

# LFSA YOUTH NEWSLETTER

FALL 2021

## The Season of Change

The seasons are changing again, and this year has hopefully looked a bit different than last year for your back-to-school, work, and travel plans! Whether you're headed to class or work in person, online, full time, or part time, it is my hope and strong suggestion that you make the most of your available time and particular circumstances and take an opportunity to learn something new outside of your daily routine - it's a nice change from the daily grind of studying and work, and you have the freedom to choose anything you'd like. Whether it's related to academics (say, a supplemental science course), an activity closer to home (like gardening or photography), or something unconventional or unexpected (such as a scuba diving certification or rock climbing), I believe that you can take at least one thing you've learned in any sort of activity and apply it to your everyday life. Try it; who knows where it could lead?

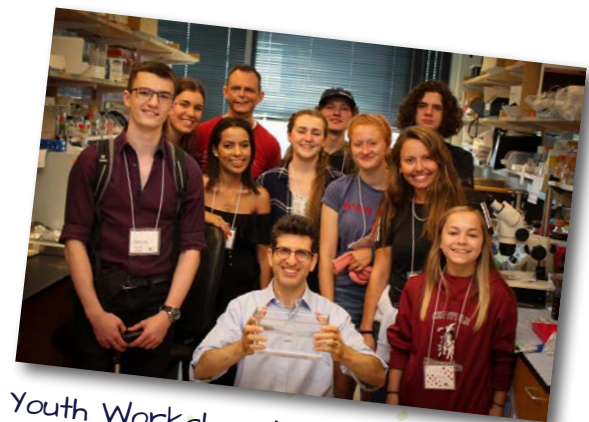
To help with this, we are providing an opportunity for you to learn more about the relationship between nutrition and LFS at our next Youth Connect meeting this September. This would be a great starting point for you to take something new that you've learned, apply it to your life, and see a positive impact; see page 4 for more information!

We hope you enjoy this edition of the Youth Newsletter. Keep reading to get to know NCI researcher, registered dietician, and our September Youth Connect speaker, Camella Rising, Ph.D., M.S., R.D.N., and our LFSA - Canada Youth Chair, Anna Joy Ryan. You will also find more information on upcoming events and a link to an inspiring interview featuring a doctor with a unique perspective on her patient care.

Stay healthy, and we hope to see you soon at one of the upcoming events!

**Cameron Block**

*USA Youth Program Chapter Chair, LFSA*



*Youth Workshop Aug. 2019 - Boston*

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## An Inspiring Read

Dr. Shekina Elmore is not only an oncologist, but an LFS patient, herself. In this interview by Orly Nadell Farber on *statnews.com*, Dr. Elmore speaks about how her diagnosis enables her to uniquely understand and care for her cancer patients, and how it has impacted her experience and outlook in medical school. Though becoming an oncologist is certainly not the only or "best" way to make the most of your diagnosis, Dr. Elmore's is a great example of how you can use LFS as a strength and an advantage in your life.

<https://www.statnews.com/2018/08/31/shekinah-elmore-cancer-doctor-patients/>

# Meet Camella Rising, Ph.D., M.S., R.D.N., NCI Researcher and Registered Dietician



## Can you tell us a little bit about the work you do at the NCI?

Sure! I'm a behavioral scientist in the Clinical Genetic Branch (CGB) at the NCI. My current work focuses on developing a better understanding of health behaviors and communication behaviors of individuals — especially adolescents and young adults (AYAs) — and families living with LFS. But I don't want to stop at merely understanding. I'd love to work in partnership with people living with LFS to discover how nutrition and communication about LFS (e.g., with your family, your healthcare providers) can help manage living with LFS, cancer, and life in general!

## How/would you say that your background in nutrition and dietetics plays a role in your research work today?

I now see how my career in nutrition and dietetics has come full circle. Although it was 20 years ago this year, I vividly recall my rotations in oncology and the pediatric bone marrow transplant unit during my dietetic internship at UC San Francisco Medical Center. I was touched by so many children and families and loved the opportunity to work directly with people to help them navigate challenges related to diet and nutrition. For many years after that internship and prior to beginning my fellowship at NCI, I worked in public health nutrition and studied population health; honestly, I never imagined I'd have another opportunity to work directly with people again. It has been a pleasure and a privilege to work directly with people again by talking with AYAs with LFS through our study at the NCI. Through those conversations, I'm realizing that the questions many of us have — what and how to eat for better health — are also questions that may be top of mind for individuals and families living with LFS. I'm looking forward to exploring that more through my research.

## Is there anything interesting that you have learned through your research in families with predisposition syndromes that you would like to share with our young adult readers?

There are so many interesting things! By talking with AYAs with LFS, our research team is learning about some of the ways AYAs take their mind off things and adjust to living with LFS, such as through enjoyed activities (e.g., hobbies, entertainment, time with

friends), physical activity, diet, and work. We're also learning that talking about LFS can be complicated, depending on who is on the receiving end of the conversation. We hear from many AYAs about how they advocate for themselves and educate others about LFS (e.g., in medical encounters). There is a certain wisdom that AYAs living with LFS have that is well beyond their years! In the near future, our research team plans to initiate a study that will involve partnering with AYAs with LFS to design intervention research. We hope that research designed in partnership will better meet the specific needs of AYAs.

## What has led you to do what you do today as a researcher?

Close to 10 years ago, when both of my children reached school age, I started exploring next steps for my nutrition and dietetics career. I learned about a doctoral program in health and risk communication at George Mason University near our home in Fairfax, Virginia and, after taking a class in digital health communication, knew that it was for me! What I hadn't expected was the number of cancers my family would face at the outset and throughout my doctoral program, each new diagnosis and recurrence rocking our world. I had a professor who suggested that, by focusing my research on family communication about cancer, I might feel empowered and help the scientific community and other health care providers better understand challenges individuals and families often face when it comes to communicating about cancer. My research fellowships at the NCI have provided a wonderful space for me to think about work on my research interests in both nutrition and communication behavior in families with cancer predisposition syndromes.

## What is one piece of nutrition-related advice that you would like to give to a young adult with LFS?

Ooo, just one? That's tough! My suggestion is to keep in mind that your whole diet matters. This is not the impression one may get on social media (unless you follow a Certified Specialist in Oncology Nutrition, for example, like @CancerDietitian or organizations such as @CookforYourLife). However you digest your news (dietitians love food puns), there are many misleading and confusing messages about "superfoods," single foods, single nutrients, and dietary supplements that can prevent, control, or cure cancer. Although certain foods and nutrients have been associated with reduced cancer risk in large population studies, the takeaway is that eating those foods in the context of an overall healthy diet matters. I look forward to talking to you more about nutrition in the context of LFS during the next Youth Connect meeting on September 18th! **Please tell me more about nutrition topics you'd like me to discuss by completing this 1-minute survey: [https://ncidccpssurveys.gov1.qualtrics.com/jfe/form/SV\\_3DEAXs7oxAeaiai](https://ncidccpssurveys.gov1.qualtrics.com/jfe/form/SV_3DEAXs7oxAeaiai)**

## What is one fun fact that not many people know about you?

My oldest son was born under a volcano, we say in our family. Many years ago, we had the pleasure of moving to Sicily for my husband's job and Mt. Etna felt like it was practically in our backyard (it erupted twice while we were living there). It was very special to learn about the food, culture, and warm people of Sicily!





## Meet Anna Joy Ryan, LFSA - Canada Youth Chair!

### Tell us about yourself!

I live in the suburbs of Vancouver, in the province of British Columbia (BC), Canada. Over the past three years, I have been working towards completing a bachelor's degree in Health Sciences. And although I'm not absolutely sure of what to pursue after I graduate, I am fully confident in my desire for a career in healthcare. In my spare time I enjoy going out with family and friends, running and hiking in BC's beautiful forests, and watching a binge-worthy TV show.

### Can you tell us a little bit about your involvement with the LFSA?

My family was first introduced to the LFSA in 2013, when my parents attended the organization's 2013 symposium in Boston. It wasn't until 2017, however, when there was news of an LFSA Youth Workshop in Utah, that I began my own personal involvement with the organization. For the first time I was able to connect with other people my age who understood the challenges of LFS, and I established long-lasting relationships with many of the teens and families who attended the workshop. Over the past few years I have attended more workshops and symposiums, and have served as the Youth Chair for the Canada Chapter. I collaborate with Youth Chairs from other international chapters to organize fun, educational, and meaningful experiences for the youth and young adults in the LFSA Youth Program.

### What keeps you motivated every day?

This is a big question! There are many things in life that motivate me to keep moving forward. One of my most meaningful sources of motivation is the relationships I've cultivated over the years with many people who have done amazing things, who inspire me to do the same. Medical professionals who save lives, children who boldly go after their big dreams, friends who study

hard to obtain their dream job, parents and grandparents who pour their lives into supporting their families, and acquaintances who see the silver lining in difficult situations. It is these people in my life whose stories motivate me every day.

### What is one piece of advice that you would like to give to another young adult with LFS?

LFS and cancer can significantly complicate a teen's or young adult's plan for their future. While it is important to carefully plan for the future, especially when there is the possibility of a cancer diagnosis (or a current diagnosis), it is equally as important to recognize and enjoy what you can do and achieve in the present. Plan for "smaller" goals or activities that you can do now, and work through the bigger picture of your future one step at time. For example, while I am planning and working towards "bigger" goals (such as professional employment), I also make time to go on walks with friends, spend time with my family, and enjoy other daily enriching activities.

### What is one fun fact that not many people know about you?

Well, several years ago my family owned a sailboat, and we would sail a lot during the spring and summer months. Vancouver has a beautiful coast line with lots of little islands that we could sail to, or we could spend all day on the water. There were many wonderful memories on our little boat that I will always remember as some of the best moments with my family.

# Save the Date!

## YOUTH NNECT

LFS Association | Youth & Young Adult Program

### Saturday, September 18



Join us for a fun discussion with Camella Rising, Ph.D., M.S., R.D.N., about nutrition and LFS. You will be able to chat with Camella and ask her any of your diet or nutrition-related questions, and if you stick around, you can take part in a “mix and mingle” with our Youth Chairs and youth participants afterwards. Please take a moment to click the link (or scan the QR code) to complete this short survey and let Camella know what you would be interested in hearing her talk about:



<https://bit.ly/3kSsFXr>

**We look forward to seeing you all there!**



After a successful virtual Youth Workshop last year, we are happy to announce that this year's 2021 Youth Workshop will be virtual, as well. Everyone will have an opportunity to join in on the action, no matter where in the world you live!

For updates on these events and for the official date of the Workshop, keep your eye out for announcements on our Facebook page: [facebook.com/lfsassociation/](https://facebook.com/lfsassociation/)