

LFSA YOUTH NEWSLETTER

FALL 2023

Hello Everyone!



The Youth Workshop in NYC was a tremendous success! It's truly special to have had the opportunity to meet new people, reunite with friends from all corners of the globe, share our experiences, listen to inspiring speeches, and delve deeper into our understanding of LFS while engaging with specialists.

And, of course, we had an absolute blast!

It's incredible to witness how the LFSA family is continually growing, expanding its reach across the globe. We now have youths from all around the world – Latin America, France, the United States, Africa, India – it's truly remarkable!

We understand that breaking the ice can sometimes be a bit daunting, and you might feel a tad self-conscious. The beauty of it all is that when you're among fellow young people and patients who share the journey of Li-Fraumeni syndrome, you can simply relax! Yes, that's the honest truth. Since you're all navigating the same condition, connecting and feeling at ease becomes second nature.

Here's a suggestion for you! If you already have friends with Li-Fraumeni syndrome, that's fantastic. Have you ever thought about sending them a message to check in and see how they're doing? Or if you haven't yet had the chance to make a close friend or establish contact with another patient, why not extend a warm hello? It's easy when you share your life with trustworthy individuals, trust me!

You can initiate connections with other patients online through platforms like Facebook or Instagram. And if you're feeling adventurous, why not arrange to meet up with them?

We've provided a list of pages for you to follow, where you can meet new people with Li-Fraumeni syndrome and stay connected:

@lfsaassociation – LFS Association Instagram page
@lfsabrazil – Brazilian page on Instagram
@lfsacanada – Canadian page on Instagram
@lfsafranceyouth – French Youth page on Instagram
@lfsagermany – German page on Instagram
LFSA page on Facebook: www.facebook.com/lfsassociation

Isabel Costa
Latin America Youth Program Co-chair, LFSA
Email: icosta@lfsassociation.org



Speaking of the Youth Workshop... Allow me to introduce you to Barbara! This year marked her very first time attending the Youth Workshop, and she couldn't be more excited! What's even more remarkable is that Barbara underwent a preventive mastectomy and is now dedicated to assisting other patients in coping with their diagnosis.

Hi! Tell me more about you!

Hello! My name is Barbara, I'm a 27 year-old Brazilian lawyer currently living in France studying to acquire a Master's degree in International and European Law.

How did you know about LFSA?

I found out about LFSA through a friend who has participated in the association for a few years. She not only introduced me to the association but also convinced me to participate in the 2023 Youth Workshop.

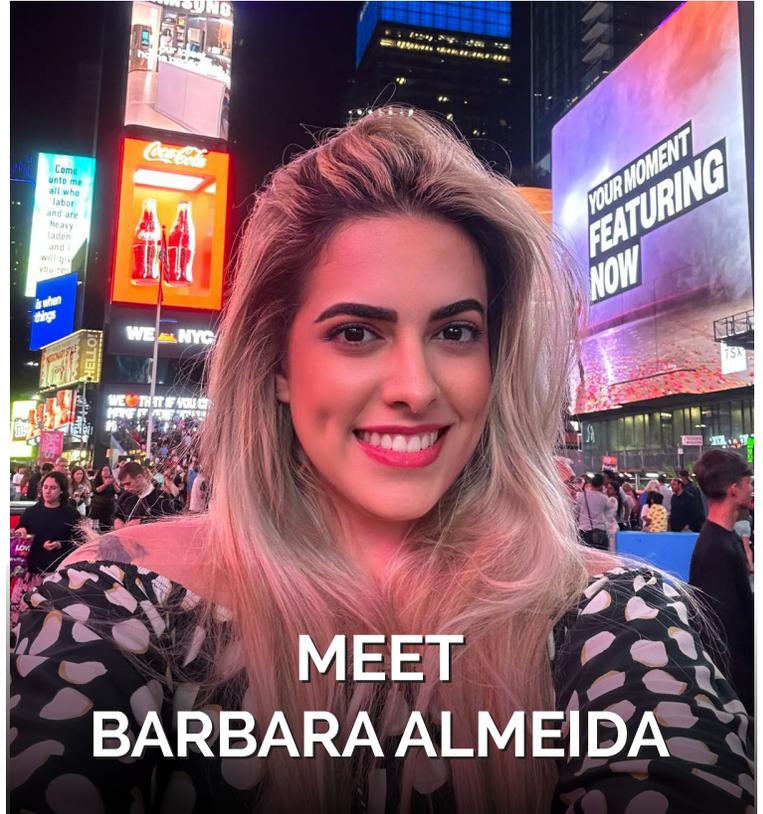
This year you went to your first Youth Workshop! How was your experience?

It was an amazing experience! It's really hard to describe how you feel there, but I can definitely say that it's completely worth it. I was afraid of what I was going to feel and hear from others. In the end, I wish it could have lasted longer. The LFSA is really a family where we feel welcomed and understood.

What is your advice for youths who have been diagnosed with LFS?

Try not to flip out with the diagnosis. I know it's hard and we have our moments. But it's not a horrible sentence and you're not alone. Once you understand that you're not alone and that you can really talk about it with people that understand perfectly what you're talking about everything changes. With the diagnosis you have the possibility of a different future, you have hope. With the association you have the opportunity to meet incredible people from all over the world and, most importantly, you have a new family.

Don't hesitate to reach out and connect with Barbara on her Instagram page: @babs.almeida!



THE POWER OF MUSIC

Music is like a universal language with an incredible ability to touch our hearts, unite people, offer comfort, and bring immense value to individuals and communities in countless beautiful ways. Its positive impact extends across various aspects of human well-being and enriches our diverse culture.

Music provides a wide range of benefits to individuals and communities. Here are some key advantages of music:

Social Connection: Music brings people together. Whether through shared musical experiences at concerts or dancing with friends, music fosters social bonds and enhances a sense of belonging.

Emotional Expression: Music offers a powerful means of emotional expression. It helps people convey and process

their emotions, whether it's joy, sadness, anger, or love.

Stress Reduction: Listening to soothing music can reduce stress and anxiety. Music has the ability to lower cortisol levels (a stress hormone) and promote relaxation, which is why it is often used in therapy and relaxation techniques.

Therapeutic Value: Music therapy is a recognized form of therapy that can be used to address a variety of physical, emotional, and psychological issues. It's especially effective in helping individuals with autism, dementia, and other conditions.

We've compiled a joyful and uplifting [playlist](#) with cheerful songs for you to enjoy!

Scan Here! >>





MEET DAVID HOYOS!

Meet David, a 29 year-old living in the USA. He's currently in his first year as a Ph.D. student in Computational Biology and Medicine in New York City. His program is a joint effort between Memorial Sloan Kettering Cancer Center, Weill Cornell Medicine, and Rockefeller University. Right now, he's doing research in Dr. Benjamin Greenbaum's lab.

David's academic journey started at Princeton University, where he majored in Physics and dabbled in Applied and Computational Mathematics and Biophysics. Beyond his studies, David has enjoyed some fun adventures, like learning Mandarin and practicing Aikido. It was during his time at Princeton that he got really interested in Biophysics and decided to pursue a Ph.D. in quantitative biology.

Why did you choose to study Li-Fraumeni syndrome?

After college, I had the opportunity to join Dr. Benjamin Greenbaum's laboratory at the Icahn School of Medicine in New York City. Dr. Greenbaum also had a physics background and was just starting a laboratory which was actively working on many exciting topics such as viral evolution and cancer immunotherapy in creative ways. He was using tools from physics and mathematics, like statistical mechanics and information theory, to come to deep insights in biology. It was a great environment to do research in and it felt like exciting things were happening all the time – I felt like a kid in a candy store.

One of the first research projects I worked on with Dr. Greenbaum was regarding the *TP53* gene. The *TP53* gene is a well-known tumor suppressor that is the most mutated gene in cancer. I came to realize that despite being the most-studied gene in cancer, there existed fundamental open questions in the cancer field regarding *TP53*. Although the p53 protein is just 393 amino acids long, it is subject to hundreds to thousands of different mutations across cancers. Notably, just eight of these mutations, called "hotspots", are responsible for one-third of all *TP53*-mutated cancers. The reason was not known. It was proposed early on that mutational biases drove the presence of hotspots, whereas others believed it had to do with their functional advantage or their immune evasive capacities. During this time, we worked with Dr. Arnold Levine, who was Dr. Greenbaum's advisor at the Institute for Advanced Study and known for the discovery of the *TP53* gene (and friend of the LFSA), and with Dr. Marta Łuksza, a close collaborator of Dr. Greenbaum known for her pioneering work on viral and cancer evolution. We derived a mathematical model that defined a "free energy" for p53 mutations which balanced these different hypotheses and accurately explained the existence of the *TP53* hotspots. During this time the lab moved to Memorial Sloan Kettering Cancer Center.

How is it to work with Dr. Arnold Levine?

Working together, we learned through Dr. Levine about Li-Fraumeni syndrome and *TP53*'s central role in the syndrome. As anyone who has met him knows, Dr. Levine

is incredibly passionate about the Li-Fraumeni Syndrome Association, and this passion was infectious for a newcomer to the field like me. When we learned that our ideas could contribute to improving the quality of life of those with the syndrome, it quickly became one of our main focuses of research. Since then, we have been involved in a number of different projects related to Li-Fraumeni syndrome. Most recently, we have been doing ground-breaking work on quantifying the role of the immune system in controlling Li-Fraumeni syndrome-associated breast cancers and in relating the fitness of p53 mutation to diverse Li-Fraumeni syndrome phenotypes. I have had the opportunity to now have attended two LFSA conferences (National Cancer Institute and New York City), one of them being my first Youth Conference. These meetings have been very special for me and are highlights in my career and life. They are so unique. At these conferences, I laugh with people, play games, share experiences, ask questions, and think of solutions together. Lots of ideas have stemmed from conversations at LFSA meetings. I have made friends for life. I feel as a community we are working together. I leave empowered to do more.

What is your favorite part about your job?

My favorite part of my job is getting the opportunity to think "outside-of-the-box" on pressing issues, such as cancer, which are important to all of us. I get to think about cancer in terms of information, code, numbers, and theoretical principles. I feel that we are participating in and pioneering a new revolution in cancer research and treatment that will one day (soon) change the lives, for the better, of those dealing with cancer. The laboratory I work in is phenomenal—the team's chemistry is exceptional and everybody is so smart, but also humble. The lab accomplishes so much that I sometimes forget it is just a few of us. I am grateful to have mentors like Dr. Łuksza, Dr. Levine, and Dr. Greenbaum, as they have been role models in thinking about science in a unique way.

What do you like to do for fun on your days off?

For fun, if I am not thinking about science, I like to practice martial arts and go biking. I am also a big Star Wars fan. I love my dogs and hang out with them any chance I get.

Let's get to know Johanna and Niclas a bit better now! They are our new friends from Germany who attended the Youth Workshop for the first time. I'm sure their stories will inspire you!



Hi! I'm Johanna, but you can call me Jovi too. I am 20 years old. I was born and grew up in a small town near Hamburg in Northern Germany together with my parents, three siblings, a cat, rabbits and chickens. Currently I live in an apartment in Hamburg with my boyfriend and am a student in German language and literature and art history. Alongside my love of nature and of being active, my passion is acting which I've been doing for about 10 years.

Where do you see yourself in 5 years?

Since I love acting, my plan is to actually study it after my current classes, that's why I see myself in university in 5 years. But first things first, I see myself alive and content with my life, hopefully having discovered more about myself and life in general, and being able to live in less fear about the future of this planet.

What's your biggest dream?

My past self would have said: "being an actress in Hollywood or in big theaters". I don't know. Doing what I love and reaching people with it. Participating in changing the world to a better place. Living in peace and spending lots of time in nature.

Do you think the event somehow changed the way you deal with the Li-Fraumeni syndrome? If yes, how?

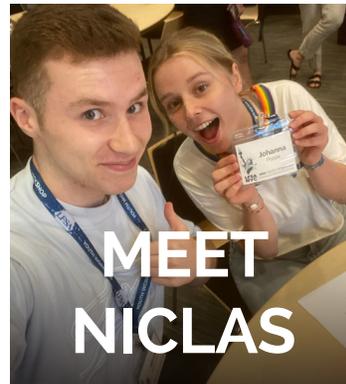
Yes, for sure. The biggest part is that before the event I didn't know any other person with the syndrome. Connecting with and talking to other affected people has helped a lot. The lectures took away some of my fears. At some points, it was really emotional. But that was actually good because it felt somehow empowering. And I have met such wonderful people.



What would you like to say to other youths with the syndrome?

That's a good question. I would say, try to find a balance between minimizing your cancer risk and enjoying your life (which is not easy). Be good to yourself. Get tested regularly and get help for your mental health, if necessary. It's totally understandable to have more fears and worry more than others. And last but not least:

connect with others if possible! Talking helps so much. Either through LFSA activities or online. You are strong.



My name is Niclas Schweiger. I'm 18 years old and I live Oldenburg, Germany. I was born near Munich and lived there the first four years of my life.

I have one sister named Elena and used to have another called Alina. Alina also had LFS and sadly passed away due to cancer this year.

I'm currently living on my own in an apartment for the first time and my favorite hobby is going to the gym.

How do you see yourself in 5 years?

In 5 years, I hope to be in good physical and mental condition and healthy. The most important thing for me is to spend time with my family and friends.



What's your biggest dream?

My biggest dream is to have a successful business and a loving family. I just want to enjoy my life and also travel a lot. The LFS diagnosis didn't really affect the way I envision my dreams, since I know that I am relatively safe due to all the checks I'm doing. The workshop was awesome and I had a really good

time. The people there were so nice. I definitely made a lot of friends there and I'd like to thank the LFSA for that. It was really good to meet other LFS patients, because they can just instantly relate to your situation.

What would you like to say to other youths with the syndrome?

I'd just like to say that you should never give up and follow your dreams.

When life feels
overwhelming, just
remember that
you're not alone.

We hope you've enjoyed this newsletter!