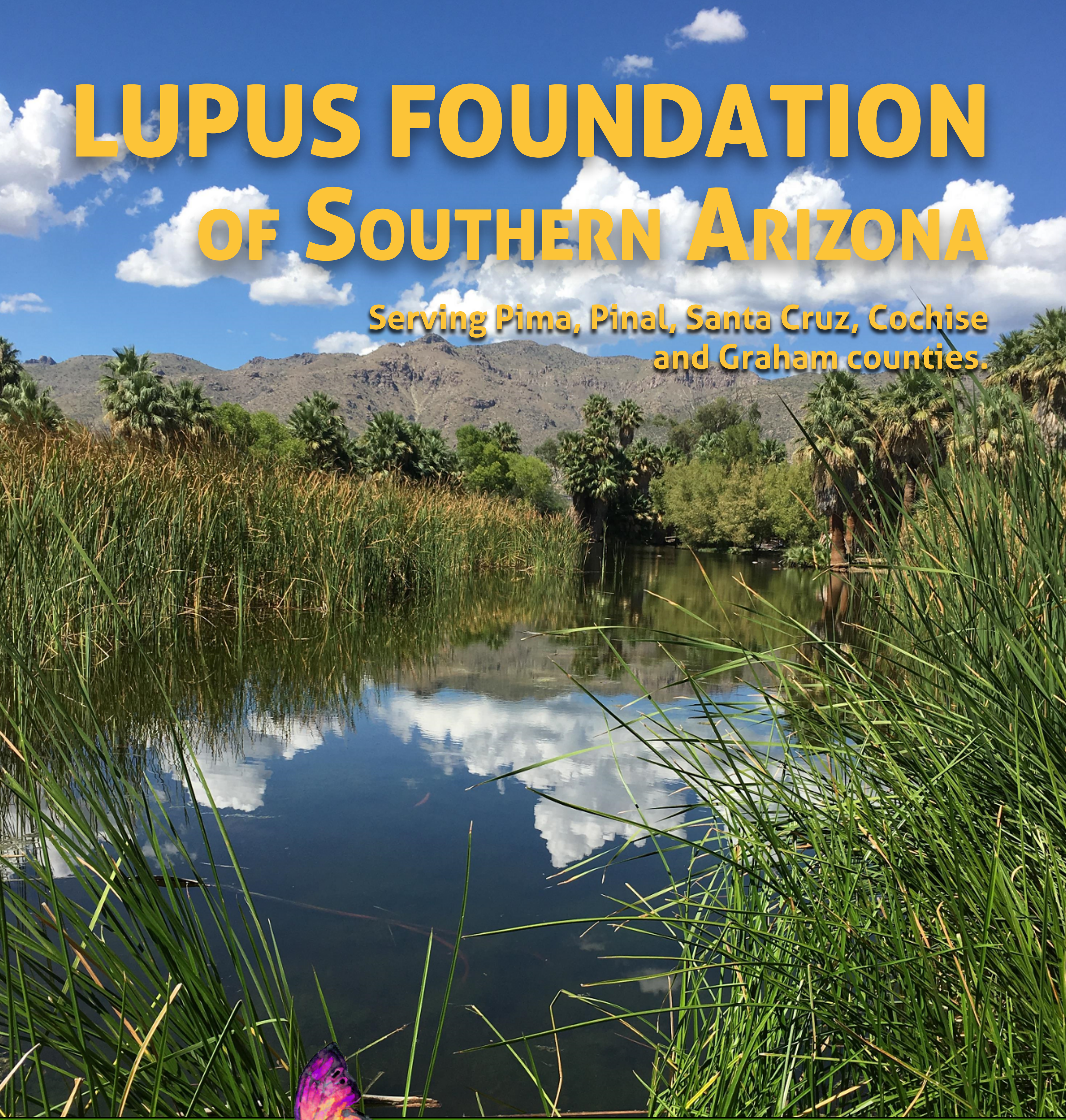
LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



Spring 2019

IN THIS ISSUE:

- ☐ Calendar
- ☐ Letter from the President
- ☐ LFSA in the Community
- ☐ LFSA Events
- ☐ Lupus News
- ☐ LFSA Q & A Series

CALENDAR

April
13th

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.

3rd Wednesday of Each Month - 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.

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
Wendy Black
Sherri Fritz

LETTER FROM THE PRESIDENT

This is the season of Health Fairs, 40-degree temperature fluctuations, hints of Spring in the desert! It's also time to say thanks to YOU, our sponsors, community partners, donors, walkers, gala attendees, volunteers, vendors and all who help us fulfill our mission. The Board of Directors and I could not do the work of the foundation without your contributions of time, talent and treasure.

The November 4th Gala at Skyline Country Club was an amazing success! We honored Rebecca Shields, past President of the Foundation, and Dennis Shields, of Finley Distributing Company for their outstanding generosity. We helped Tame the Flame of Lupus and enjoyed a beautiful evening.

Please mark your calendars and plan to JOIN US! at one or both of our major fundraisers this year. Saturday, April 13, 2019, is the 18th Annual Walk the Loop for Lupus at Reid Park. GO TO www.walktheloop.dojiggy.com. There's still time to sponsor, donate, get a team together and register to walk! BE THERE!

SAVE THE DATE for Hit the Links Golf Tournament at Omni Tucson National Resort, Friday, October 25, 2019. Get in the swing! Sponsor and register for this event at www.birdeasepro.com/hitthelinksforlupus. Please see page 7 of this magazine for details and sponsorship information.

With your support, the Partial Scholarship Program continues to attract participants. Scholarships have been awarded to 13 women since 2015. So far this year the LFSA Cares Fund for non-medical needs has met the request of a mother, caring for her daughter, who has Lupus, and her two young children, with a one-time payment of rent and utilities. We have also been able to honor the memory of a young Lupus patient, by helping her family with funeral expenses. Each of these programs pulls at the heartstrings of all of us, Board members and donors alike, as Lupus patients struggle every day to live their best lives with this unforgiving disease. Your contributions help us provide support, education and resources to patients. You read their stories in these pages.

We continue to raise awareness in the communities of Southern Arizona, inviting others to spread this message of support through their contributions, distribution of information to patients in the medical setting, volunteers and participation in our fundraising events. We want patients and families to know, THEY ARE NOT ALONE. Together we PARTNER with you, our STRONGEST SUPPORTERS, to meet these needs now and into the future

Thank you, again.

Sharon Joseph, President

LFSA SCHOLARSHIPS - CHARIS ROYAL

Charis Royal

LFSA: How did you learn about the Lupus Foundation?

Recipient: I've been participating in the Miss America system. Part of what we do is work with charitable organizations, so I started looking for organizations in Tucson that help people with disabilities. Because I have lupus, I looked for lupus organizations. I found your organization which is one of the few in Arizona that works with lupus.

LFSA: How did you learn about the scholarship program?

Recipient: I was looking through your website and stumbled upon your scholarship program. I'm in the last semester of my second master's program. I was pleasantly surprised to find a scholarship that was lupus specific.

LFSA: What are your academic goals at this time?

Recipient: I've already graduated with two bachelor's degrees and one master's. I'm graduating from my second master's this semester, and then I'm applying to medical school. My second master's is in Emergency Management. I've been an EMT for the past five years so I'm planning to go into emergency medicine or trauma surgery.

LFSA: How has lupus impacted your ability to attend school?

Recipient: I was diagnosed when I was twelve. They started me on medications because I was having a lot of issues with my joints. I had bad reactions to the medication. Not only was I missing school because of my lupus flareups, but also because of the medication side effects. Being diagnosed at that age, you also have to battle with the mental health of having lupus. Everyone kept telling me I wasn't going to be able to achieve the things I wanted to achieve. I've known I wanted to be a doctor since I was seven. Having lupus has only strengthened that, but there were a few years when I thought I wouldn't be able to be a doctor because of my lupus. It took me until I was fifteen, when I met a doctor who encouraged me and helped me to overcome those doubts, before I could move forward. I now share the same philosophy with students with disabilities at the college level. You have to find ways to work with your conditions, not against them. I wake up in the morning, check in with my body, then prioritize. I'm doing a lot of stuff, but some days I can't get to everything on my list.

LFSA: How are you managing your lupus?

Recipient: I take Plaquenil to manage my lupus. I only had one flareup last year which is probably the best it's ever been. As far as lifestyle, I exercise regularly. I do things that are soft on my joints. I try to stay healthy and active without pushing my body too hard.

LFSA: How has our scholarship program helped you?

Recipient: I was concerned that I wouldn't be able to finish my second master's due to some program changes. Your scholarship is helping me finish my degree without taking out another loan, which is greatly appreciated!

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

Recipient: Don't ever let people tell you that you can't do things because of your condition. Everyone is different. Everyone can find ways to work with their own body. It's all about how you work with it, not what other people say.

EDUCATION
SCHOLARSHIPS
AVAILABLE!

WWW.LUPUS-AZ.ORG

WALK the LOOP FOR LUPUS

SATURDAY APRIL 13, 2019 @ REID PARK

REGISTER AT:
WWW.WALKTHELOOP.DOJIGGY.COM

7:00 AM REGISTRATION
AWARDS CEREMONY
SILENT AUCTION
LIVE ENTERTAINMENT

THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

520.622.9006
www.lupus-az.org

4602 E. Grant Road
Tucson, AZ 85712

LUPUS FOUNDATION OF SOUTHERN ARIZONA
4TH ANNUAL GALA

The Lupus Foundation of Southern Arizona's 4th Annual Gala was a huge success! We would like to thank our title sponsor, Finley Distributing, as well as all the evening's sponsors and attendees. Captain Cheryl Horvath from Tubac Fire District was our keynote speaker for the evening. Heidi Armand, a lupus patient, talked about her own experiences with lupus and why giving to the LFSA is so important. Rebecca Shields, former President of the LFSA Board, was this year's honoree. Dennis Shields, of Finley Distributing, was also presented with an award for his support of the Lupus Foundation. Guests were hosted to a fabulous silent auction and dual course meal. A fun time was had by all, and most importantly, much needed funds were raised to support LFSA's mission in serving the Southern Arizona Lupus community. Thank you all for your support!




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

☐ **Hole in One Sponsor - $3,000**

- Signage at golf tournament and promotion materials
- Logo on scorecards
- Two Foursomes and lunch

☐ **Eagle Sponsor - $1,500**

- Signage at golf tournament and promotion materials
- One Foursome and lunch

☐ **Birdie Sponsor - $750**

- Signage at golf tournament and promotion materials
- Two Golf Registrations and lunch

☐ **Platinum Hole Sponsor - $300**

- Signage at hole or tee and event materials
- One Golf Registration and lunch

☐ **Hole Sponsor - $200**

- Signage at hole or tee and event materials

☐ **Golf Registration - $125**

- Golf Registration and lunch

HIT THE LINKS
FOR LUPUS
GOLF TOURNAMENT

Lupus Facts and Statistics

Source: National Resource Center on Lupus

How common is lupus and who does it affect?

The Lupus Foundation of America estimates that 1.5 million Americans, and at least five million people worldwide, have a form of lupus.

Lupus strikes mostly women of childbearing age. However, men, children, and teenagers develop lupus, too. Most people with lupus develop the disease between the ages of 15-44.

Our best estimate based on available data on incidence is 16,000 new cases per year. The Centers for Disease Control and Prevention (CDC) are currently gathering updated data for all ethnic sub-populations in the US, so we anticipate this number will change. The fact remains that lupus is a devastating and life-changing disease that currently has no cure.

What are the 4 different forms of lupus?

Systemic lupus accounts for approximately 70 percent of all cases of lupus. In approximately half of these cases, a major organ or tissue in the body, such as the heart, lungs, kidneys, or brain will be affected.

Cutaneous lupus (affecting only the skin) accounts for approximately 10 percent of all lupus cases.

Drug-induced lupus accounts for about 10 percent of all lupus cases and is caused by high doses of certain medications. The symptoms of drug induced lupus are similar to systemic lupus; however, symptoms usually subside when the medications are discontinued.

Neonatal lupus is a rare condition in which the mother's antibodies affect the fetus. At birth, the baby may have a skin rash, liver problems, or low blood cell counts, but these symptoms typically disappear completely after six months with no lasting effects.

What is the impact of health disparities on people with lupus?

Lupus is two to three times more prevalent among women of color—African Americans, Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians and other Pacific Islanders—than among Caucasian women. Recent research indicates that lupus affects 1 in 537 young African American women.

The groundbreaking LUMINA (Lupus in Minority Populations: Nature vs. Nurture) study reported that African American lupus patients are more likely to have organ system involvement, more active disease, and lower levels of social support compared with white lupus patients.

A 2014 study found that minority women tend to develop lupus at a younger age, experience more serious complications, and have higher mortality rates.

What are the economic impacts of lupus?

A 2008 study published in Arthritis & Rheumatology found that the average annual direct health care costs of patients with lupus was $12,643.

The study also determined that the mean annual productivity costs (lost hours of productive work) for participants of employment age was $8,659.

Thus, the mean annual total costs (combining direct costs and productivity costs for subjects of employment age) was $20,924.

A Lupus Foundation of America membership survey found two of three lupus patients reported a complete or partial loss of their income because they no longer are able to work full time due to complications of lupus. One in three have been temporarily disabled by the disease, and one in four currently receive disability payments.

This same survey found that one in four patients receive their health care through a government-sponsored program, such as Medicare or Medicaid.

65% list chronic pain as the most difficult aspect of lupus

$20,000 is lost annually by each lupus patient in healthcare and lost productivity

How long does it take to get diagnosed with lupus?

There are many challenges to reaching a lupus diagnosis. Lupus is known as "the great imitator" because its symptoms mimic many other illnesses. Lupus symptoms can also be unclear, can come and go, and can change.

On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.

A majority (63%) of people with lupus surveyed report being incorrectly diagnosed. Of those reporting incorrect diagnosis, more than half of them (55%) report seeing four or more different healthcare providers for their lupus symptoms before being accurately diagnosed.

Thank you to all our Community Partners!

HOLUALOA® COMPANIES
Real Estate Investment & Development

THE LEHMAN
FOUNDATION

Albertsons® SAFEWAY

National Bank
OF ARIZONA

The Jones Family

Radiology Ltd.

ARIZONA
FINLEY
DISTRIBUTING

WELLS
FARGO

Catalina Pointe
Arthritis & Rheumatology Specialists, PC

Agero
Safe. Smart. Driven.

LONG REALTY
Cares
Foundation

THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Arthritis Center

JIM CLICK
HOLMES TUTTLE

Encompass Health
Rehabilitation Hospitals

Tucson
Medical
Center

LFSA Q & A SERIES

DR. ERNEST VINA, MD, MS - UA ARTHRITIS CENTER

Dr. Ernest Vina, MD, MS

LFSA: Why do you think lupus is so difficult to diagnose?

Dr. Vina: I think there are various reasons why that is the case. Lupus is often called the 'great imitator' because it has the same or similar symptoms as many other diseases. Arthritis is very common among lupus patients, but pain in the joints can also be due to other diseases, like osteoarthritis, rheumatoid arthritis, or even active infections. Lupus may present with the butterfly rash, or redness of the cheeks, but redness of the cheeks can also be due to different skin conditions or medication side effects. And lupus symptoms also tend to come and go and may only last for a few days, so people may ignore the symptoms and not go to the doctor right away, or by the time they see a doctor, the symptoms may already be gone. And there isn't one specific test for lupus. Many people, even many physicians, believe that having a positive ANA confirms the diagnosis, but this isn't true at all. A positive ANA is not highly specific, and it can be seen in patients with infections, those with other types of autoimmune diseases, and even in normal men and women without any disease.

LFSA: What is your protocol for working with patients who might have lupus, and what is it that helps you arrive at a diagnosis?

Dr. Vina: I base a diagnosis of lupus on patient symptoms and several different lab test results. I conduct a very thorough medical history, including what symptoms are most bothersome to the person, what other medical problems they have, what medications they are taking and their family history. I then perform a comprehensive physical examination. Based on all that information, I order a series of blood and urine tests, to confirm a diagnosis of lupus, but also to rule out other diseases that might mimic the symptoms of lupus.

LFSA: What advice would you give other doctors who treat lupus patients?

Dr. Vina: I would advise other physicians to not immediately attribute lupus patients' complaints or symptoms to lupus itself. For example, fever is a common complaint. But fever can also be due to an infection, a side effect of a medication, or it may be due to other conditions. Physicians need to conduct a thorough investigation when patients present them with varying symptoms that may seem like they are from lupus. Patients need to be treated based on the actual cause of the symptoms. I would advise physicians to listen to their patients very carefully, including their patients' medical history. Symptoms can be highly informative. In a lupus patient with a fever, for example, it's important to determine if it's a high or low grade fever, whether or not it's a recurring symptom, or if it's accompanied by other symptoms, like coughing. The patient's history may sometimes be enough to determine the cause of the patient's symptoms.

> *"I would advise other physicians to not immediately attribute lupus patients' complaints or symptoms to lupus itself..."*

LFSA: What research are you engaged in currently?

Dr. Vina: I have a strong interest in examining disparities in the outcomes of patients with autoimmune disease. Systemic lupus is much more common in racial and ethnic minorities. We know these patients tend to have worse outcomes than Caucasian patients with lupus. They have higher mortality rates, and they are more likely to develop complications.

(continued on following page)

(continued from previous page)

My primary research is focused on examining the factors that may contribute to these poorer outcomes. These factors may include demographic variables, but they may also include psychological factors and social factors like social support , beliefs and attitudes toward medication, providers, and the healthcare system itself. In Tucson more than a quarter of the population is Hispanic, so this is a particularly important issue to address. My intent is to improve the outcome of all patients with lupus regardless of their ethnicity or other personal identifiers.

LFSA: In your opinion, what are the connections between lupus, RA, and other autoimmune diseases?

Dr. Vina: An autoimmune disease is where a person's immune system mistakenly attacks their body. At this time we do not know the specific reason for this. We do know that some people have a genetic predisposition to developing autoimmune disease. Their genes may dictate whether or not they will develop a specific disease. We also know that environmental factors can contribute to the development of disease. Certain viruses have been implicated in the development of both lupus and rheumatoid arthritis. Hormones also play a part. Lupus and RA are much more common in women than in men. We also know that exposure to smoke or cigarettes can worsen the disease and can change people's response to medications.

LFSA: What are your predictions about future treatments for lupus and other autoimmune diseases?

Dr. Vina: In the last few decades we have been successful in developing biologic drugs that help treat patients with autoimmune disease. I predict there will be more research in the future to develop more of these biologic agents that can help treat patients with lupus. I also believe more research will focus on the efficacy of medications, but also on how we can improve lupus patients' quality of life without simply relying on medications. For example, exercise can significantly improve a person's well-being, and addressing mental health issues can significantly impact a person's life.

LFSA: Any final thoughts?

Dr. Vina: Lupus is a challenging disease to diagnose, and once diagnosed it can be even more challenging to treat due to the variety of symptoms that can mimic other conditions. It's a matter of being very thorough with a patient's history and physical examination. Other diseases must be ruled out in order to avoid confusion and to optimize treatment. With a thoughtful approach, patient outcomes can be greatly improved.

LFSA: Thank you, Dr. Vina, for taking the time to speak with us today!

Dr. Vina: Thank you!

THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Arthritis Center

1501 N. Campbell Avenue
PO Box 245093
Tucson, AZ 85724
(520) 626-5026

CLINICAL TRIAL CONSIDERATIONS: JUST THE BASICS ON CLINICAL TRIAL PARTICIPATION

by Debra Burge,
Arizona Arthritis and Rheumatology Associates

The drug development process begins with the discovery of a molecule. The molecule continues to evolve; passing through multiple phases of pre-clinical testing and clinical trials until FDA approval for marketed use is granted. Clinical trials are directed by a carefully designed protocol, conducted in a clinical setting (hospital or medical office), and strictly regulated by national and international regulations. During the clinical phases (or clinical trials) the drug is tested in humans and the majority of supportive data is collected. These clinical trials, more specifically the second and third phases, are dependent upon the participation of patients who have the diagnosis for which the medication is intended to treat. This is where the clinical trial volunteer comes in...

Clinical trial volunteers are, in my opinion, the absolute most important component of drug and interventional treatment development in the pharmaceutical industry. There are many valuable elements without a doubt; yet I see none as critically important as the people who consent to research participation. Without the participant in the clinical trial the opportunity for a molecule to be granted approval for prescribed use would be nonexistent. Clinical trial patients, or subjects as defined by the industry, are the heart and soul of every clinical trial. Much like a heart provides life to a person, the research participant serves as the muscle pumping life into an investigational medicinal product.

Where does one begin to look for a study? There are many resources available; I recommend starting with the national database in which every clinical trial conducted is required to register: www.clinicaltrials.gov. The website is very user friendly with verified and federally regulated information. This database is updated frequently so the most up to date information is provided. This website is the industry's central hub for information about current, past and upcoming clinical trials in the United States and globally. Each study listed in clinicaltrials.gov will have detailed information about the requirements for inclusion (what characteristics a patient must have to be eligible) and exclusion (characteristics that a patient cannot have to be eligible). Also included in the database are all the locations (or research sites) where the research is being conducted, the physicians in charge of the research at the site, and how many patients the trial is looking to enroll. Currently in the United States a total of 66[1] clinical trials are registered through www.clinicaltrials.gov as actively seeking Lupus patients in the United States.

Another important thing to be aware of when seeking a study to participate in, is the informed consent process. The informed consent document is provided to the patient which contains details of all the aspects of the trial. No patient can have information collected or procedures performed until the informed consent is signed by the patient, or patient’s legally responsible representative. The consent should be written in non-technical language, provide contact information for study staff, detailed information about the human subject’s protection, organization governing the research trial, risks and benefits involved with participation, information to be collected from the patient, procedures to be performed, the number of people needed, patient options other than participating in the trial, what the patient can do in the event something goes wrong while on a clinical trial medication and what will be done with the information obtained from the participant. A patient should be given as much time as they require until they completely understand the consent before they sign. Above all else a patient is NEVER to feel pressured sign the consent to participate. The patient is a volunteer, offering their time and personal information. The decision to withdraw is available at any time and without consequences to treatments or medical care.

> *"...trial volunteers are the absolute most important component of drug and interventonal treatment development..."*

(continued on following page)

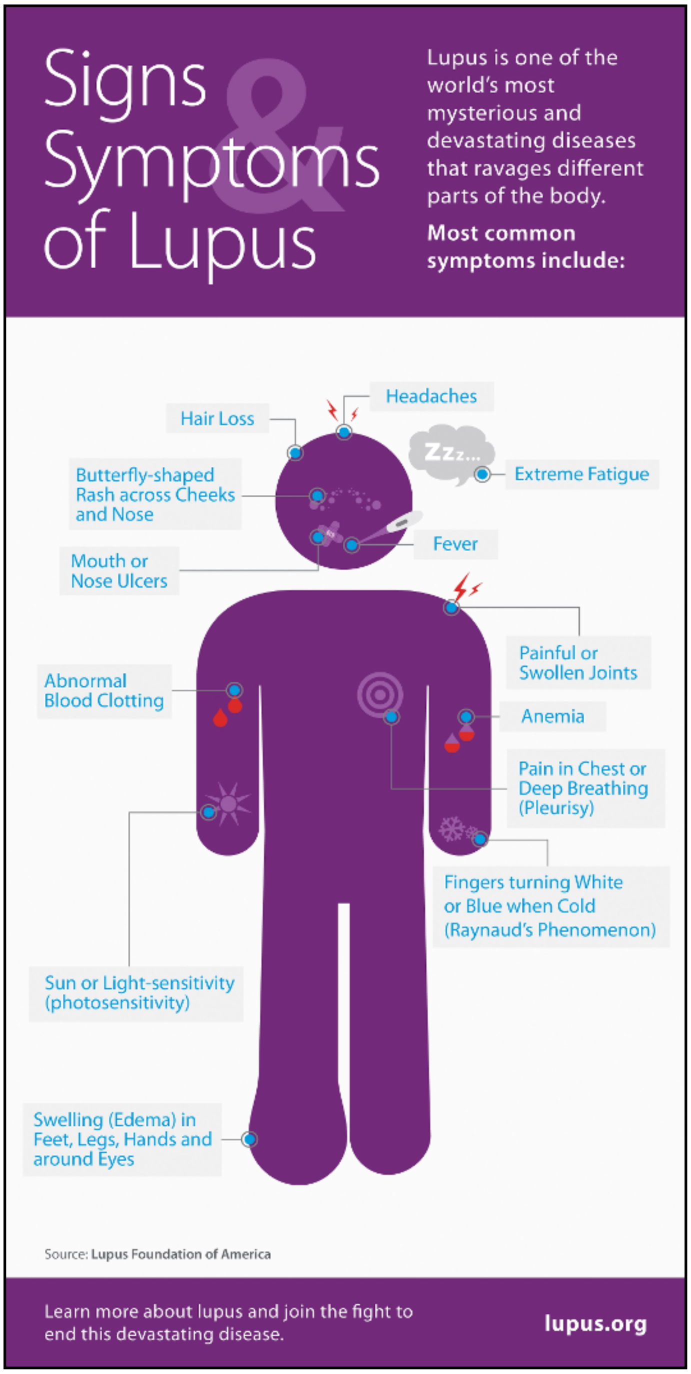
(continued from previous page)

Before I began conducting clinical trials in a rheumatology setting, I had minimal knowledge about Lupus or the many other autoimmune diseases. As I learn more and more, I am finding that Lupus is a disease that does not have many treatment options. It has multiple symptoms and frequent missed diagnoses and affects an estimated 322,000 Americans [2]. It's important to consider these factors and the limited treatment options available. As a research coordinator, I find a degree of empowerment in the role I play in hopefully helping to provide more ways of treating this disease. I find a sense of pride in patients who volunteer for clinical trials as well. They are kind-hearted people who grant science permission to explore, collect information and comprehensively evaluate their lives via their diagnosis. Taking an active role in the advancement and availability of treatments for a disease can be done through participation in clinical trials.

Clinical trials can often be misunderstood, like the Lupus diagnosis itself. Deciding to enroll in a trial is a personal decision. If in doubt, consult your physician. Knowledge of what the study requires of the participant, understanding the terms of the consent and speaking with family members or friends will help make the decision a little less daunting. Without participants of actual patients, understanding the safety of a medication and how well it will work is impossible. Popular jargon considers that participation in clinical trials makes a patient "a lab rat" or "guinea pig," as if a mad scientist with an evil laugh is going to cause green skin or a third eye in the patient being studied. Ethically conducted research is far from these images. I encourage readers to consider a clinical trial as a way of playing an active role in their treatment. More information about the rights and protection of a clinical trial patient can be found at www.fda.gov.

[1] www.clincaltrials.gov (accessed 11Mar2019); term: Recruiting Studies Lupus in the United states

[2] Helmick CG, Felson DT, Lawrence RC, et al. Estimates of the prevalence of arthritis and other rheumatic conditions in the United States: Part I. Arthritis Rheum. 2008;58(1):15–25. PubMed PMID: 18163481. doi: 10.1002/art.23177.



Lupus is one of the world's most mysterious and devastating diseases that ravages different parts of the body.

Most common symptoms include:

Source: Lupus Foundation of America

Learn more about lupus and join the fight to end this devastating disease.

Marisela Gregory is a lupus patient and attendee of various LFSA support groups and events. She recently presented at our Living with Lupus support group where she gave a talk on the benefits of exercise.

LFSA: When did you first learn you had lupus?

Patient: It was 2008 through my primary doctor. They had me on heavy pain meds and the doctor decided I should be checked for lupus.

LFSA: What were your symptoms at the time?

Patient: A lot of fatigue, joint pain.

LFSA: Did you go to a rheumatologist?

Patient: My primary care doctor referred me to a rheumatologist.

LFSA: How quickly did you get your diagnosis?

Patient: It was actually quick. After the lab work, my doctor called me in for a follow up and that's when she told me.

LFSA: What was it like when you found out?

Patient: I think I had started preparing myself, so when she told me, I didn't feel so shocked, but when I went home afterwards I started crying. I said 'wow, I have it' and it finally hit me.

LFSA: What are you doing to manage your symptoms?

Patient: I started eating better, avoiding gluten, dairy, legumes, and nightshades. I exercise daily. Nothing strenuous, just something that gets me moving. I give myself one day off. I stick to a bedtime routine that involves unwinding, turning off electronics, taking medications. I make sure I take all the medications and supplements the doctors give me.

LFSA: What medications are you taking?

Patient: My doctor has me on lots of supplements. He's also recommending low-dose naltrexone, which is something I haven't tried yet.

LFSA: You teach exercise, correct?

Patient: Yes, I'm certified but not teaching currently. I'm working and have other things going on right now.

LFSA: How has exercise helped you with your symptoms?

Patient: Exercise has helped reduce stiffness in my joints. I would say I start off like an old car, but once I get moving, I feel a little bit more human. I keep reminding myself how I'm going to feel afterwards with the little energy boost that you get, and I like that feeling. That's what helps me get through the day.

> *"I wake up in pain and go to bed in pain. When you take care of yourself, whether through nutrition or exercise, that's what's going to help you find the balance."*

LFSA: What do you think your greatest challenge is right now?

Patient: Fatigue and pain. I wake up in pain and go to bed in pain. When you take care of yourself, whether through nutrition or exercise, that's what's going to help you find the balance. The pain never really goes away, but it does feel better when you're proactive.

LFSA: You need to feel some sense of control.

Patient: Yeah, that's a good way of describing it.

LFSA: Who are your biggest supporters right now, and how are they helping you?

(continued on following page)

(continued from previous page)

Patient: My older sister, my daughter, and my lupus buddies. Every time I call my older sister, she listens to me. A lot of people don't do that, and she'll listen to anything I have to tell her, and she's even said I'm her hero, because in spite of how I feel, I'm still doing what I'm doing. I just keep going. I don't give up. My sister saw me at the lowest point and she's seen how things have changed. My daughter is my biggest cheerleader. She says 'you can do it mom!'. We go for walks together. And then there are my lupus friends. They're the ones who truly understand how I feel. Joining the support group and meeting these amazing people has been great. They're always passionate, and it's nice that we can laugh together.

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

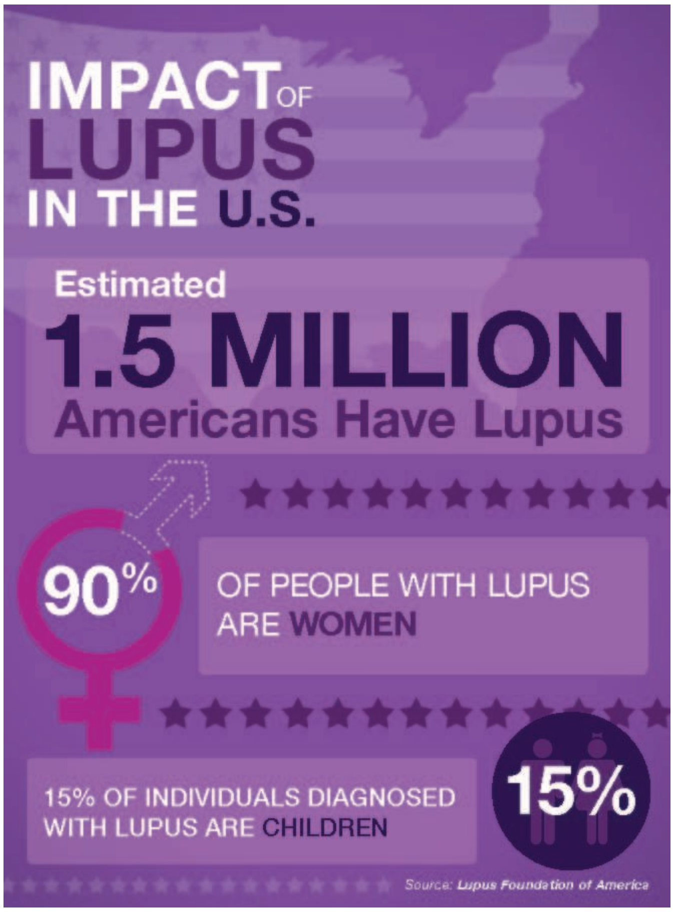
Patient: You're not alone on this journey. You have to reach out to others. You have to read about ways to help yourself, and don't be afraid to ask for help. I think we all need that little push, to get pointed in the right direction. The support group has helped me by telling me about doctors, different treatments. It's very helpful.

LFSA: Anything else?

Patient: There's something I wrote a few years ago:

In a perfect world, I would have no pain in my body. I would never say I'm glad I have so many aches and pains, but I will say that having aches and pains has reminded me to push myself more every day. They have motivated me to prove to my doctors that I will not give up doing the things I love. I may be slower but I haven't stopped. Life has taught me to make the best out of every situation. I'm thankful to all the beautiful people who have come into my life, and who have been an inspiration in one form or another.

And I still feel this way.



IMPACT OF LUPUS IN THE U.S.

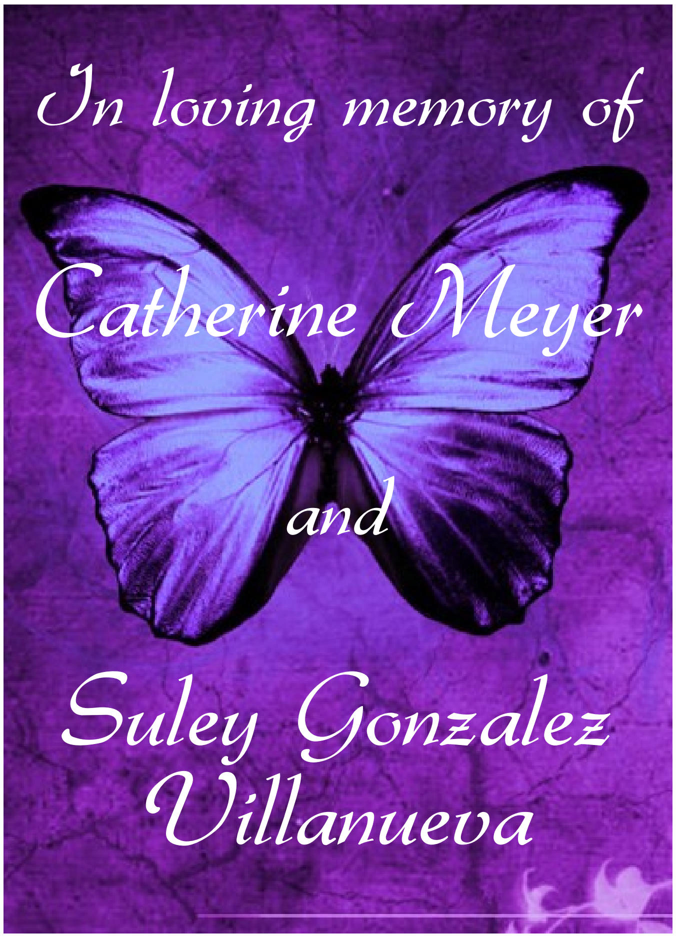
Estimated 1.5 MILLION Americans Have Lupus

90% OF PEOPLE WITH LUPUS ARE WOMEN

15% OF INDIVIDUALS DIAGNOSED WITH LUPUS ARE CHILDREN

15%

Source: Lupus Foundation of America



In loving memory of

Catherine Meyer

and

Suley Gonzalez Villanueva

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

THE LUPUS FOUNDATION
OF SOUTHERN ARIZONA

Community Education
LFSA Bi-Annual Magazine
Lending Library
Living with Lupus Outreach
Health Fairs

Monthly Support Meetings
Resource Kits
Counseling
Patient Retreats
LFSA Cares
Emergency Medical Fund
Education Scholarships

Annual Walk the Loop for Lupus
LFSA Gala
LFSA Golf Tournament