

LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



Fall 2019

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CALENDAR

April

18th

Walk-the-Loop-for-Lupus

There's still time to Sponsor the Walk, put together a team and sign up to walk. Go to www.walktheloop.dojiggy.com to sign up to today!

October

25TH

Hit the Links for Lupus Golf Tournament

Join us at Omni Tucson National for the Hit the Links for Lupus Golf Tournament. Go to birdeasepro.com/hitthelinksforlupus for Sponsorship opportunities and sign up.

1st Wednesday of Each Month - Coffee Talk

The coffee talk group meets at the LFSA office on 4602 East Grant Road the 1st Wednesday of each month at 6:00 PM. Open to the public.

2nd Tuesday of Each Month - Benson at Benson Hospital

This group meets in the Training Room at Benson Hospital the 2nd Tuesday of each month at 6:00 PM. Open to the public.

3rd Wednesday of Each Month - Living with Lupus Support Group

The support group meets at the LFSA office on 4602 East Grant Road the 3rd Wednesday of each month at 10:00 AM. Open to the public.

4th Wednesday of Each Month - Sierra Vista at Canyon Vista Medical Center

This group meets in the Thrive Room at Canyon Vista Medical Center the 4th Wednesday of each month at 6:00 PM. Open to the public.

For more information, visit www.lupus-az.org and "like" us on Facebook



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

Joan Redford, Treasurer

Shaima Namazifard, Secretary

BOARD MEMBERS

Lani Baker

Sherri Fritz

LETTER FROM THE PRESIDENT



As we enter a new Fiscal Year at the Lupus Foundation of Southern Arizona, we celebrate the achievements of 2018-2019. We are grateful for another banner year! On behalf of the Board of Directors, I say, **THANK YOU!** to our community partners, sponsors, individual donors, participants, volunteers, vendors, behind the scenes helpers and all who help us fulfill our mission.

The 18th Annual Walk the Loop for Lupus, April 13, 2019, at Reid Park, was a huge success. We welcomed new sponsors, increased the number of Walk Teams, thanks to some amazing Team Captains, had a great time dancing to the music and raised much needed funds for the foundation. **Please mark your calendars for next year's Walk the Loop, scheduled for Saturday, April 18, 2020, at Reid Park. Time to start working on your Award-Winning Team Costumes!** Let's make this one bigger and better than ever!

Through your generosity, in August and September, we sponsored 17 Lupus patients for a Women's Retreat and 5 Lupus patients and their significant others for a Couples Retreat at the Omni Tucson International Resort. The retreats provided opportunities for input and sharing of ideas, fun activities and time to relax and renew ourselves in body and spirit.

The partial Scholarship Fund, Emergency Medical Fund and LFSA Cares for non-medical emergencies, continue to help individual patients in need. As I participate in numerous Health Fairs throughout the region each year, I often encounter Lupus patients and many individuals who have never heard of LFSA. Through networking, research and follow up we were able to begin a new Support Group in Sierra Vista in August and one in Benson in September.

Don't miss reading the LFSA Q & A Series in each magazine, featuring individual patients and their stories and Q & A interviews with medical professionals. In this issue, you'll hear from Dr. Amy Sussman, MD, Nephrologist, about her work with patients who suffer from Lupus Nephritis. Tyler Pierce, LFSA Administrative Associate, plans, conducts and transcribes all the interviews you see in each issue of the LFSA Magazine. These interviews provide insight into the lives of Lupus patients and the medical professionals who partner with them to decide their most effective treatment protocols. Tyler works hard in putting together each issue of the LFSA Magazine. Great job, Tyler!

There's still time to register for LFSA's Hit the Links Golf Tournament at the Omni Tucson National Resort, Friday, October 25, 2019! Get in the Swing and register at www.birdiespro.com

Together we PARTNER with you, our STRONGEST SUPPORTERS, to meet the needs of Lupus patients now and into the future. Thank you, again.

Sharon Joseph, President



LFSA EMERGENCY MEDICAL FUND: TORI MICHARSKI



Tori Micharski

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

Recipient: When I moved to Tucson, I looked up the Lupus Foundation. It was close to where I lived, and it was highly recommended.

LFSA: How did you learn about our Emergency Medical Fund?

Recipient: I came to one of your support groups. The group was small enough that I was able to speak one on one with you guys. That's when I learned about your programs. After the group, I requested assistance.

LFSA: How has lupus impacted your ability to work and live the life you want to live?

Recipient: It has caused me to change my career path. I found that working with people and helping them has kept me active in work. The pleasure and enjoyment of that provided mental health benefits. Lupus also changed the physicality of my work. I had to move into more of an office setting, something less physical. You never know when something might happen, like a flare. Lupus has impacted the kinds of jobs I can take on versus the ones I want to take on. It's caused me to look for jobs that offer time off or short-term disability, the things that make it possible for me to work when I can work.

LFSA: What was your medical situation and how did that create a financial crisis?

Recipient: The initial diagnosis of lupus was confusing for me. Nobody explained what you have to do or how to do it, and the best way to avoid a financial crisis. Three years into my diagnosis I was working, dealing with lupus, but was overwhelmed by medical expenses. I couldn't possibly afford to pay all at once, which is what my creditors wanted me to do. When

you're in crisis, you do what you have to do, but there are consequences. It can take years to get to a resolution. The lawyers wanted everything paid all at once. It felt inhumane, the way they treated me, considering what happened with my health.

LFSA: How did our Emergency Medical Fund help you resolve your situation?

Recipient: It was resolved relatively quickly. I submitted my request for assistance and the Lupus Foundation handled the rest, by paying the full sum directly to the law firm involved in the dispute. Once that larger debt was settled, I was able to take care of other debts, which allowed me to get my life back on track.

LFSA: How has life changed since then?

Recipient: After finishing my term of service at AmeriCorps, I continued working in the human service field. It's a field where it's understood what a person goes through in situations like mine. That support has actually improved my health. I've stayed active and engaged. I feel less alone. I've been able to pay down debts. Just recently I took a job at La Frontera, where I work with people going through the same things I went through. I'm helping people understand benefits around their disabilities and other concerns.

LFSA: Is there anything else you would like to tell our readers?

Recipient: Reach out to people who understand what you're going through. Support groups are very helpful. Anyone who will listen. The mental and emotional support makes all the difference. Also, reach out to community centers and mental health centers where you can get an advocate to walk you through things. Don't be afraid to ask questions. You can do this, but not without help.

LFSA: Thank you for speaking with us today!

Recipient: Thank you for having me!



HIT THE LINKS FOR LUPUS 2019 GOLF TOURNAMENT

FRIDAY - OCTOBER 25, 2019

REGISTRATION: 7:30 AM SHOTGUN START: 8:30 AM

@ OMNI TUCSON NATIONAL



Trophies

Lunch



Goody
Bags

Raffle
Prizes



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- One Golf Registration and lunch

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Golf Registration - \$125

- Golf Registration and lunch



HIT THE LINKS
FOR LUPUS
GOLF TOURNAMENT



LFSA WOMEN'S AND COUPLE'S RETREATS A HUGE SUCCESS!



Women's Retreat



Women's Retreat



Couples Retreat



Women's Retreat



Couples Retreat



Couples Retreat



PUS
T/FINIS

WALK
the **LOOP** FOR
LUPUS



SATURDAY APRIL 18, 2020
@ REID PARK



New Study Shows Benlysta Alters B Cells in People with Lupus

August 21st, 2019, lupusresearch.org

Newly published research found that belimumab (Benlysta®) effectively reduced the number of B cells, a type of white blood cell that makes antibodies. According to the prescribing information, belimumab is “a B-lymphocyte stimulator (BLyS)-specific inhibitor indicated for the treatment of patients aged 5 years and older with active, autoantibody positive, systemic lupus erythematosus who are receiving standard therapy.”

It is thought that belimumab works by targeting BLyS, also known by scientists as B-cell activating factor (BAFF), a protein that helps B cells survive and produce more antibodies. In this study, scientists compared blood cells from healthy people versus those with lupus taking belimumab or standard-of-care. Patients treated with belimumab showed lower levels of a key subset of B cells.

Earlier research by two scientists funded by one of the Lupus Research Alliance’s heritage organizations—the Alliance for Lupus Research—helped set the stage for the development of belimumab. It was already

known that B cells malfunction in lupus by producing antibodies that attack patients’ own DNA. In the late 1990s, our funded researchers discovered that the protein BLyS/BAFF also stimulates B cells and helps them survive. With his grant, Dr. William Stohl of University of Southern California tracked patients with lupus for more than a year and found that half of them had increased levels of BLyS/BAFF at least part of the time, suggesting that the protein has a role in lupus.

Dr. Robert Carter, now Acting Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) also received our Target Identification in Lupus grant in 2000 and helped further clarify the effects of blocking BLyS/BAFF. Using mouse models of lupus, he and colleagues demonstrated that blocking BLyS/BAFF decreased the levels of antibodies that targeted the animals’ own cells and reduced some of their lupus symptoms.



Thank you to all our Community Partners!



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AMY SUSSMAN, MD

UNIVERSITY OF ARIZONA DEPARTMENT OF MEDICINE



Amy Sussman, MD

LFSA: What led you to choose nephrology as your specialty?

Dr. Sussman: Well, I could go on forever because I love nephrology! There are things like disease prevention where we focus on diseases like hypertension and diabetes, and then we learn about the immunological aspects

that are involved, including diseases like lupus. So being a good immunologist, a good physiologist, and a good preventative doctor makes nephrology really challenging and exciting. Also, I have the most powerful relationship with my patients. I may meet a patient who has early stage chronic kidney disease, and I follow them for a long time, and maybe despite my best efforts, my patient progresses to dialysis, and I stay with them, every step of the way. When you go through that with a patient, it's very personal. That's not something other specialists get to do, and I love it.

LFSA: How should someone prepare for their first visit with you?

Dr. Sussman: I think the most important thing with any doctor is to be a good historian. We need to know a patient's medical history, as well as any medical problems or surgeries. We also need to know their family history, because a lot of kidney diseases, and lupus in particular, tend to run in families. We also need to have a good idea of new symptoms so we're aware of what they are and how they might be contributing to the disease process.

And then the other thing is to be prepared to learn. Certainly they're not going to grasp everything. What I like to do during that initial visit is to really explain to my patients what I

think is going on. This is the disease process, how it's occurring. And these are the things that we can do right now, to help treat this and help slow the progression. So education is really important. The patient needs to be open and receptive. And they have to understand that part of getting better is the shared partnership the two of us have. And that includes being proactive to carry out the things I'm asking them to do, so that we can make sure we have the best outcome.

LFSA: How can someone tell if their kidneys are in trouble and what should they watch out for?

Dr. Sussman: So specifically related to lupus, some signs they can be watching for include experiencing sudden swelling in their hands or feet. Swelling is a big sign that tells us that a person is probably losing protein in the urine and

"...education is really important. The patient needs to be open and receptive."

that they are kind of holding on to salt and water. Sometimes they also describe having very foamy urine, where the toilet bowl is just filling up with lots of bubbles. That's also a sign that they are probably losing a lot of protein in their urine. Another one would be new onset blood pressure that's high. They've never had high blood pressure and suddenly it's very high or worse than before. That's another sign they have problems with the kidneys related to lupus. Also, their GFR might be down and there's a lot of protein in the urine or blood in the urine, based on lab results.

LFSA: When should someone see a nephrologist?

Dr. Sussman: I usually say that anytime the kidney is compromised, for example, when the GFR number is below normal, usually around 45 to 50% of kidney function, that's when they should see a nephrologist. Also, when somebody has normal kidney function, but they've got blood and protein in the urine that is abnormal.

LFSA Q & A SERIES

And in particular, if this is a patient who has been diagnosed with lupus, they absolutely need to see a rheumatologist.

LFSA: How does inflammation affect the kidneys and what can be done about it?

Dr. Sussman: So when you think about our kidneys, they have about a million little filtering units. Their job is to filter blood. In this filtering unit there is kind of a network of blood vessels that is the core part of the filtration system. This is what lupus targets and where the inflammation happens. We think our patients have some kind of underlying genetic predisposition. And then, during their lifetime, they're exposed to some kind of environmental trigger. It could be that they are exposed to a virus or a bacterial infection, a carcinogen in the environment, or some exposure that turns on this tendency toward autoimmunity. So essentially, we start with environmental triggers and suddenly a protein that's in the body is seen as foreign. The body then makes antibodies to that protein. That antibody binds to that protein, trying to get rid of it. And it does that by activating all of these inflammatory mediators. This is what causes destruction to the kidney over time.

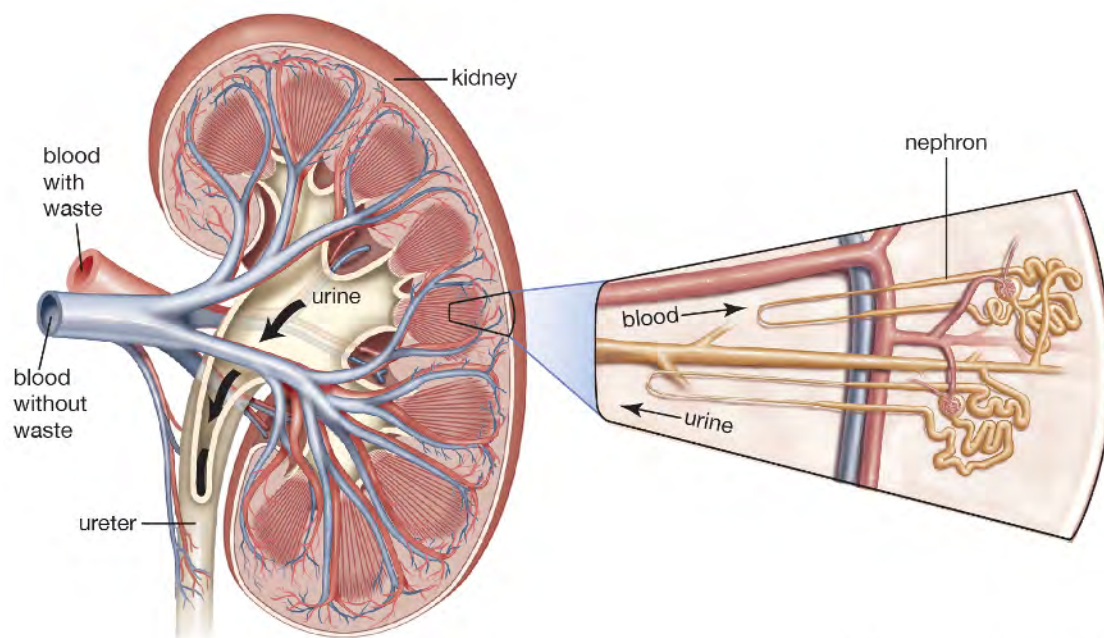
LFSA: How do you treat somebody who has ongoing inflammation or scarring of their kidneys?

Dr. Sussman: Treating ongoing inflammation is the target of our lupus therapy, through therapies that modulate the immune system. We're targeting components of our immune system to stop producing these inflammatory mediators. Some of these are chemo therapeutic agents, for example, a lot of our patients are very familiar with cytoxin, that essentially helps to calm down the inflammatory response. But we have new biological therapies that are very helpful, that

specifically target certain areas of the immune system, allowing us to target the area that is creating the inflammation without hurting other parts of our body.

LFSA: Please explain what is happening when a person's GFR is too low.

Dr. Sussman: So the functional unit of the kidney is the nephron. If I have a lot of inflammation in my kidney over time, I destroy these nephrons, so that I don't have the ability to filter. So one of the ways to assess kidney function is to look at something called the glomerular filtration rate. Essentially that's the rate at which we're filtering blood. Normally we do about 120 mls per minute. We filter a ton of blood, you know,



minute by minute, but when we start to destroy these nephrons, we may only have 45 mls per minute or 30 mls per minute of blood being filtered. And it's important because when you look at GFR, that is really the best indicator of kidney function. And that's very helpful for us because when we start to think about somebody who has a significant impairment in their function, they may not be able to live without kidney replacement therapy because of the solids and the toxins that build up in their body. So that's why GFR is so important. It goes low because they have such advanced kidney disease that those nephrons essentially scar, and we cannot bring those back once they scar.

(continued from previous page)

LFSA: And the ultimate solution is a transplant.

Dr. Sussman: So what we try to do when the GFR gets to around 20% is line our patients up for a transplant workup. We can't really start before that because sometimes people won't progress. But once they get to this point, they are actively looking for living donors, getting medically suitable so that they're able to accept the kidney and getting listed for either a deceased donor or a living donor. This is our ultimate goal. And sometimes this takes time. Some of our patients will progress very quickly and those patients would be on dialysis, either through chemo dialysis or the kind of dialysis through the belly, until they can get a transplant.

LFSA: What role do diet and exercise play in treating patients with kidney disease and more specifically with lupus nephritis patients?

Dr. Sussman: I cannot underscore enough how important diet and exercise are to kidney function. My approach to patients who come to my clinic is to look at every aspect of their life, from social to dietary and everything else. Diet plays a huge role, particularly with our patients with lupus nephritis. Our patients are generally very sodium avid, which means they hold on to salt which worsens their actual disease process. So we tell our patients to be on a strict low sodium diet. If they have a lot of protein in their urine, we ask them to avoid excessive amounts of animal protein, because it can be detrimental to their kidney disease. We also recommend people think about more of a plant sourced diet, particularly plant protein. If our patients eat meat, leaner meats are better. And there's newer data coming out for chronic kidney disease in general, saying that plant sourced diets were actually better at slowing the progression of disease. So a diet high in fruits and vegetables and plant sourced proteins, avoiding excessive amounts of protein, and low sodium. Getting a patient to see a dietitian or nutritionist so they really understand the importance of diet is going to be key to their success. Exercise is also very important. There's some data in terms of chronic kidney disease that if even if you exercise 10 minutes a day, that has probably contributed to

slowing the progression of disease. One of the big things I think people overlook is when a patient has lupus nephritis, they also have a disproportionate amount of cardiovascular disease. It is absolutely key to be physically fit so that you can minimize cardiovascular events from happening.

LFSA: What new research is taking place to help people with late stage kidney disease?

Dr. Sussman: One of the most exciting developments is the Precision Medicine Initiative, which aims to understand how somebody's genetics, their environment and lifestyle contribute to their disease process, and

"One of the most exciting developments is the Precision Medicine Initiative, which aims to understand how somebody's genetics, their environment, and lifestyle contribute to their disease process..."

how to determine the best approach to prevent or treat their disease. We're learning how to identify genetic markers that may predict who will get kidney disease and how to mitigate it. That's probably the most exciting thing going on today. The other really cool initiative is the Kidney X Initiative. It's a public/private partnership between the US Department of Health and Human Services and our National Society of Nephrology to accelerate innovation in the prevention, diagnosis, and treatment of kidney disease. They're accelerating the development of drugs, devices, biologics and many other therapies that could help with disease prevention, disease diagnosis, and disease treatment. They've made it easier for innovators to move drugs, therapies and devices through the FDA so that they become available to our patients.

LFSA: That is exciting. So what brings you hope about today's research in the area of lupus nephritis?

Dr. Sussman: If we understand somebody's genetic makeup, we can develop therapies that are specifically targeted and tailored to that person. Previously so many of our therapies were targeted when our patient had an exacerbation of illness. Significant inflammation was occurring, so let's quiet down the inflammation. That's all we had. It was suboptimal because a substantial amount of disease and pathology has already happened and we can't bring that back. So now what people are looking at in lupus nephritis, in addition to genetics and tailoring treatment to the individual patient, is understanding where in the inflammation cycle the disease process begins. Can we use different drugs to prevent an exacerbation from ever happening? I think this is going to be a very powerful tool we can use in our patient population.

LFSA: Is there anything else you'd like to add or say specifically to our lupus patients that you feel strongly about or that you think they might want to hear?

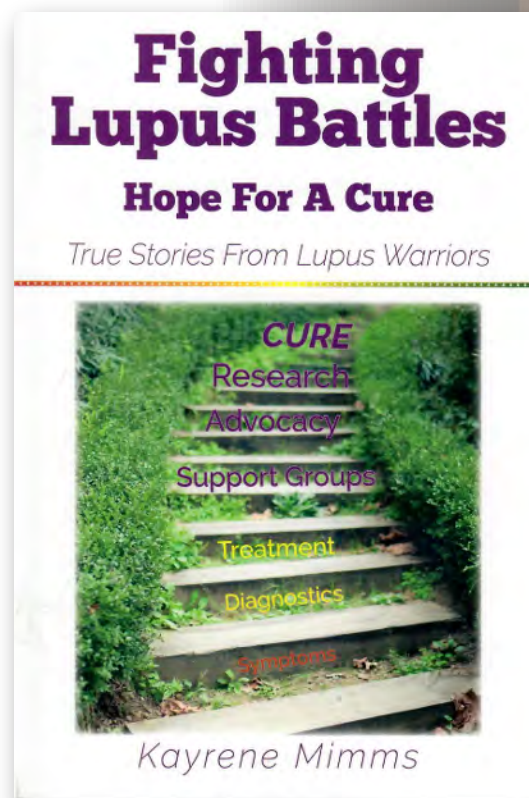
Dr. Sussman: One of the most important things when you're dealing with a chronic disease, is your perception. If you see everything in a positive way, it impacts your physical well-being. And if you are proactive in your care, then I think you've got a great shot at doing the best you possibly can. It's incredibly important for patients to stay positive and to believe they have the strength to carry themselves through. Also, having a partnership with the right nephrologist and the right rheumatologist is very important. A patient needs to feel like they are part of a team and they are the one who is defining treatment. There is nothing more powerful than that.

LFSA: We really appreciate you taking the time to speak with us today!

Dr. Sussman: Thank you for having me!



Now at LFSA's Lending Library:



Fighting Lupus Battles -Hope For A Cure

*True Stories From
Lupus Warriors*

by Kayrene Mimms

Come check it out
today!

LFSA Q & A SERIES

The following is a conversation between Dylan Johnson and his mother, Michelle, who was diagnosed with lupus.

When did you first learn you had Lupus?

In 2002, after months of trying to figure out why I was so tired, I had flu-like symptoms, and pain all over, and after many visits to the doctor's office, my primary care physician completed blood tests and as a result sent me to a Rheumatologist who diagnosed me with Lupus. I was relieved knowing at least there was a name for what I was going through and a little scared because I had no idea what the heck Lupus was? I had never heard of it. I cried when I first was diagnosed, but it wasn't because I was sad. I didn't know enough about it yet to be sad. I cried, because I thought with a diagnosis I would be able to get back to normal. But what I learned over time was that I would need to find a new normal. This was just the beginning of my journey.

How has being diagnosed with Lupus impacted your life?

In so many ways! It truly has been a journey of exploration, experimentation and personal growth. At first, I became determined to learn everything about it and worked with my Rheumatologist to "get better." I tried many medications, Plaquenil, Prednisone, Orencia, Methotrexate, and Vicodin to name a few, to try and manage the symptoms. Some were to

address the original symptoms of Lupus, others were to address the side effects of the medications and others were to address new symptoms that would appear, like mouth ulcers, brain fog, and depression. Giving myself shots, receiving infusions, and going to regular doctor's appointments became commonplace. This went on for about ten years. At that point in my journey I realized that medication was only part of the answer.

How has the Lupus Foundation been a part of your journey?

My Rheumatologist told me about the Southern Arizona Lupus Foundation and the SLESH (Systemic Lupus Erythematosus self-help) course. It was an eight week course that provided the information and support that I needed just when I needed it. I learned the basic facts about Lupus, how to take a more active role in my healthcare, ways to manage my pain and fatigue, and most importantly, that I wasn't alone. This was the beginning of realizing that I had the power to make choices to create my best life.

Each year my family, friends, and I participate in the Walk the Loop for Lupus sponsored by the Southern Arizona Lupus Foundation. I am so grateful that the foundation was there for me



when I needed support and my hope is that they will remain a resource for the fight against this disease and a support for those struggling with it.

How has being diagnosed with Lupus changed you?

After about ten years of managing my symptoms with predominantly medications and having had a personal loss that made me take stock in my life, I decided to go in a different direction. I finally, realized that in order to be fully myself again, I needed to mourn the loss of who was before I was diagnosed and create and embrace a new me. I realized I needed to identify what and who was important in my life and place my focus and energy in that direction. So this was the beginning of learning to create balance in my life, pace myself, take time for myself, take naps, have rest days, and look at different alternative treatments to address my symptoms.

What are you doing to manage your symptoms?

First of all, I make a deliberate decision to choose happiness every day. I focus on what I have, not what I have lost. I no longer think of myself a sick person. I just see Lupus as another challenge in my life not my whole life. When I decided to change my thinking it opened my mind to new ways to manage my symptoms. I found acupuncture, massage, meditation, taking fish oil and other natural anti-inflammatories and using essential oils as great tools in helping to create the life I want to lead.

What is your greatest challenge when it comes to managing your lupus?

It isn't always easy to take care of myself and don't always take the time to do what I know I should do to stay healthy. But I am very lucky, because the people in my life that really know and love me, call me out on this, and remind me of the importance of self-care.

Who are your biggest supporters and how are they helping you?

First and foremost, my husband has stood by me every step of this journey. He has helped me in many ways, too numerous to mention. My children support me with their consistent love

and understanding. My friends and family have all been with me on this journey too. They understand my limitations; they nurture strong and loving relationships, and join me each year in my efforts to support the Southern AZ Lupus Foundation at the Walk the Loop for Lupus.

If you could say one thing to our readers, what would it be?

The way we see ourselves; the thoughts that go through our minds, have so much power. We need to embrace that and use positive energy to keep us living our best lives. We can only be the best versions of ourselves and that is good enough. Remember you are not your diagnosis, you are much more.

Anything else you want our readers to know?

Stay strong and don't give up!



- ▶ 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.

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



THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

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