



LFSA YOUTH NEWSLETTER

LFSA KICKS OFF FIRST YOUTH NEWSLETTER

As part of the LFSA's expansion and growth, we're excited to launch our first LFS Youth Newsletter.

This newsletter is specifically designed to help young people with LFS live their lives to the fullest and stay connected with one another. We've created this newsletter in the hopes that you will find the content valuable and that it will aid you in your own goals to grow and thrive. Issues will include interviews with your LFS youth peers, as well as, information from medical experts on topics like health, fitness, nutrition, and genetics. We also plan to keep you updated on the latest LFS events and news. That said, we want this newsletter to be valuable for you so please, please share your feedback and

suggestions for topics you'd like us to cover in future issues. It is our goal to make this newsletter for LFS Youth and by LFS Youth so we're also looking for people interesting in writing articles, conducting interviews, and more. Email jperry@lfsassociation.org to let us know what you're interested in or if you'd like to participate in creating our next issue!

Thanks for reading and stay tuned for our next issue in June 2018!

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WHAT DO KATY PERRY, ELLEN DEGENERES, AND KOBE BRYANT ALL HAVE IN COMMON?

They are all famous people who meditate!

"It puts me in the best mood. I wake up and just prop myself up in bed for 20 minutes...It's changed my life, it's changed how I think about things. I meditate before I write a song, before I perform. I feel my brain open up and I feel my most sharp."
– Katy Perry

"It feels good. Kinda like when you have to shut your computer down, just sometimes when it goes crazy, you just shut it down and when you turn it on, it's okay again. That's what meditation is to me." – Ellen DeGeneres

"I meditate every day. I do it in the mornings for about 10 to 15 minutes. I think it's important because it sets me up for the rest of the day...Meditation can help you go with the flow. Let your thoughts pass like ships in the night" – Kobe Bryant

Katy Perry, Ellen DeGeneres, and Kobe Bryant are not the only successful people who meditate, other well-known meditators include Oprah Winfrey, Kendrick Lamar, and Angelina Jolie. So, what is it about meditation that has all these famous people doing it?

What the Science Says About the Effectiveness of Meditation?

The National Center for Complementary and Integrative Health describes meditation as, "A mind and body practice that has a long history of use for increasing calmness and physical relaxation, improving psychological balance, coping with illness, and enhancing overall health and well-being." Many studies have investigated meditation for different conditions, and some research suggests that meditation may reduce stress, ease symptoms of anxiety and depression, and help people with insomnia. Some types of meditation may particularly increase positive feelings and actions toward yourself and others! Numerous studies show that meditation improves academic performance, at every school level. Studies show that with regular practice (at least once or twice a day), students will see improvements ranging from health and well-being to academic performance, for example one report showed 41% of students allocated to the meditation group benefitted from improvement in both Math and English scores!

With all the benefits, it's no surprise that so many successful people have great things to say about meditation. But, meditation isn't just for celebrities and athletes, meditation has benefits for everyone!

What is Meditation?

There are many different types of meditation practiced, so if you try one style and it doesn't feel right for you, there are many others out there! Most meditation styles have four elements in common: a quiet location with as few distractions as possible; a specific, comfortable posture (sitting, lying down, walking, or in other positions); a focus of attention (a specially chosen word or set of words, an object, or the sensations of the breath); and an open attitude (letting distractions come and go naturally without judging them). Examples of different meditation styles include Mindfulness Meditation, Insight Meditation, and Transcendental Meditation (TM). There are tons of websites, apps, and books to help you learn about meditation and how to meditate. We invite you to begin your meditation journey by exploring the different type of meditation styles and trying out one that seems right for you! Write in to let us know how it goes! If you have any questions or concerns about trying meditation, please reach out to a parent, physician, or another trusted adult for guidance.

How Do I Meditate?

One meditation method, mindfulness meditation, involves sitting on a chair, the floor, or a cushion, closing your eyes, and bringing your attention to the sensations of breathing. Notice what it feels like when the air enters your nostrils on your inhale, or how your abdomen expands and retracts when breathing in and out. In this meditation practice, you do not try to control your breathing, but attempt to be aware of your natural breathing process and rhythm. When you're doing this practice, your mind will often wander. Everyone's mind wanders, A LOT, so don't be discouraged! When this happens, just take note that your mind has wandered in an accepting, non-judgmental way, then return to focusing on breathing.

EVENTS

LFS Youth Fundraiser

Oct 20-21, 2018 | Chicopee, MA

Join us at a gymnastics invitational to raise funds for our upcoming LFS Youth Workshop!

Salute! Hartford 2018

Oct 27, 2018 | Hartford, CT

LFS presents the 4th annual Salute! Benefit dedicated to supporting the critical research required to raise awareness, provide support, and improve the health of LFS patients.

LFS Youth Workshop 2019

Aug 23- 25, 2019 | Boston, MA

We are thrilled to announce that the LFS will be holding our 2nd Youth Workshop at Dana-Farber Cancer Institute.

Have an LFS Event you would like to promote?

Send an email with the event details to jperry@lfsassociation.org.

<< References:

"12 Science-Based Benefits of Meditation." Healthline, Healthline Media, www.healthline.com/nutrition/12-benefits-of-meditation.

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"10 Benefits of Meditation for Students - Research Overview." Transcendental Meditation: LATEST NEWS & OPINIONS, 8 Oct. 2015, tmhome.com/benefits/10-benefits-of-meditation-for-students/.



A GENETIC COUNSELOR'S PERSPECTIVE

An Interview with Katherine A. Schneider, M.P.H., L.G.C., Co-Chair the LFS Genetic Counseling Advisory Group

Why did you choose genetic counseling as your profession?

I have a sister with Down syndrome and went to college to become a special education teacher. I needed one more science class in my senior year and took Genetics – and just fell in love with it. Then I found out about the career of genetic counseling, got my Master's degree, and never looked back!

What is your favorite part of your job?

My favorite part of the job is being able to work with so many amazing patients and families. Being able to help people before, during, and after the genetic testing process is very rewarding. I also enjoy lecturing and writing. In fact, I have written a textbook on Cancer Genetic Counseling which is now in its 3rd edition.

What advice would you give to someone considering your profession?

Genetic counseling is a wonderful career choice, with many different specialty areas. The National Society of Genetic Counselors (www.nsgc.org) has great information for people interested in learning more about genetic counseling. You can also contact a genetic counseling training program or talk to a practicing genetic counselor.

Where do you see cancer research/treatment in 5 -10 years?

This is such an exciting time to be working in cancer genetics. I think in 5-10 years there will be many more personalized strategies for the detection and treatment of cancer. And hopefully, by then, we will be talking more about strategies for the prevention of cancer, possibly including gene therapy (fixing damaged genes).

What is your favorite personal hobby or sport?

I have three sons so I do love watching all kinds of sports. However, every summer I combine two of my favorite hobbies by spending a week in Utah where I get to hike at one of the beautiful national parks and attend the awesome Utah Shakespeare Festival.

Q & A WITH A PEDIATRIC ONCOLOGIST

An Interview with Dr. Kratz, LFSA Germany Chapter Chair and Director of the Department of Pediatric Hematology and Oncology, Hannover Medical School



What are a few things that bring you satisfaction in your career?

1. Getting to know affected families and children and seeing that their condition improves and their fear disappears
2. Contributing to research activities and new observations that have impact for patients
3. Interacting with and contributing to the important work of support groups, such as LFSA

Why did you choose pediatric oncology as your profession?

I chose pediatric oncology because childhood cancer remains a leading natural cause of death in young individuals. The field is characterized by relentless efforts by many, which has resulted in improved outcomes for patients. I wanted to contribute to this important process. Also, I wanted to interact with affected children and their families to help them getting through difficult times.

How did you get involved with LFS?

As a young doctor, I was impressed by one of my professors who appeared like a walking library and was able to diagnose the rarest of conditions by simply examining the patient. During my postdoctoral fellowship at the University of California San Francisco with Prof. Dr. Kevin

Shannon, I learned more about the genetic basis of childhood cancer. Both individuals inspired me to focus my career on the causes of childhood cancer. Understanding the cause of a disease is the best way of effectively fighting a condition. I was very fortunate because I had the incredible opportunity of working at the National Cancer Institute (NCI) as an investigator in the Division of Cancer Epidemiology and Genetics lead by Dr. Joseph Fraumeni Jr. Upon my return to Germany, it was clear to me that I wanted to continue endeavors similar to those I had at the NCI. Together with my friend and colleague, Prof. Dr. Stefan Pfister from Heidelberg, we were able to secure a grant to develop a LFS/cancer prone syndrome registry.

Why did you become the chapter chair for LFSA Germany?

I was inspired by the work of Jenn Perry and Holly Fraumeni whom I met in person during the most successful LFS youth workshop in Utah. It is crucial for families, support groups, health professionals and scientists to work together to make progress for individuals with rare conditions such as LFS. In addition, support groups are important because physicians often do not have sufficient knowledge and time for affected families with rare disorders. Therefore, I wanted to help launch a LFS support group in Germany.

Where do you see yourself, cancer research/treatment in 5- 10 years?

Hopefully, the community will have made helpful progress for individuals with LFS, like better cancer prevention strategies, better and more risk-adjusted cancer surveillance, fewer people the diagnosis of LFS will be missed, and trials specifically for patients with cancer prone syndromes such as LFS.