

LFSA YOUTH NEWSLETTER

SUMMER 2022

Happy Summer to Those in the Northern Hemisphere!

Summer brings with it both a desire and opportunity for a slower pace of life, but also a greater freedom to take part in activities that may not be possible during the rest of the year. Whether you are planning to travel or stay close to home, try something or new or improve in something familiar, remember to take time to rest. Rest for your body, for your mind, for your daily activities. Being busy is not necessarily the same as being productive, and rest is an important part of a productive lifestyle. I would argue that rest enables you to accomplish more - to go a farther distance without burning out. When you think about it, this means that rest can be just as productive as the activity itself!

A great way to integrate rest into your life is through art! Our friends from the Hirsch Wellness Network taught us the basics of Zentangle, an easy, relaxing art method that allows you to create beautiful images using basic elements such as lines, dots, and curves to draw patterns. The result is a calm mind and a paper full of unique patterns that you can proudly display! If you weren't able to participate live with us in May, feel free to follow along with the recording posted to the [Youth Program page](#). Fill out the form with your shipping address and we will send you your own art kit to use and enjoy.

Have a great summer, and enjoy the newsletter!

Cameron Block,
USA Youth Program Chapter Chair, LFSA
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Meet Yasmin Shaaban, LFSA - Latin America Chapter Co-Chair!



Tell us about yourself!

Hi! As you may have read, my name is Yasmin, and I'm a 29-year-old Brazilian woman. I graduated with a degree in architecture and urban planning in Brazil in 2015, worked as an English teacher and freelance architect for 3 years (however, national economic crises that affect the construction field are not fun when you're a newly graduated architect, ha ha ha).

Later, I decided I wanted to try pursuing an academic profession to become a researcher. In 2019, I came to Japan to start my Master's degree at Yokohama National University with a scholarship from the Japanese government, which I graduated from last year. I'm currently in my first year as a Ph.D. student at the same university.

I'm a very passionate person and I like doing and experimenting with many things. So many things, in fact, that it's actually hard to keep track of them all! Most recently, my favorite activities include learning yoga, reading, relaxing in open-air hot springs, exploring/taking pictures of Japanese cities and nature, having fun with my family and friends, petting cats, and watching animations, series, and movies! But as I said, I have many hobbies that are not part of my routine at the moment, and I have even more interests that I'd like to explore one day in the future.

One of my unusual hobbies, if we could call it that, is reading and researching medical information. Biology is something that my brother and I learned to love with my mother, who happens to be retired from biomedicine and is very passionate about her former field of work. This awkward "hobby" turned out to be extremely useful for all three of us, since my mother and brother were both diagnosed with LFS. After their diagnoses, we decided to get in touch with other family members from my mother's side, and although not everyone was willing to get tested, some who did were also found to be positive for the same mutation.

Can you tell us a little bit about the work you do for LFSA – Latin America?

I work as someone who can provide support for both patients with LFS and their family members. When first receiving their diagnosis, people often face a huge emotional turbulence, feeling as if their world was suddenly turned upside down and then crumbled. Many new patients fear for their children, for their siblings and parents, and of course, for themselves. The initial diagnosis can be scary, and there can even be a grieving process, along with phases of anger, denial, bargaining, etc., as if the life they once knew was over, forever. When feelings and thoughts seem like complete madness, it can be difficult to know what to do next. That's where I help them. I guide them by talking to them a lot, sharing my family and my friends' LFS experiences, and sharing, literally, all the best information I can get my hands on that can be useful to them (while doing my best for it not to be too overwhelming or too technical).

Dr. Maria Isabel Achatz and the LFS Association are my primary sources of great information to support the new patients and their families in their journey of LFS by connecting them to what and who they need. Finding the right specialists, hospitals, and medical facilities for testing that are the closest, and financially most accessible to them, are some of the first things I do after the initial chaos of the diagnosis has calmed down. I manage a Facebook group for Brazilian LFS patients and their families so they can ask questions, find some answers, and support each other. It's useful for them to have a collective access to quality information and to know about research fundraising events, educational/LFS awareness events, and also to organize their own LFS family meetings. In fact, some older patients created a WhatsApp group in which they can talk continuously about their doubts and share information of their health situations to their new friends who share the same difficulties.

What is the most common thing you hear from LFS patients in Brazil when you meet them?

Many times, they ask me how I am related to the syndrome or if I have it, too. After that, they usually open up about feeling very anxious with the diagnosis and have many questions about their options and how to best regain control of their lives.

What is your favorite part about where you live?

My favorite thing about Yokohama is that there are so many new things to explore! Japanese cities can be very different from western ones, and they exist in harmony with nature, which is both beautiful and amazing. Yokohama is also quite an international city, so I get to know people from many different nationalities with a wide variety of backgrounds.

Have you noticed any differences between how people view a genetic condition like LFS in Japan and Brazil?

The only person I've known who had LFS in Japan was a 3-year-old Japanese Canadian boy (his father is Canadian, and mother is Japanese). He had great energy and would never let the genetic condition and its challenges bring him down. He loved to dance, sing, and shuffle, just like other Brazilian children with LFS that I know of, and he always had a very positive attitude. But I've never met any adult Japanese LFS patients, so I don't have enough knowledge about their side to make a better comparison.

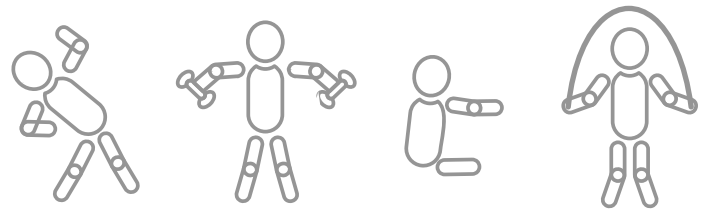
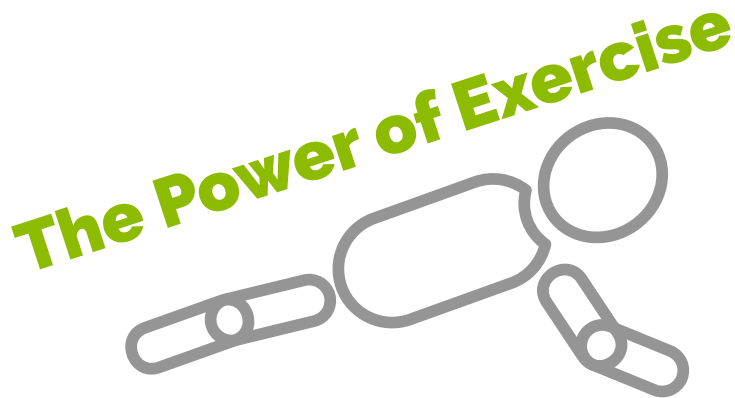
What was it like to have the LFSA come down to Brazil and develop relationships, internationally?

It was honestly one of the most rewarding experiences I've ever had. Both times when Jenn and Holly came to the Brazilian LFS meetings, the LFS patients and their families were ecstatic! Their eyes would glow, they would be very eager to tell the association's president and vice-president about their experiences with the syndrome, with cancer, and with life while having the mutation

in Brazil. They felt truly heard and so relieved that they were not alone. I remember some of them telling me how they felt reassured that there were people who had never even met them, lived in a different country, and spoke a different language, and yet were still fighting for them. Fighting for their rights, for their health, for the awareness of their condition, and sponsoring research that could save their lives and many other lives in the future. I felt so honored to be a part of that.

What is one thing you would like to learn to do if time and money were no obstacle?

I'd like to learn how to speak as many languages as possible, fluently. Firstly, because I really enjoy learning languages and was always fairly good at it, and secondly, because if the few languages I speak now have opened so many doors, connected me to so many people, made me learn so many new things, and helped so many patients, imagine what could be done if I knew even more?! Besides, I also love to travel and talk to local people. Seems like the best investment ever!



in the Fight Against Cancer

Many of us have heard exercise is good for your body and for your mind. It improves mental health, energy levels, sleep quality, and supports how you move throughout the day. But did you know that some studies have shown exercise to be beneficial for cancer prevention?

According to the National Cancer Institute ⁽¹⁾, people who are regularly active have lower rates of certain types of cancer than those who aren't. Some of the ways that exercise works to prevent cancer are by:

- Reducing inflammation
- Improving immune system function (our immune system helps our bodies fight cancer, not just viruses and infections!)
- Helping to prevent obesity, a risk factor for many cancers
- Causing food to travel through the digestive system quickly, which reduces the amount of time any possible carcinogens (cancer-causing substances) come into contact with GI tract
- Preventing high levels of insulin (a hormone that controls blood sugar levels in the body)
- Lowering the levels of sex hormones, such as estrogen

Research is now emerging with the news that exercise has the potential to affect breast cancer cells in the body. Cancer patients at Dana Farber and Yale University followed a supervised aerobic and strength-training exercise program before surgery to remove their

tumors. When scientists examined their tumor tissue after surgery, they found that the exercise program had led to changes in genes expressed by tumor cells (gene expression is a tightly regulated process that allows a cell to respond to its changing environment. In cancer cells, gene expression doesn't work the way it should.). This was the first time that exercise has shown to have a direct effect in breast cancers in patients. ⁽²⁾

It's simple to reap the cancer-fighting benefits of exercise in your daily life!

Try to aim for 30 minutes every day of any activity that you enjoy that also gets your heart rate up. It can be anything like sports, yoga, walking, swimming, or dance, and it doesn't have to cost you a thing. Try searching for different classes online; there are countless options to take advantage of without leaving your own home!

Be sure to consult with your doctor before starting any new exercise program.

1. <https://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/physical-activity-fact-sheet>
2. <https://blog.dana-farber.org/insight/2017/01/cancer-prehabilitation-benefit-cancer-patients/>



Meet Dilshaad Ahmed, Student and LFS Patient from India!



Tell us about yourself!

Hi, I am Dilshaad Ahmed. I'm 19 years old and am in my first year of my bachelor's degree studies. I am planning to start a computer operations course in July.

Where do you live?

I live in Gorakhpur, which is a town in the state of Uttar Pradesh in India.

What are you most passionate about?

In my free time, I love writing and like to express my emotions in my journal.

Do you have any specific plans or aspirations for the future?

I want to become a computer professional and develop computer software in the future.

What is one way your LFS diagnosis has impacted you in a good way?

I was diagnosed with LFS in 2018. My mother, elder brother, and elder sister have passed away due to Li-Fraumeni syndrome, and I am now living with my other brother and sister. I receive regular LFS screening under Dr. Sameer Rastogi at All India Institute of Medical Science.

This LFS diagnosis and losing my mother, brother, and sister have brought me closer to my younger brother and younger sister, and I have become more attached to them. I have started valuing my relationships more, and I take my health seriously and understand the importance of going for screening on a regular basis.

Do you have any advice that you would like to give to other young adults living with LFS?

I would say that if anyone in your family has LFS, get yourself screened. Go for check-ups and meet with your doctor regularly, and encourage everyone in your family to get themselves screened, as early diagnosis can help in deciding future treatment. One must not ignore health and take it very seriously.

*Many thanks to **The Sachin Sarcoma Society** for facilitating this interview with Dilshaad! The Sachin Sarcoma Society provides support and guidance to Li-Fraumeni syndrome patients in India, working with Dr. Sameer Rastogi at All India Institute of Medical Sciences to help care for these patients. Visit the **LFSA - India Chapter** page for more information on our work in India.*