



LFSA

YOUTH NEWSLETTER

WINTER 2024



Hello Everyone!

At the recent International LFS Association Symposium, we were deeply reminded of the incredible power of community, especially among us young people. It's in moments like these — when we come together to share knowledge, ask questions, and offer unwavering support — that we see how much stronger we are collectively.

Seeing so many of us united by a common purpose was inspiring. Every story shared, every question asked, and every piece of information exchanged not only brought us closer but also equipped us with the tools to face the challenges that come our way.

Events like this one reinforce the importance of staying informed and connected. Knowledge is truly our greatest ally, and when paired with the support of a compassionate community, it becomes a force for resilience and hope. Together, we can approach each challenge with more confidence, courage, and optimism.

Let's keep building these connections, empowering each other, and proving that, united, we can achieve so much more than we ever could alone.



Isabel Costa

LFS Association Youth Program Coordinator

Barbara Almeida

LFS Association Youth Program Coordinator





We all know how difficult it is to receive a diagnosis, especially when it comes after the experience of one or more cancers, whether in ourselves or in a family member. We are familiar with the fear of the unknown, the anguish, the tension, and all the doubts about the future. And perhaps, because it's so hard to cope with so much information, especially at the beginning, many of us believe that the best strategy is to hide the problem and not talk about it. We leave the elephant in the room, staring at us, without realizing that the best way to face it — no matter how challenging it may be — is precisely through speaking.

In psychoanalysis, for example, there is the concept of the cathartic method, a therapeutic procedure through which an individual can process their feelings by revisiting the traumatic events through verbal expression.

It is through speech that we process our emotions, whether in formal therapy or in conversations with close people. That's why talking is not only important; it's the best solution. Through speaking, we understand that we are not alone, that our pain is not only ours. When we share, we are embraced. And as social beings, we need these exchanges to survive, regardless of age, gender, race, or religion.

Parents as Partners

It's natural that we want to spare those we love from all the bad things — our fears, insecurities, and difficulties.

As a society, we have the unfortunate habit of underestimating the capacity of children and adolescents to understand difficulty. So don't feel guilty: you're not the only parent who behaves this way. This is a widespread issue, present in various cultures and countries.

However, most of us carry some childhood memory where we sensed something our parents didn't directly tell us, whether because it was a difficult topic or considered "adult conversation."

Of course, we shouldn't approach a child the same way we would an adult, but that doesn't mean we should avoid introducing young people to the difficult subjects around us. The lack of dialogue, however, makes it harder for children and adolescents to express their fears and anxieties. On the other hand, they often deal with these topics with more ease than we, adults, do. It's worth reflecting that, in some cases, growing up with a diagnosis like Li-Fraumeni syndrome can, in a way, normalize something for them that we, adults, had to learn to cope with over the years (and that many of us are still processing).

Therefore, it's better to have the courage to expose these things to our children and allow them to express themselves and share their feelings, than to deprive them of knowing something that, we must not forget, is also their right to know.



Meet Dr. Junne Kamihara

We'd like to introduce Dr. Junne Kamihara, a pediatric oncologist in Boston and the director of the Pediatric Cancer Genetic Risk Program at Dana-Farber/Boston Children's Cancer and Blood Disorders Center.

To start, could you share a bit about yourself and how you discovered your interest in genetics and pediatric cancer? What inspires you most about working with young patients?

I am a pediatric oncologist in Boston, and the Director of the Pediatric Cancer Genetic Risk Program at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. The program is for children, adolescents, young adults and their families with known or suspected genetic risks of cancer. Our goal is to provide the best clinical care and to offer access to cutting edge research for families with cancer risk like Li-Fraumeni. I had the opportunity to start the program together with genetic counselor Jaclyn Schiendia and our colleagues in 2014. We realized at that time that we wanted to have a special place for young people with cancer risk to have care, support, and access to research all in one place.

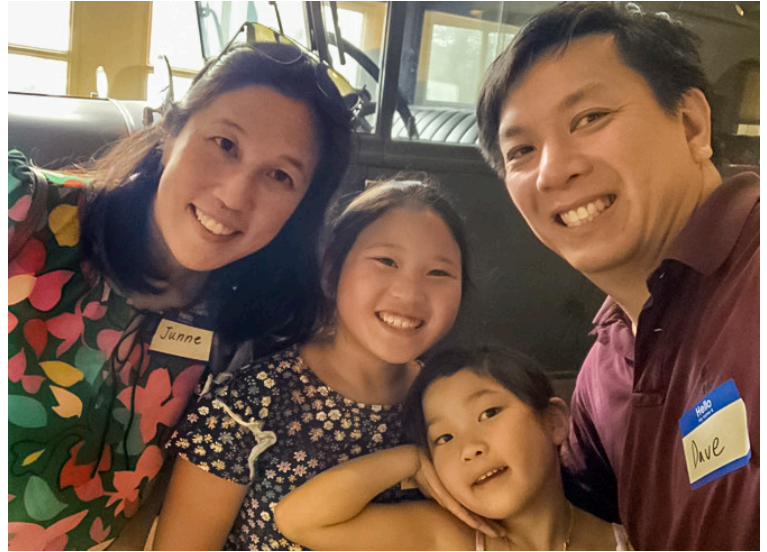
I developed an interest in genetics during graduate school, when I worked with Dr. David Housman studying Huntington's disease. I had the opportunity to go to a region of Venezuela where several large families with Huntington's disease live, which brought the impact of genetics really home for me. My interests in oncology started at a younger age when my favorite aunt was diagnosed with ovarian cancer and since that time I have lost many people close to me due to cancer. As a doctor in oncology, I feel honored to be trusted and invited into the lives of families during very stressful times, which motivates me to dedicate my efforts to both clinical work and research aimed at fighting cancer.

I am privileged to work at the intersection of genetics and pediatric oncology, and I love working with young people. It is such an honor and joy to get to walk with them on their journeys and I am constantly inspired by their courage, their energy and their willingness to be open with me and welcome me as part of their team. It is truly a gift.

For young people with Li-Fraumeni, knowing they have a rare condition can be challenging. What do you think they can do to balance health and everyday life in a positive way?

I am continually amazed with the young people I work with, who instead of being discouraged by LFS, find ways to thrive. They face challenges with the outlook that "knowledge is power", finding ways to be proactive and positive when possible.

At the same time, I always tell young people that it is important to be kind to yourself, and to acknowledge that it



Outside of work I enjoy spending time with my 4 children (2 pictured here, together with my husband who is also an oncologist!). We love to go to the beach, cook together, and sing and dance in the kitchen!

is not always an easy road. It is wonderful to be able to lean on the support of the people who surround you and who care about you. Your care team, other youth, your friends and family are with you on this journey... You are not alone!

In your experience, do young people and adults react differently to a genetic diagnosis? How do you see young people approaching this issue?

I love working with young people because they are so honest, so quick to embrace others, and so enthusiastic for the future. Those are gifts that they bring not only to the teams in the clinic or hospital, but also to other people in similar situations.

Do you think there are any myths or misconceptions about Li-Fraumeni? What message would you like to share to help clarify or dispel these?

It is important to know that we are learning that all LFS is not the same, and can look very different from one family to the next, even from one person to the next in the same family. There is still so much that we need to learn about why this is the case to help support families in the best way that we can.

One misconception I have heard is that we should not be doing genetic testing or talking about LFS with young people because "there is nothing we can do about it".

There is so much we can do that includes partnering with individuals with LFS and their families to be proactive about early detection and treatment, to offer support and community, and to engage in research that will continue to inform treatments moving forward.

Are there any new studies or breakthroughs in Li-Fraumeni research that make you feel excited or optimistic?

This is an exciting time for LFS research. Technologies have moved forward in a rapid way and are allowing us to think out of the box to better understand LFS. This promises to lead us down new avenues for treatment and prevention options. For example, we are working as part of a collaboration with multiple institutions to think about parts of the genome that we used to think of only as "junk" DNA called repetitive elements. It turns out that these areas are controlled by p53 and can stimulate our immune system, which may help us to understand how to mobilize the body's own immune system to fight cancers in LFS. At the same time, we are also making strides in thinking about how to work closely with youth and families to help empower individuals with LFS. Some of you may have been a part of the project led by Dr. Jenny Mack in a collaboration we had with LFS youth to develop an educational/communication tool for young people with cancer risk called AYA-RISE. This tool allows adolescents and young adults to learn about their risks and recommended screening, to support them through their journeys.

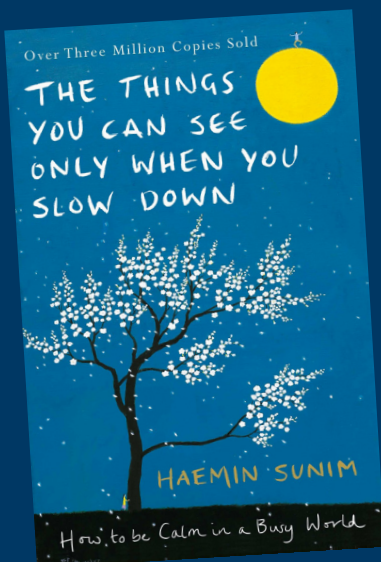
I am excited that we are no longer talking only about early detection and finding tumors early, but that we are really starting to talk seriously about early cancer interception and even cancer prevention. None of us can do this alone, yet by working together I look forward to the day when we can prevent cancer from even happening!



FUN FACT

Have you heard of somatic mosaicism? Our golden retriever named Yuki (which means happiness in Japanese) has a black ear due to somatic mosaicism.

Book Recommendation



"The Things You Can See Only When You Slow Down" by Haemin Sunim is an interesting, calming, and wise book that teaches us to embrace mindfulness and find peace amidst life's challenges. For young people dealing with the stress of Li-Fraumeni syndrome, this book is especially helpful.

By discussing topics such as self-care, relationships, and resilience, the author offers tools for managing anxious thoughts that can easily spiral out of control. Sunim's wisdom reminds us that, although Li-Fraumeni syndrome often makes us wait for the next challenge, there is power in living in the present, finding joy in the small things, and moving at our own pace.

With short, reflective passages, Sunim encourages us to pause, breathe, and regain perspective, showing that slowing down can ease anxiety and strengthen our resilience. This book serves as a comforting reminder that even when everything feels overwhelming, we can find calm and clarity by appreciating each small moment. If you're looking to reconnect with yourself and escape the noise of life, "The Things You Can See Only When You Slow Down" is a truly worthwhile read.