

LFSA YOUTH NEWSLETTER

WINTER 2022

Happy 2022!

Many of us have created resolutions, set intentions, and planned goals for the year ahead. Now that we're over one month into the New Year, how are those resolutions holding up? I have no doubt that many of you are still going strong. For those of you who haven't had the chance to think up a goal or change you'd like to make, have dropped your original plan, or would like to boost your current progress, could we make a suggestion? Incorporate small acts of creativity into every day. Check out our article on creativity to learn more about the research on how it can improve your life, and some practical ways to get started!

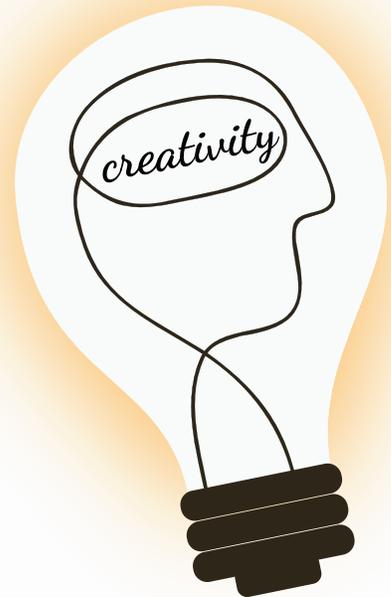
This year brings with it an exciting announcement: the LFSA now has a chapter in Africa! We are so pleased to have it headed by Samuel Omolo, a biotechnologist focusing on comparative oncology who studies the *TP53* gene within tumors in animals in the wild. How lucky we were to be able to interview him for this issue! I know you will enjoy learning more about him and his work as much as we did.

Lastly, we have featured an interview with the wonderful Chiky Fernandez, an LFS young adult whose joyful and proactive perspective are a great inspiration to all of us. It's another great reminder that your diagnosis is what you make it; when you keep your eyes fixed ahead and choose to keep taking just one step at a time no matter how tough it gets, you will get to the light at the end of the tunnel, and will even be able to carry some of that light with you in the dark.

We hope you enjoy. If there is any topic you'd like to see featured in the next newsletter or if you have any questions, please feel free to reach out.

Take care!

Cameron Block,
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Meet Samuel Omolo, Biotechnologist, LFSA Africa Chapter Chair



Where do you live?

I live in Nairobi, Kenya, and was born and brought up in Kisumu County, Muhoroni Sub-County.

How would you say the perception of and care for LFS in Africa differs from western countries such as the U.S.?

LFS diagnosis and research are at their infancy in Africa. We need to put a lot of energy into familial screening to identify these families. We also have plans for capacity building in order to have platforms and facilities that can handle LFS cases. This will lead to LFS ultimately being included in government policy adopted across Africa, which puts rare diseases in national programs.

Most people think genetic bottlenecks (*incidents of disease*) in Africa are due to witchcraft. This is *not* the case, and to the people of my continent, know that LFS is not witchcraft, but a genetic disorder.

Can you tell us a bit about your work?

My focus is on comparative oncology, looking at cancer in the wild at Kenya Wildlife Service (KWS), a collaborative research project between Arizona Cancer Evolution Center (ACE), University of Utah, and University of California Santa Barbara, where I focus on mutation rates in the *TP53* gene within tumors in the wild (CDC's One Health).

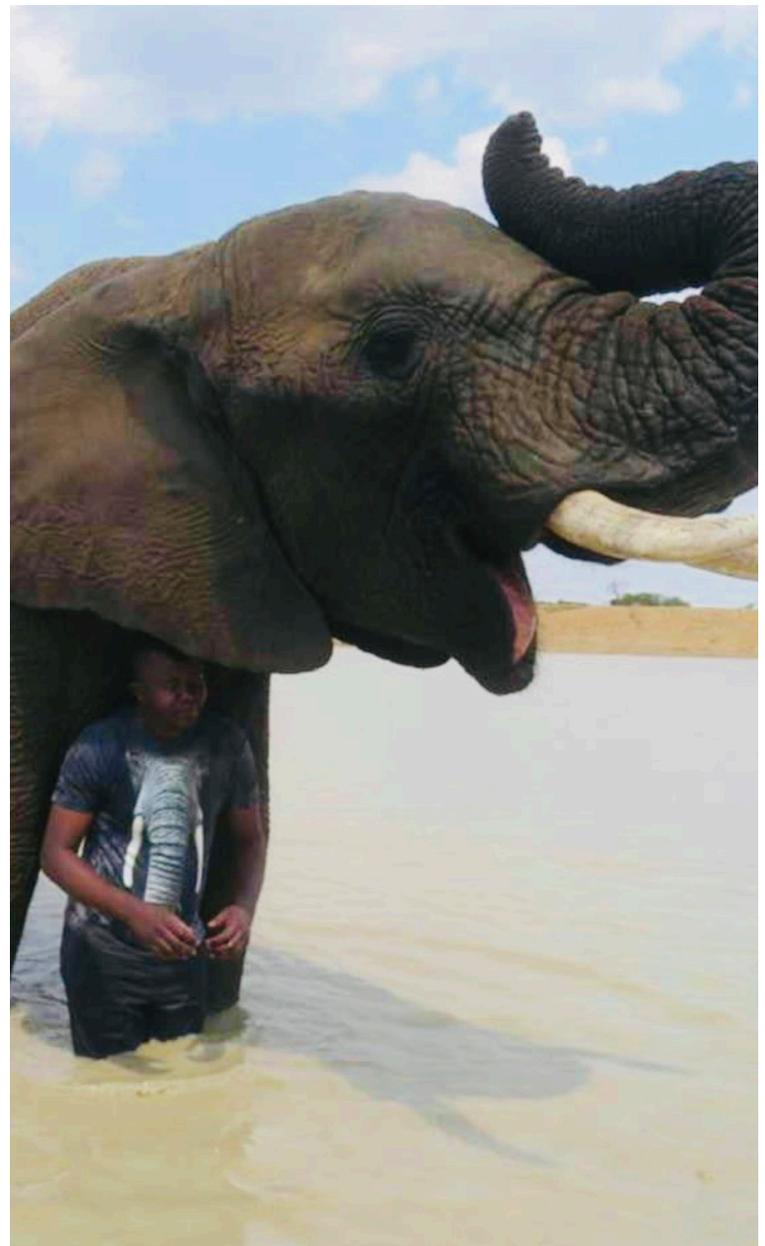
This global collaboration raised my interest in looking at the genomic landscape of *TP53* in LFS families, mapping the first LFS families in Africa, raising awareness for rare types of cancer, and ensuring Africa contributes part of this important global data through cutting edge genomic research. I am looking forward to greater collaboration, capacity building, and setting up strong diagnostic platforms and cancer treatments for LFS patients during my tenure as the chairman for LFSA – Africa.

What animal(s) do you find most interesting to study, and why?

Elephants are my favorite animal, as they have evolved over millions of years to fight off cancer. They have 20 copies of *TP53* and thus almost never get cancer, while human beings have only one copy. This evolutionary strategy may be able to cure cancer in the near future; that's why we need to conserve this wonderful species.

What do you enjoy doing in your free time?

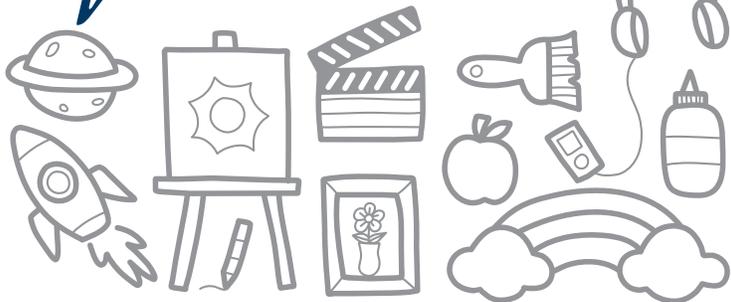
I enjoy game drives (*safaris*) and planting ornamental flowers and palm trees. Let's make the world green and make our homes forests. With flowers we keep bee health safe, which is important because bees are the main drivers of agriculture and our environment.





MORE THAN A HOBBY

the power
of creativity



Some of you may be familiar with this scene: You have finally convinced yourself to try to do something creative, and just finished putting the finishing touches on your project. You step back and take a gander at your masterpiece... and are disappointed with your, perhaps, less-than-brilliant results. So you label yourself as "not very artistic," and are off to find another activity. However, Jonah Lehrer, *Wall Street Journal* columnist and author of the book, *Imagine: How Creativity Works*, argues that science shows that creativity (which can simply be defined as the act of creating something) is a trait and talent that all humans share, are capable of, and can improve in [1]. You could say that we were all created with the ability to create! Creativity can include engaging in the classical arts, moviemaking, photography, and endless other activities. But, if you are still skeptical, would you be willing to give it a try if you knew that the simple act of creating (literally anything),

is incredibly beneficial and therapeutic for your mind and body, no matter your end result or skill level?

In the medical field, the benefits of art and creativity for patients are becoming more well-known. A study of the effects of art therapy on pediatric oncology patients found that the patients "were able to better express underlying emotions, developed more effective coping skills, and experienced a reduction in adverse side effects" during their treatments [2]. In fact, art therapy has been shown to possibly alter hormones and neurotransmitters in the brain, and even change the perception of pain [3]. Creativity during treatment for a health problem is a wonderful time-passer and distraction at least, and a powerful therapeutic at most!

Lung cancer physician, Dr. Lynne Eldridge, explains how art can even help with processing emotions: "It's said by some scientists that emotions are felt first in images and only later in words. For this reason, art can be a way to tap into what you are feeling inside before you can describe it in words" [3]. Whether you're stressed over school or are experiencing anything like joy, anger, sadness, or confusion over circumstances in life, creativity is a healthy way of expressing and processing those emotions without the pressure of having to put them into words. Additionally, the act of creating can be helpful in creating a sense of control during difficult times [4]. You are in charge of choosing the medium, the color, the sounds, the words, the scene, the movement, the individual pieces, and the order in which they all are arranged. This sense of control is something that you don't often have in life, and it may be something worth trying when waiting for results of any kind.

Creativity doesn't just benefit you during uniquely challenging and emotional times; it is a positive addition to everyday life. A study from the University of Otago in New Zealand on 650 young adults showed that participating in small acts of creativity every day can boost your well being. The participants who engaged in creative activities on one day experienced positive emotions like energy, enthusiasm, and excitement the next day. These results surprised researcher Tamlin Conner. "Research often yields complex, murky, or weak findings," she says. "But these patterns were strong and straightforward: Doing creative things today predicts improvements in well-being tomorrow. Full stop" [5].

It is not difficult to jump into a creative activity, and you don't need special equipment to get started. Try taking photos or filming short films with your phone, coloring in an adult coloring book (mandalas are popular choices), journaling, or planting a small, even indoor, garden. It doesn't need to be a large project, and, as shown by the study above, it doesn't need to take much time. Try just 15 minutes a day, and see how it positively impacts your day-to-day life!

Sources:

1. https://greatergood.berkeley.edu/article/item/how_creativity_works
2. <https://pubmed.ncbi.nlm.nih.gov/28888499/>
3. <https://www.verywellhealth.com/art-therapy-for-people-with-cancer-2248957>
4. <https://www.curetoday.com/view/art-as-therapy-after-a-cancer-diagnosis>
5. https://greatergood.berkeley.edu/article/item/doing_something_creative_can_boost_your_well_being



Meet Chiky Fernandez!



Where do you live?

I live in Miami, Florida.

How has your LFS diagnosis impacted you for the better?

My LFS diagnosis has impacted me in ways I could've never imaged. Overtime, after my diagnosis at age 8, I became a spokesperson and mentor for kids and parents who were going through the same thing. One time I got on a phone call when I was 14 to help guide and console a mother whose son had been diagnosed. She had no idea what lied ahead or where to place her ever-growing emotions. LFS has made me a person that is willing, ready, and confident enough to help a grieving family get through their hardships. I am forever grateful for LFS.

When the situation arises, how do you navigate talking with friends/other people about LFS?

Because I have been talking about it and informing people of LFS for so long, I'm not fearful when it comes to telling my close friends and family. When I tell someone, I just try to explain it to them the simplest way that I can, and usually they will have questions, so I answer those after. I welcome the questions because it's important that everyone knows about LFS.

If you had the chance to become internationally famous for any reason, what would you most want to be known for?

I would like to be a well-known songwriter, which I am pursuing now. My love for music actually started with my diagnosis of Rhabdomyosarcoma at age 3. *Three Little Birds* by Bob Marley was the song we would sing in the car on my way to my chemo treatments. Eventually, the valet guy who parked our car would carry me inside to the elevator and sing the song with me. That is the earliest memory I have of music, and *Three Little Birds* is still "my song."

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

I would tell them to stay on top of their monitoring and always have a spokesperson with you. I would not be here without my mom and her knowledge of absolutely everything. She is the one who suggested I get my prophylactic mastectomy earlier when I was 20, rather than later, because they had found a benign, not malignant, mass on one of my breasts. After getting back the pathology from my mastectomy, we learned that I had already had DCIS. The cancerous cells were already in my body, they just hadn't formed into tumor yet - and there is no telling when they would have. The most important thing is to be informed and ready to conquer anything. Had I not done my mastectomy when I did, it is very likely that I would have been diagnosed with something in the near future. I am grateful my mom was educated enough to follow her intuition and save my life.