

LFSA YOUTH NEWSLETTER

SPRING 2021



INTERNATIONAL LI-FRAUMENI SYNDROME AWARENESS MONTH

May 3  p53

Happy May!

This month is a special one in the hearts of everyone at the LFSA; it is LFS Awareness Month, and International LFS Awareness Day is May 3 (as in 5/3 - for TP53). With the help and support of the National Cancer Institute, we are working tirelessly to make Li-Fraumeni syndrome widely known. Why? It is awareness that improves the care of LFS patients, for when their doctors are familiar with this condition, it can often affect treatment plans and health management to the benefit of the LFS carrier. It is awareness that will lead many who simply think they or their families are "cursed" with cancer to realize that there may be an answer in their genes, leading to testing, surveillance, and to, ideally, a greater quality and quantity of life. It is awareness that drives research, for when more patients are identified, the more researchers and doctors are motivated

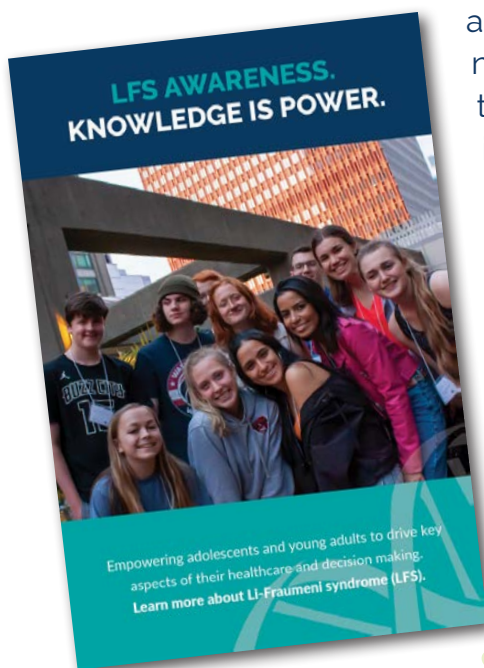
and the quest for a cure is supported. Doctors and researchers are now finding that Li-Fraumeni syndrome is not as rare as was once thought, and spreading awareness will only help with identifying more individuals and families.

To learn more about LFS Awareness Month and for helpful resources to share with others (and to see our new young adult awareness brochure!), visit: <https://www.lfsassociation.org/lfs-awareness-day/>

Know that the future is bright, no matter the present circumstances!

Cameron Block

USA Youth Program Chapter Chair, LFSA



Meet Lamia Alsubaie, Genetic Counselor and LFSA Chapter Chair in Saudia Arabia!



Lamia Fahad Alsubaie is a genetic counselor and blogger specializing in genetic medicine. She is senior genetic counselor at King Abdulaziz Medical City - National Guard Health Affairs, and she launched the first specialized cancer genetic counseling clinic in Saudi Arabia. Lamia is a part-time research genetic counselor at King Fahad Medical City and a part-time instructor at the genetic counseling Master's program at Al-Faisal University. She serves as the chapter chair for the LFSA - Saudi Arabia.

It was Lamia's ingenious idea back in 2018 to designate May 3 as LFS awareness day, representing the TP53, 05/03, as in the 5th month the 3rd day! Thank you, Lamia, for adding such a clever and significant designation to LFS Awareness, worldwide!!

Tell us about yourself!

Born and raised in Saudi Arabia, I completed my undergraduate studies at King Saud University and then moved across the globe to NYC pursuing my dreams. In 2015, I came back with a degree in Genetic Counseling from Sarah Lawrence College and have since been passionately providing genetic counseling services at King Abdulaziz Medical City. As a people person, I enjoy learning about different cultures and worldviews while making others comfortable in my presence, which I find especially helpful when meeting new patients in my clinic. Aside from the pandemic, 2020 was a year of change for me: I started my Ph.D. in Medical Genetics, and got married to an amazing man on New Year's Eve.

Why did you choose the field of genetic counseling as your profession?

I first heard about genetic counseling from my supervisor back when I was a research student in the genomics lab. He was impressed by my love for genetics and by my openness and communication skills, and thus encouraged me to consider genetic counseling. As I started navigating the profession, it seemed like a great fit for me as it balances between science and patient care. I knew this career would be a great way for me to share my enthusiasm for genetics by translating complex information to patients and helping them understand and adapt to their diagnoses. Besides, the multiple professional pathways available for genetic counselors were very appealing to me as an ambitious, lifelong learner.

In what ways would you say caring for patients with genetic predispositions in Saudi differs from the US?

A handful of social norms in Saudi, such as consanguinity, affect predisposition to genetic diseases and thus the way we counsel our patients. Saudis tend to have strong family ties and we often find ourselves in the clinic dealing with intersected, numerous family members, making it difficult to determine the primary patient and our primary obligation. It can also be challenging to collect medical information from previous generations in the family due to a lack of access to hospitals in the past. Also, some diagnoses, including cancer and mental illnesses, can be stigmatizing or perceived as taboo. This sometimes leads to unusual requests from legal guardians to withhold information for the sake of the emotional wellbeing of the carrier and/or affected member.

Out of the many ways that you contribute to the cancer genetics field, can you pick one thing you do that excites you the most?

Cancer genetic counselors translate genomic raw data and scientific information to improve screening, management, and treatment options for patients. It is fascinating to witness the progress of testing, interpretation, and surveillance/therapy in this fast-paced genomic era, and the most thrilling and rewarding part of it is seeing the positive impact on the patient's life.

What do you like to do on your days off?

I like spending quality time with my family and friends doing various activities. Traveling is something I enjoy too - I will always find an excuse to visit places and discover new sights in the area. I am also a bookworm with a habit of asking people I meet for book recommendations, which presents me the opportunity to explore new and different topics every time.

If not a genetic counselor, what would you be?!

As a kid, writing was how I expressed my creativity and ideas. My imaginary world inspired all my stories and I crafted my first piece in seventh grade. Had I not been a genetic counselor, I believe I would have become a writer.



Meet Pascal!

Tell us about yourself!

I live close to Hannover, Germany, next to the "Steinhuder Meer." We have a little old farm house and we breed miniature horses. We also have five dogs, two cats, four sheep, and two pigs. I like to water-ski and hang out with friends.

How has your LFS diagnosis impacted you for the better?

It has made me stronger and I live life as it comes. Worry less and live more.

What would you like to do or study in the future?

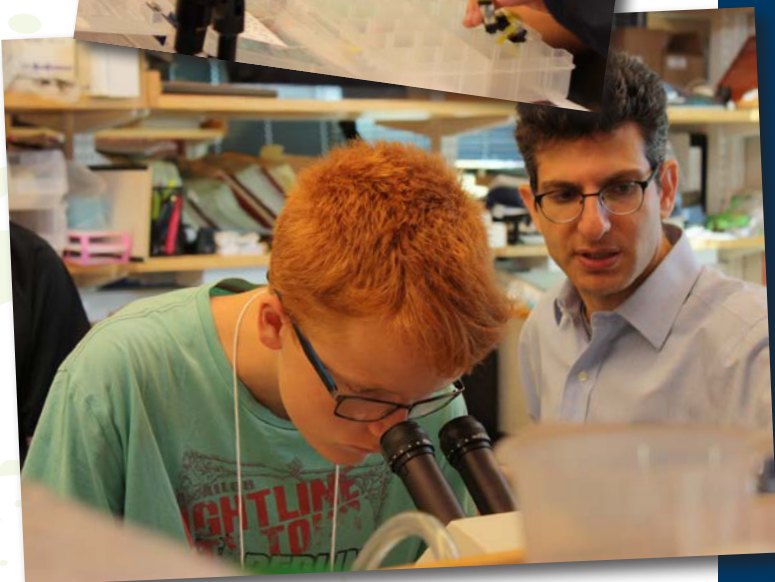
I finish school this summer and then I will start to learn to be a paramedic. First two years are mostly in school and after that I will have to choose. I can go to the German Army or to one of the organizations that does the paramedics and rescues.

What was your favorite part of the 2019 Youth Workshop in Boston?

I really enjoyed building the DNA, but everything was a really huge experience and I am thankful that I had the chance to travel to Boston and be a part of the workshop.

What is one piece of advice that you would give to other young adults with LFS?

Keep going and live your dreams, life is worth it.



Save the Date!

YOUTHCONNECT

LFS Association | Youth & Young Adult Program

Saturday, June 19th

We are so thrilled to announce a new event for our Youth Program members: LFSA Youth Connect! Youth Connect is a quarterly virtual event for our young adult participants to be able to learn from and engage with a medical expert in the LFS field and make new friends with other LFS youth.

For this first Youth Connect meeting, we will hear from Rowan Shepherd, a postdoctoral researcher at the Peter MacCallum Cancer Centre in Victoria, Australia, who has done research focusing on the psychosocial impacts of LFS and other genetic syndromes on young adults. The remainder of the meeting will be dedicated to an interactive social time for our youth participants. LFS can feel like an isolating diagnosis at times, and this is a wonderful chance to make some new friends or say "hi" to familiar faces, all in a relaxed, safe, and fun space - there are virtual games planned!

The date and time for this meeting is
Saturday, June 19th, at 3:00pm EDT

It is our hope that this event will make you smile and leave you feeling educated, supported, and connected. We hope to see you there!

To sign up or for any questions, please email Cameron Block:
cblock@lfsassociation.org