# LUPUS FOUNDATION OF SOUTHERN ARIZONA

Serving Pima, Pinal, Santa Cruz, Cochise
and Graham counties.

*Winter 2021*

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# CALENDAR

April
17th

## VIRTUAL Walk-the-Loop-for-Lupus

There's still time to Sponsor the Walk, put together a team and sign up to walk. Go to **go.dojiggy.io/walktheloop** to sign up!

November
5

## Hit the Links for Lupus Golf Tournament

Join us at Omni Tucson National for the Hit the Links for Lupus Golf Tournament, November 5th, 2021. Go to **birdeasepro.com/hitthelinksforlupus** to sign up!

## Lupus Support Groups

**Online Coffee Talk Support Group: 1st Wednesday of Each Month, 6pm**

**Online Living with Lupus Support Group (alternating dates):**

**January 20th, 10am**
**February 11th, 6pm**
**March 17th, 10am**
**April 8th, 6pm**
**May 19th, 10am**
**June 10th, 6pm**
**July 21st, 10am**
**August 12th, 6pm**
**September 15th, 10am**
**October 14th, 6pm**
**November 17th, 10am**
**December 9th, 6pm**

**Online Men's Lupus Support Group: 4th Wednesday of Each Month, 6pm**

### OUR MISSION

**To provide support, education and partnership to those affected by Lupus, while promoting the development and enhancement of health and social welfare at the local level.**

**The Lupus Foundation of Southern Arizona exists for one reason only... and that is to provide all possible support to those dealing with the disease.**

**Please let us know if you have any questions about our listed support services or if you would like to suggest additional opportunities that the Foundation might explore in serving the local Lupus community.**

## BOARD OFFICERS

**Sharon Joseph, President**
**Shaunna Kowalewski, Vice President**
**Sherri Fritz, Treasurer**
**Shaima Namazifard, Secretary**

## BOARD MEMBERS

**Jacquelyn Shope**
**Joshua Taylor**

# LETTER FROM THE PRESIDENT

As I reviewed the fiscal calendar from October 1, 2019 to September 30, 2020, I noticed a few more health fairs to attend, support groups and the Golf Tournament on October 25, 2019 to finish off the calendar year. We kicked off our first restaurant fundraiser at Chipotle in early January and the Annual Walk was set for April 18, 2020, along with some additional fundraising events through the rest of the year.

Who would believe by early March, we would be living this very different reality? I hope all of you are staying safe. At LFSA, we wanted the support groups to continue meeting, so at the end of March, we began hosting groups on Zoom. Nothing beats meeting in-person. But at least Zoom allows us to stay connected and find support. Try Zooming with us!

We postponed and subsequently had to cancel the April 18, 2020 Walk. In its place was the first LFSA Virtual Walk on July 18, 2020. Thanks to our sponsors, team captains and their teams, individual walkers, raffle donors and board members, it was a great success! Now, we need your help to celebrate the 20th Anniversary of the LFSA Walk. SAVE THE DATE! for Virtual Walk #2 on April 17, 2021.

The October 2019 Golf Tournament fundraiser was the best ever! A big Thank You to our sponsors, golfers, volunteers and behind the scenes supporters. In this new fiscal year, we hosted a safe, socially distanced Golf Tournament on November 13, 2020. We raised funds, renewed old acquaintances and added new sponsors and golfers. Thank you to all who sponsored this event and played on one of the beautiful Omni Tucson Resort courses. We had a great time and hope to see you again later this year!

COVID 19 has had huge impact on the operations of non-profits. The Board of Directors made some important decisions this year, to preserve our mission to Lupus patients, their families and the Southern Arizona community.

With this issue, the annual LFSA Magazine will be mailed to Lupus patients on our mailing list. If you did not include your address on the Intake Form or it has changed, please call us. The Magazine is also available on the website.

Thank You to those of you who donate to the foundation every year. Through your generosity we make a small difference in the lives of patients and their families and raise awareness in the Southern Arizona community. Lupus changes lives. We are seeing more and more clinical trials produce promising treatment and greater awareness throughout the country and in the halls of Congress. There's hope.

Please take care of yourself and your families. For those who have lost loved ones, friends or co-workers to COVID-19 or any other illness, our thoughts are with you.

Sharon Joseph, President

# LFSA's Limited Scholarship: Selena Tang

**LFSA:** How did you first learn about the Lupus Foundation?

**Patient:** I first discovered the Lupus Foundation upon being diagnosed with lupus. My family and I were confused and panicked about this rare diagnosis and disease. My rheumatologist recommended the Lupus Foundation to guide us and give us resources and information. I called a few days later. We came into the office to see what you were about. Sharon gave me a patient journal and several books to help me better understand the disease.

**LFSA:** When were you diagnosed with lupus, and what have you done to manage your illness?

**Patient:** I was diagnosed in December of 2018 at age sixteen. I met with a rheumatologist, and that's when I began to manage my illness. I did what my doctor told me to do. I took prednisone, and hydroxychloroquine. I took a break from school because of my intense joint pain. I remained physically active, improved my diet, and took care of my mental health. Little adjustments, here and there, have made a difference. The way I lived my life back then is very different from the way I live my life now. Dropping out of school at sixteen was difficult, but I'm back in school and successfully managing my lupus.

**LFSA:** You met with a counselor at our office. What was that like?

**Patient:** Early in my diagnosis I was in shock and extremely fearful. I thought I wouldn't be able to graduate high school or go to college. Meeting with your counselor was very helpful. It wasn't like a therapy session.Your counselor provided support at a time when I really needed it, along with resources to help me manage my anxiety.

**LFSA:** What are your educational goals?

**Patient:** When I was very young, I became interested in medicine. My grandfather had health problems, and later, when I was twelve, my father began to struggle with autoimmune disease. Finally, when I became ill with lupus, I felt indebted to those in the healthcare profession who helped me manage my disease. At that point, my aspirations toward healthcare became even stronger. I am currently a biomedical science major, but am also interested in getting a second degree in neuroscience. I plan to go to medical school afterwards. From there, we'll see about a specialization.

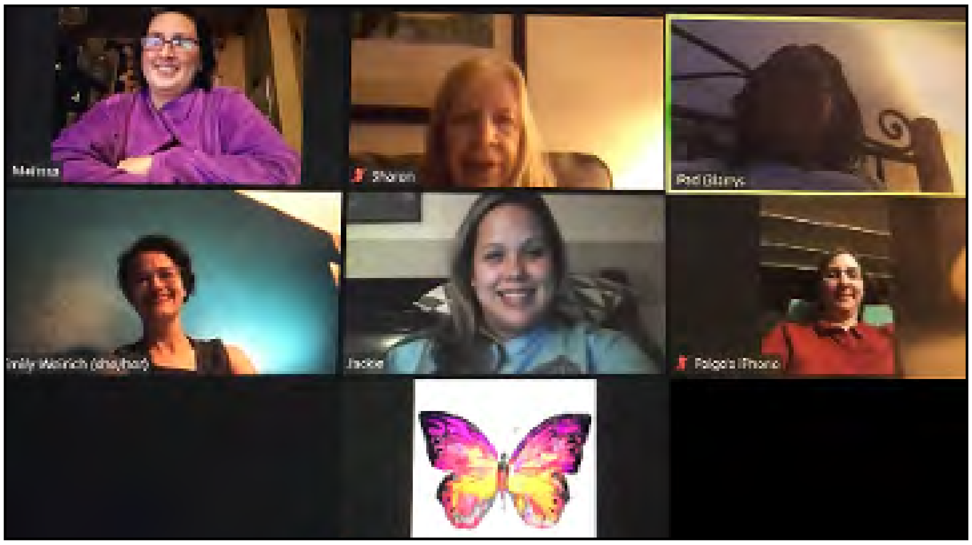
**LFSA:** How has our limited scholarship program helped you pursue your goals?

**Patient:** The scholarship has allowed me to pursue my education without having to work to help pay tuition. I've been able to focus on my studies while reducing my stress level. This has been really important for me and my family.

**LFSA:** Any final thoughts?

**Patient:** I have a special place in my heart for young people diagnosed with lupus. Lupus is a difficult disease at any age, but when we are young, it can be especially frightening. I'm so grateful to the Lupus Foundation. You've helped me get through some really tough times. I will continue to feel grateful, and will remember the Lupus Foundation as I complete my education! 🦋

# LFSA's VIRTUAL SUPPORT GROUPS AND ONLINE FORUMS



Before the coronavirus pandemic prevented us from meeting in person, the Lupus Foundation of Southern Arizona had increased its in-person support group offerings to include groups in Sierra Vista and Benson, adding these options to the existing Living with Lupus support group, and the Coffee Talk support group. When the pandemic hit, all four groups were recreated online, via the Zoom meeting platform. At the same time, an online lupus men's group was added for men struggling with lupus either personally, or in a caregiving capacity. Today, four online support groups remain: two Living with Lupus support groups, the Coffee Talk support group, and the Lupus Men's group, with meetings held monthly via the Zoom platform.

Please join us

Wednesday, December 23rd, 6pm
for an online

MEN'S LUPUS
support group!

ZOOM meeting room number:
860 259 1248

Attendance of these online groups has been steady despite technical limitations, and while most attendees agree that in-person meetings would be preferable, the online format has increased access for homebound lupus patients and those living in geographically isolated areas. As the pandemic wanes, and in-person services resume, the online format will likely continue, either as a standalone offering, or as an integrated component of in-person meetings.

As part of the LFSA's social media outreach, a Facebook group, Southern Arizona Lupus Warriors, was created to fill in the gaps between online and in-person meetings. This invitation-only group allows approved members to post and discuss topics in a secure, moderated environment, while participating as much or as little as desired. So far, the group has provided much-needed support and information to more than thirty members. To join this group, simply go to the group page and request to join. Our moderators will approve your request, provided you are a lupus patient or have a family member struggling with lupus. You may be asked to fill out our online intake form if you haven't already done so in the past.

In addition to a strong presence on Facebook, the LFSA has increased its presence on Instagram, with regular posts including event announcements and community partner recognition. This process of social media integration will continue, with a focus on community engagement and online fundraising. 🦋

# Walk-a-thons in the time of COVID: Virtual - 2020 and 2021

The 2020 Walk the Loop for Lupus was originally scheduled for April 18, 2020 as an in-person event at Reid Park. But when the coronavirus pandemic hit, we were forced to cancel the event until further notice. It soon became obvious there would be no large gatherings in parks, stadiums, or any other large forums in the foreseeable future. We felt an obligation to the generous donors who had already supported us and to the walkers who had registered, and decided to hold a Virtual Walk on Saturday, July 18, 2020.

We made the transition from an in-person to an online event, announced the Virtual Walk on all our platforms, informed sponsors, team captains, volunteers, walkers, and exhibitors, and made lemonade out of lemons! It was different. We missed the great crowd of supporters, friends, and patients at Reid Park. However, the online raffle was a great success, thanks to our raffle prize donors, ticket sales, and several happy winners! Team captains who registered the most walkers and who raised the most funds won a Heineken Beach Cruiser. A few walkers shared what they did to "walk" for Lupus. All in all, generous sponsors and donors, enthusiastic team captains, and dedicated walkers, helped to make our 2020 first ever Virtual Walk a success!

In 2021 we will celebrate the 20th anniversary of the LFSA Annual Walk. With COVID numbers at their highest levels, the large crowds we gather at this annual event prohibit us from holding an in-person celebration. So, we're kicking off the LFSA second ever Virtual Walk. Mark your calendars for Saturday, April 17, 2021 and join the celebration! We're planning a great event, with raffle prizes, incentives for walkers, and an immersive experience, so we can "see and hear" from individual walkers and teams.

The Lupus Foundation of Southern Arizona relies entirely on community fundraising and charitable donations to fulfill its mission. We hope you will join us and do your part to raise funds for the programs that support women and men with Lupus. We need your help to ask companies you know to sponsor this event or donate a prize, register friends and family to participate in the virtual walk, receive a t-shirt, donate a prize yourself, and buy raffle tickets.

Please help us celebrate 20 years of Walking for Lupus! Stay tuned for the details! 🦋

THANK YOU TO ALL OF OUR SPONSORS!

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## 20TH ANNUAL

# VIRTUAL WALK the LOOP FOR LUPUS

**SATURDAY APRIL 17, 2021**

**ONLINE AND EVERYWHERE!**

**REGISTER AT: WALKTHELOOP.DOJIGGY.COM**

# Hit the Links for Lupus, November 13th, 2020

HIT THE LINKS
FOR LUPUS
GOLF TOURNAMENT

Our Hit the Links for Lupus golf tournament fundraiser was held at Tucson Omni National on November 13th, 2020. Significant changes were made to provide a safe and enjoyable experience for our attendees, including social distancing, masking, and outdoor seating. Attendees enjoyed a beautiful, socially-distanced day golfing, followed by a great lunch. We met more than a few new golfers and had a chance to greet old friends.

Overall, it was a safe, successful day at the Omni. Trophies were awarded to the winners, and several happy faces left with great prizes, promising to return next year. All proceeds will support patient programs including scholarships and LFSA Cares medical and non-medical emergency needs. 🦋

> "Proud to be a sponsor this year!"
>
> -Crest Insurance Group

> "Thanks to Lupus Foundation of Southern Arizona for a fabulous day of golf!"
>
> -Tucson Appliance Company

# LUPUS PATIENTS SPEAK: GETTING THROUGH 2020, AND LOOKING FORWARD TO A BRIGHTER 2021.

My family managed just fine. We live in a more rural area and neither me nor my husband's work closed so daily life didn't change too much for us. Thankfully both our jobs are relatively physically distanced from other employees and neither of us have had co-workers fall ill. I had a bit of a longer wait to refill my hydroxychloroquine prescription and now I apparently need my rheumatologist to send a pre-authorization to my insurance company so the pharmacist can dispense it. I alternated in-person and tele-visits with my rheumatologist. This works fine for me because my lupus is well controlled and his office is over an hour from my house so tele-visits cut down on my need to travel.

-Michelle Johnson-Bowen

* * *

2020 was a difficult and trying year.  Because I am high risk, I made sure I followed the directions from the CDC. One of the best things that helped was contact with other Lupus patients through the Lupus Foundation. The Coffee Talk Group has become one of my most appreciated groups. I have become friends with many of those that participate and love hearing and keeping in touch with them. It's a safe place to ask questions and to feel like I'm not alone in coping with all of this. I'm hoping to get the vaccine as soon as I am eligible. I am still planning on participating in Coffee Talk although these days we do it through Zoom.

-Diane Porrazzo

* * *

The year 2020 was a challenge. I started wearing a mask when I heard that the COVID virus spread through water droplets. My partner and I stayed close to home except to shop for food, pet food, or prescriptions. I canceled my gym membership, stopped going to church and choir, etc. I have been on Plaquenil for nearly 20 years and I had trouble refilling the prescription when unfounded claims of its efficacy with COVID became popular. My faith grew as well in 2020, as did my desire to get my home and life organized. For 2021, I bought a stationary bike and began a workout program. I am also meditating and reading my Bible more consistently. I believe that our mental, physical, and spiritual lives are more important than ever. I will continue to stay vigilant by minimizing time in public spaces and by getting the vaccine as soon as I am able.

-Clare Johnson

* * *

This year was really hard, but I didn't give up. In my city, social security isn't available because of COVID 19, but it didn't stop me from getting better. I didn't have a job but always tried to work on my own, making and selling desserts, so I could have money to pay for doctors and labs. The way forward in 2021 is to stay strong and continue to get better. I need to keep thinking I can control this illness, and win this battle. I look forward to finding a permanent job and being productive again.

-Valeria Navarro

* * *

My name is Mireille. I have suffered with lupus and fibromyalgia since 2004. Over the years I became frustrated with traditional medicine. Nothing seemed to have any significant impact on my illness. A friend recommended that I read the “Daniel Fast” by Susan Gregory. This book gave recipes and instructions for implementing a plant-based diet. At first, I was skeptical. Whenever I hear the word “fast," I think of starvation. However, I decided to give it a try. So, on January 1st, 2020, my husband and I took the plunge. There is no chicken, beef or pork in the diet, but seafood is okay. It’s pretty much vegetables, non-processed carbs, fruits, nuts, and lentils. Every Sunday, we would prep our meals of three servings a day for the entire week. It was a lot of work; shopping, peeling, chopping, and cooking. It took us about two weeks to get over our cravings for meat, chips, and junk food. But we did. Slowly, we began to enjoy our new diet. We noticed that we had more energy and mental clarity. We both incorporated daily workout routines, initially at the gym, but later at home when COVID-19 made going to the gym unsafe. We make it a point to weigh ourselves every Thursday. After three months, we lost 7 pounds. In six months, we lost 15. And the best news is that we have been able to keep the weight off. Our overall health is greatly improved. My husband’s blood pressure is down, and I am a lot less stressed. I will still have an occasional lupus/fibromyalgia flare up, but they are not as intense as they were, and they are shorter in length. We still go out to restaurants with friends to eat. We are just mindful of what we order. We will enjoy a glass of wine whenever the mood hits us. And we love eating popcorn while watching Netflix. Obviously, the Daniel Fast is not a cure all, but it has been a godsend for us. It has greatly helped us get through 2020. In 2021 we hope to repeat what we did in 2020 and do everything in our power to remain COVID-free.

-Mireille Bearden

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# *Thank you to all our Community Partners!*

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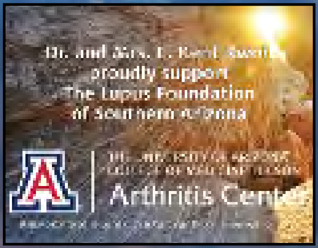

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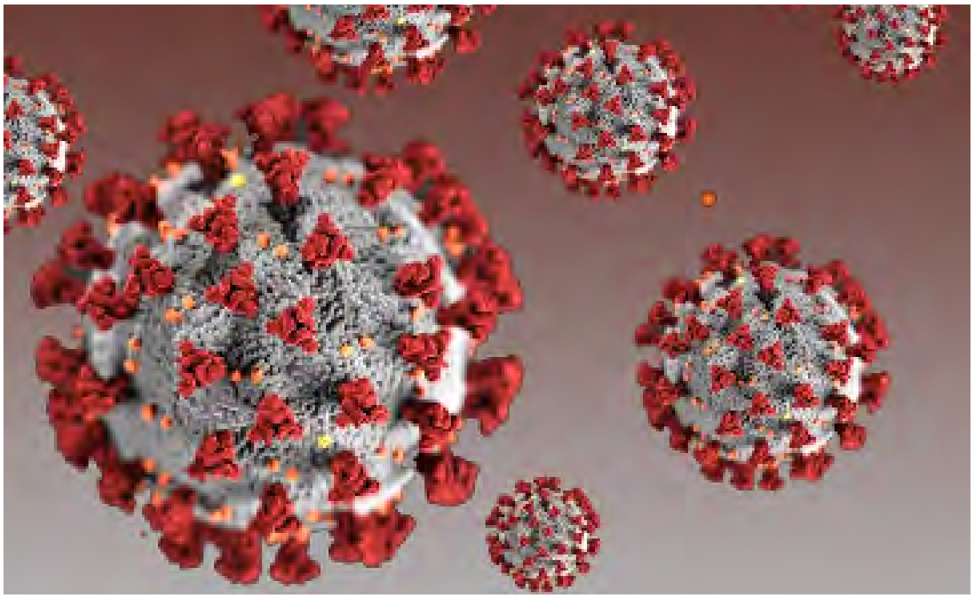
# COVID-19 AND LUPUS: WHAT WE KNOW ABOUT TREATMENT AND VACCINES

*From an interview with Karen Costenbader, MD, MPH, Director of the Lupus Program at Brigham and Women's Hospital in Boston, and Chair of the Lupus Foundation of America Medical-Scientific Advisory Council.*



**Q:** With the coronavirus pandemic in full swing, what should lupus patients do to protect themselves?

**A:** As the coronavirus pandemic continues, you should continue to do things like wearing masks, washing your hands, and social distancing. It’s also helpful to know when and where coronavirus is spreading in your community. If you live in warmer parts of the country, you may enjoy going outside, while following all the preventive measures. While indoors, avoid large groups of people, and if you must be indoors with people outside your immediate circle, wear a mask and social distance.

**Q:** Are all types of masks created equal?

**A:** N95 masks are fit-tested and are reserved primarily for hospital use. They produce a tight seal, and are able to prevent viral transmission. However, they are painful to wear and difficult to find. The next best thing is a two-layer surgical mask, followed by a two-layer cloth mask. Loose-fitting choices like bandanas aren’t nearly as effective for preventing disease transmission.

**Q:** The flu, lupus flares, and COVID-19 seem to have similar symptoms. How can we tell them apart?

**A:** It’s true that the initial symptoms of flu, COVID-19, and lupus flares are remarkably similar. The best thing to do is contact your doctor so you can be tested in order to rule out complications of lupus. Never try to diagnose yourself.

**Q:** Besides vaccines, are there any other treatments for COVID-19?

**A:** Basically, there are two phases of disease in those who get COVID-19: the initial phase, which is much like the flu, and a second phase, called a cytokine storm, where the body overreacts to the virus, leading to massive inflammation. This overreaction is similar to what happens in a lupus flare, and is treated with similar medications, for example, anti-inflammatory steroids like dexamethazone. We also have antivirals that target the virus's replication machinery. Of these, Remdesivir is potentially the most useful. Another way we are treating severe COVID-19 infections is through convalescent plasma from people who have recovered from COVID-19. This plasma helps boost immunity in acutely ill patients. Finally, we have monoclonal antibodies that attack the virus directly. Unfortunately, none of these treatments is as useful as a vaccine, which prevents infection from occurring in the first place.

**Q:** Tell us about the coronavirus vaccines and how they might affect lupus patients.

**A:** Vaccines usually work by giving your body an inactive copy of the virus. Your body then develops a memory immune response that will be used later against a real infection. Most traditional vaccines, like the flu vaccine, use this strategy. However, the current crop of coronavirus vaccines use a piece of viral protein, rather than the whole virus, to create the immune memory response. These new coronavirus vaccines are chemically inert, so they shouldn't present any specific danger to lupus patients.

**Q:** Will these vaccines cause an unhealthy reaction in people with dysfunctional immunity?

**A:** Right now we don't know since these vaccines haven't been specifically tested on people with lupus or similar conditions. Most existing vaccines don't cause lupus flares, although there is always a risk. The actual problem has more to do with people taking high doses of immune suppressing drugs that might make it difficult to mount an appropriate immune response to the vaccine, resulting in a failed vaccination. We'll know more in the future, but right now we're not sure how these new vaccines will interact with suppressed or compromised immunity.

**Q:** What about the seasonal flu vaccine? Should I get it?

**A:** Getting the flu vaccine is more important than ever. We don't want the flu circulating at the same time as coronavirus, possibly leading to a double infection. A double infection, even in a healthy individual, can be dangerous. The flu shot isn't perfect, but it's the best we've got, so we strongly recommend everyone gets it.

-This article was adapted from a live question and answer series titled "Coronavirus and Lupus - Update October 26, 2020" available on the Lupus Foundation of America's youtube channel.

- Lupus is an autoimmune disease that causes inflammation of various parts of the the body including the heart, lungs, skin, kidneys, blood, brain, and joints.
- 90% of those with lupus are women.
- Although less common, men also get lupus.
- Lupus is not contagious.
- There is currently no cure for lupus.
- Lupus is not rare. It effects 1.5 million Americans and 5 million people worldwide.
- The top 5 symptoms of lupus include fatigue or tiredness, painful swollen joints, problems with sleep, pain in other parts of the body, and skin rash.
- People with lupus do not always look sick.

# THE CORONAVIRUS VACCINE QUICK Q & A

**Q:** Were people with lupus or other autoimmune diseases included in the clinical trials for the COVID-19 vaccines?

**A:** It is unlikely that many people with lupus were included in the clinical trials for the vaccines.

**Q:** Will the vaccine be safe and effective for people with lupus?

**A:** There is no evidence that people with lupus should not receive the vaccine. According to the CDC, there is no reason to think that taking the vaccine will result in an inflammatory response (flare) for a person with lupus or other autoimmune disease. There is strong evidence from the clinical trials, however, that taking the vaccine greatly reduces the chance that a person will get COVID-19, which can be a serious or even fatal illness. Unless there is another reason not to take the vaccine, such as a history of severe allergic reactions to vaccines, it is generally recommended that people with lupus receive the vaccine.

**Q:** After I have received the vaccine, can I stop wearing a mask and go back to my normal activities?

**A:** Unfortunately, we may not be able to go "back to normal" for some time. The vaccine is important but even after both doses it will take several weeks to be fully effective. It will also take time for enough people to get vaccinated to stop the spread of COVID-19 in your community. Even after you have received the vaccine, it is crucial that you continue to follow these recommendations to protect yourself and your family:

- Stay at home as much as you can.
- Avoid high-risk activities such as travel, indoor gatherings with people outside of your household, and large gatherings even if they are outdoors.
- When you do go out, wear a mask, avoid crowds, wash your hands often, and sanitize surfaces.
- Stay in touch with your health care team and continue to follow your lupus treatment plan.
- Take care of your mental and emotional health.

# *In loving memory of Anita Baker*

Anita Baker was a great friend. I first met her as our facilitator for our Lupus Support Group many decades ago. She was kind, honest, and a community leader. She was always giving back to her community, and much of it was volunteering for our Southern Arizona Lupus Support Group, which helped many like myself who didn't know where else to turn for information about lupus. I loved seeing her at our Infusion  treatments which lasted many hours. She was a mother, grandmother, and someone I considered my friend for many decades. May she be free of pain and may she rest in peace. She was my friend, teacher, and one very smart woman. We will miss you!

-Charlotte Woods

# DIETARY FIBER AND ITS EFFECT ON LUPUS NEPHRITIS

Dietary fiber has long been considered important in the treatment of cardiovascular disease and other metabolic illnesses. But what about lupus nephritis?

Lupus, as well as other autoimmune diseases, have become increasingly common in the Western world over the past few decades. Environmental influences, combined with genetic risk factors, have been suggested as contributors to autoimmunity. Among these environmental factors, diet, and specifically the Standard American Diet--a diet chronically low in dietary fiber--has come under scrutiny as a possible risk factor in lupus and other autoimmune diseases.

In the gut, dietary fiber interacts with the microbiome in a variety of ways, producing short chain fatty acids and other beneficial compounds. Once absorbed, these short chain fatty acids have an anti-inflammatory effect on the body. Another benefit of dietary fiber is its ability to bind with cholesterol in the gut, allowing excess cholesterol to be eliminated from the system. Might short chain fatty acids, and other beneficial byproducts of dietary fiber, play a preventive role in inflammatory diseases like lupus?

In one study, lupus-prone mice were fed a low-fiber diet, while others were fed a high-fiber diet. Animals fed the high-fiber diet showed a lower antibody count and overall improved survival rate with lower kidney infiltration. While the mechanism remains unclear, researchers believe that a complex interplay between reduced gut permeability and increased short chain fatty acid production, resulting in reduced systemic inflammation, may be at work.

Good sources of dietary fiber, and especially heart-healthy soluble fiber, include black beans, oatmeal, avocados, and sweet potatoes. For those looking for an alternative, psyllium fiber, available in the supplement aisle of most grocery stores, is an excellent choice. Your heart, and possibly your kidneys, will thank you for it.

--Adapted from the following article: Eichhorst A, Schäfer A, Voll RE, et al"Influence of dietary fibre and short-chain fatty acids on the pathogenesis of systemic lupus erythematosus"Lupus Science & Medicine2020;7:doi: 10.1136/lupus-2020-eurolupus.102

Lupus Foundation of Southern Arizona
4602 East Grant Road
Tucson, Arizona 85712

THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

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