breast cancer. I was then later genetically tested and found to have a TP53 deletion. My parents and brother were tested as well and did not have the mutation, making me the first case of LFS in my family.

What has your experience been like living with LFS?

So far I have only known about LFS for two years. No one else in my family has a significant cancer history so it was all new to me. Having LFS and being diagnosed with cancer have definitely changed me. I would say mostly for the better, I try to be more grateful everyday and now I know that I am not invincible. I love my family a little harder now because I know not everyday is guaranteed, but everyday is a blessing. There are also hard days, where I am very anxious about the future but I try to live for today :).

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

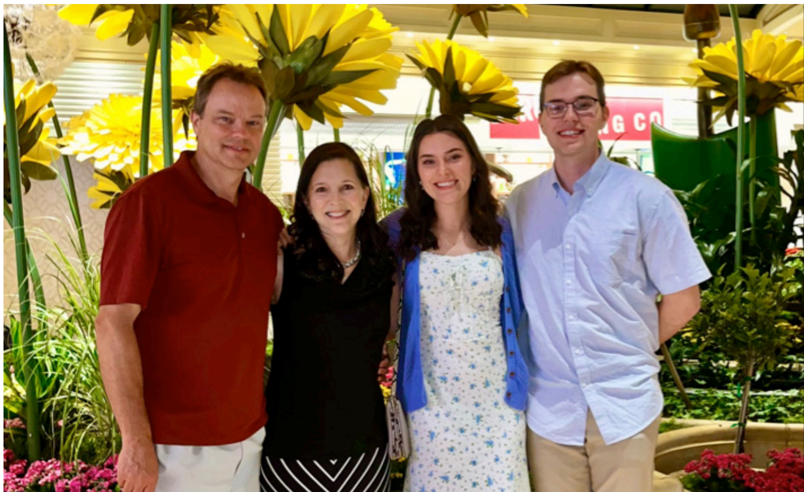
Exercising frequently and eating healthy have been a huge benefit to my physical and emotional health. Knowing that I have some control over my body gives me assurance that I am doing all that I can to stay healthy. I also have an amazing support system. My boyfriend was with me at the time that I was diagnosed and he has been with me ever since. Our relationship has only gotten stronger and I couldn't have gotten through my diagnosis without him. My parents have also been such a rock for me, going to every appointment and taking care of me through every procedure.

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

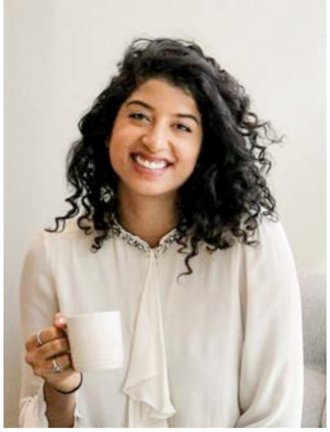
LFSA has been very helpful in helping me cope by introducing me to this amazing network of people and reminding me that I am not alone. All of the resources and events that LFSA has introduced to me are so helpful and I know that when I am ever feeling worried there are always people right there going through the same thing to support me. Also, social media in general has been very beneficial as I have been able to follow other young women who have had breast cancer and they tell their real experiences day to day living with the disease.

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

Some advice that I would give to someone who is newly diagnosed is try to not let this diagnosis affect your whole life! I know it can be hard, and in fact your whole life can be affected by it. But I have learned that we can still enjoy everything life has to offer, there is so much love, happiness and light in the world. We can achieve everything we want and there is a huge support system of other people with LFS ready to help whenever you need it. Always, please reach out and don't forget to do the activities you love. Live your life to the fullest!



This Month's Wellness Spotlight: Nutrition Tips from Brazilian Nutritionist Iara Lemos!



When it comes to health—especially for those living with LFS—food can be a powerful ally. But let's be clear: no need for extreme diets! The key is *balance*. Check it out:

One of the key principles of good health is having a varied diet. That's because different foods provide different nutrients. The color of fruits and vegetables is a clue to their properties, so naturally colorful meals are often packed with a wide range of nutrients and bioactive compounds.

To achieve this variety, it's recommended to follow a diet rich in plant-based foods like fruits, vegetables, leafy greens, whole grains, and legumes—while limiting saturated fats, processed meats, sugary foods, and alcohol. A balanced diet can help reduce the risk of diseases, including cancer.

But food is not just about nutrients—it's also about celebration, affection, and culture. That's why your diet should be diverse, respect local traditions, bring pleasure, and whenever possible, include regional foods and support local farmers.

Research on the connection between nutrition and cancer is complex, and many important questions remain unanswered. Because of this, it's important to understand that restrictive diets are usually not a good idea, and there's no scientific proof that so-called "miracle" foods can cure cancer.

That said, there is clear evidence that a healthy diet helps in both the prevention and treatment of the disease. The more colorful and varied your meals are, the stronger your body's defenses will be—and the lower the risk of nutritional issues during treatment.

Pay attention to what's on your plate. Avoid extreme diets and food trends. Remember: there are no "good" or "bad" foods—what matters is how often and how much of them you eat. Finally, seek guidance from qualified nutritionists for personalized support that meets your health needs and lifestyle.

Take-home notes:

- There are no "good" or "bad" foods—only unbalanced habits.
- The more colorful and diverse your meals, the stronger your body can be.
- Food is fuel *and joy*—take care of yourself with kindness and balance.

Take This With You

No matter how small, every mindful moment is a step toward healing.

Give yourself permission to pause, breathe, and simply *be*.
You don't have to have it all figured out — just keep showing up for yourself.
Until next time, *stay soft, stay grounded*.