

LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



Spring 2018

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CALENDAR

November

4TH

LFSA Annual Gala

Save the date! Join us at the Skyline Country Club for the LFSA 4th annual Gala - Masquerade!

April

13th

Walk-the-Loop-for-Lupus

Save the date! Join us at Reid Park for the 18th annual Walk the Loop for Lupus.

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

Lani Baker, Treasurer

Shaima Namazifard, Secretary

BOARD MEMBERS

Wendy Black

Sherri Fritz

Donna Morton

Joanie Redford

LETTER FROM THE PRESIDENT



Watching this beautiful spring turn into summer, I feel excitement, gratitude and expectation. The Lupus Foundation participated in 5 health related events including 3 Health Fairs during January and March in Tucson, Benson, and Green Valley. Three events were staffed with the help of Lupus patients living in the area. Countless men and women stopped at our table for information or to tell us their stories about a relative or friend who has Lupus or a parent who died from Lupus. Some liked the color of our pens or were happy to receive a jar opener for their arthritic hands. Others wanted to know what exactly IS Lupus? We welcomed 6 "new to the foundation" Lupus patients. We made several important connections with people from Benson and Green Valley who were eager to help us spread the word about our programs for patients through community awareness. I'm excited to work with these communities to raise awareness and create a support system for Lupus patients closer to home.

We receive ongoing financial and in-kind donations throughout the year from sponsors, businesses, donors, neighbors, families, friends, and people who donate through their places of employment in Tucson and beyond. We wouldn't be able to do all we do without your generosity. Thank You! On April 14th we walked our Annual Walk the Loop for Lupus at Reid Park. We are grateful for our faithful sponsors, new sponsors, donors, vendors, volunteers, new and returning walkers, people who went the extra mile with their own Spring Fair to raise funds, who reached out to 114 co-workers, 32 co-workers, 14 family members, made signs, wore purple and had a fun time. A special shout out to the Coffee Talk Gals and the many additional Lupus patients who walked in gratitude and support.

The Founders began this organization 40 years ago! Yes. Happy Anniversary to Us! Today we reach out to patients, families, doctors, service groups and others to help patients live with Lupus in the best ways they can. Our direct programs are strong. The April Women's Retreat hosted 12 women at Westward Look, including 6 new retreatants, one from a health fair and another from the Annual Meeting/Open House. Coffee Talk meets at 6 pm the 1st Wednesday of the month to provide peer support while welcoming new patients. Living with Lupus meets the 3rd Wednesday of the month to explore with speakers and among ourselves Lupus topics related to health, nutrition, medication and self-care.

Finally, I have great expectations for the Lupus Foundation and the work we are doing. We will be reaching out this summer to physicians, ophthalmologists, rheumatologists and other service and business professionals to let them know we are here and to invite them to help us help Lupus patients.

Save the date! Our 4th Annual Gala is November 4, 2018. Plan to come to the Masquerade, have some fun and help the cause.

Happy Summer!

Sharon Joseph, President



LFSA IN THE COMMUNITY

LFSA SCHOLARSHIPS - MELISSA WATTS



Melissa Watts

LFSA: How did you learn about the LFSA Scholarship program?

Recipient: When I was first diagnosed with lupus I was trying to figure out how to pay to continue my education. I decided to look up lupus scholarships and your website came up. I clicked on the

scholarship link and applied for the scholarship. I had been in school for a really long time, at least eight years. I received the LFSA scholarship a year ago and I have one year left before I graduate with a master's degree in Business Administration, specializing in project management.

LFSA: Where do you think you'll go once you graduate?

Recipient: I'm really hoping to get into the field of project management, however it will depend on my health. Otherwise, with my degree I can work for pretty much any business.

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

Recipient: Having lupus has affected my ability to work and attend school tremendously. It took a while to get my diagnosis. I had to cut back on working full time. I had to move back in with my family. Because of my lupus I haven't been able to absorb as much information in school as I would like to. I feel fatigued and drowsy most of the time. This is different from normal tiredness, like after a long work day. I used to work several jobs to put myself through school. Now I'm too fatigued to do that. Sometimes I sleep up to ten hours at night just to manage my symptoms.

LFSA: How has our scholarship program helped you specifically?

Recipient: I haven't been able to work as many hours as I would like to pay for school. If it weren't for the LFSA scholarship I probably

wouldn't have been able to continue with my master's degree program.

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

Recipient: No amount of money can make someone who's sick better. But it really helps immensely when there are people who can help you accomplish what you want to accomplish. My family is my biggest source of support. They're very upbeat, optimistic people. They keep me moving forward to pursue my goals, regardless of being sick. I also want to say that the Lupus Foundation of Southern Arizona has helped immensely. Without you I would not have been able to continue my education.

LFSA: We're so happy we were able to help. Let us know if there's anything else we can do for you!



WOMEN'S
FOUNDATION
of Southern Arizona

Create change. Invest in women.



LFSA WOMEN'S RETREAT SPRING 2018

WESTWARD LOOK RESORT HOTEL

This spring's LFSA Women's Retreat was a huge success with twelve women participating. The retreat was held at Westward Look Resort Hotel in the Catalina Foothills. Amanda Freed, of Align Tucson Meditation, led the group in an exercise titled "Changing Your Narrative" which asked attendees to take care of themselves first, explore their strengths and weaknesses, use what works to help them through the ups and downs of living with lupus and envision a future with positive outcomes. Attendees enjoyed meals prepared by the resort's talented kitchen staff and spent part of the afternoon painting mugs under the guidance of Nathalie O'Shea, one of the participants.

*Thank you for
this "time away"
to rest, recharge,
and remember
I am me!*

Melissa D.

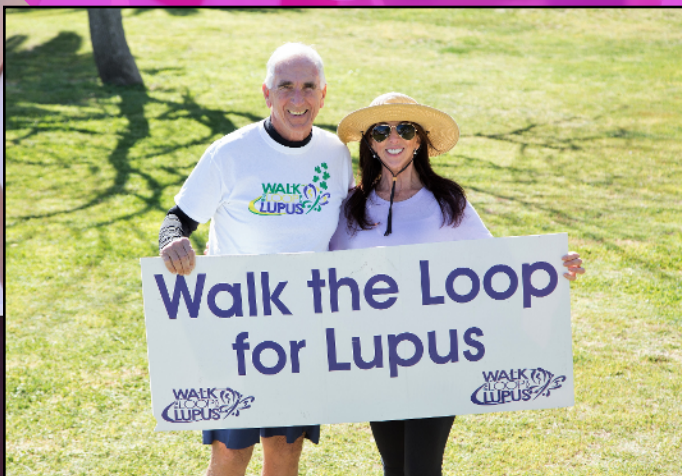


Thanks!

the **WALK**
LOOP FOR
LUPUS



*Thanks to everyone
who made this year's
Walk the Loop for Lupus
a wonderful success! See you next year!*



UV SUN EXPOSURE: WHAT YOU NEED TO KNOW

If UV light flares your lupus, you want to create a barrier between you and it:

Apply a liberal layer of a 30 SPF or higher sunscreen, one that provides broad-spectrum-protection against both UVA and UVB rays.

Wear tightly woven clothing that covers your skin, a wide-brimmed hat, and wraparound sunglasses to protect you from head to toe.

Choose light bulbs that have the lowest possible irradiance (intensity).

Cover fluorescent and halogen bulbs with light shields or glass that filters out UV rays. Look for shields with readings of 380 to 400 nanometers, which filters all types of ultraviolet light.

Use UV-blocking shades to cover windows and prevent sunlight from streaming in.

Consider tinting the windows of your car—check state laws on window tinting to see if a doctor's note is required.

-2018 National Resource Center on Lupus



Call for volunteers!

Fundraising – if you know people who might be willing to support the Lupus Foundation of Southern Arizona. If you are willing to invite them to be a sponsor for one of our 3 major fundraisers, take part in the Golf Tournament, attend the Annual Gala, or donate an item to our Silent Auction, we encourage you to call us at 520-622-9006. Remember, all donated funds remain in Southern Arizona.



Office Help – if you have a few hours to spare, we need someone to help keep the library in working order. We periodically need help compiling Welcome Kits for new patients, processing event mailings and information packets and other office tasks. Please call us at 520-622-9006.

Walking Help – if you have time to help before our major fundraising events, we usually need help to pick up t-shirts and other items, deliver Walk posters and flyers, Golf Tournament and Gala flyers. Or, if you're interested in helping before or during our main fundraising events, or delivering information packets to offices, let us know. If you want us to add your name to this list, please call us at 520-622-9006.

LUPUS INFORMATION

Statistics everyone should know about lupus

Lupus News Today - 7/10/2017

Lupus is a difficult disease in many ways, but one of the hardest parts for lupus sufferers is diagnosis. There isn't a simple test that patients can take to tell doctors they have it, and it often takes a while to arrive at the correct diagnosis.

Because lupus is known as "the great imitator," it takes an average of six years for people to be diagnosed with it after they start presenting symptoms.

We've gathered statistics from both Right Diagnosis and the National Resource Center on Lupus to give you a little more insight into this often misunderstood disease.

About 63 percent of people with lupus were originally incorrectly diagnosed, which is something that must be taken into account when reviewing lupus statistics. Nobody can be sure how many people with the disease may have been misdiagnosed, or are still living with an incorrect diagnosis. Because lupus is known as "the great

imitator," it takes an average of six years for people to be diagnosed with it after they start presenting symptoms.

There are roughly 1.5 million Americans that are currently living with lupus, and approximately one in every 250 people may end up developing it at some point in their lives.

Lupus is a predominantly female disease: 90 percent of lupus patients are female and a major subset are women of color. A recent survey found that one in every 537

African-American women is affected by the disease.

Lupus develops mainly in individuals between the ages of 15 and 44, however, a survey

showed that 73 percent of Americans between the ages of 18 to 34 have either no knowledge of the disease or barely know more than its name.

About 78 percent of people that have lupus reported that they're handling it well and 84 percent said members of their family are their main support network.

There might be a direct correlation between the fact that patients identify family members as their main support system and the fact that genes play a significant

role in lupus. Twenty percent of people that suffer from lupus have either a parent or sibling with the disease. Even if they don't have a family member who has lupus, there's still a very big chance they have a family member with another autoimmune disease.

Lupus can be divided into four types: the systemic, which accounts for about 70 percent of cases; the cutaneous, which accounts for around 10 percent; the drug-induced, which is responsible for about 10 percent; and finally the neonatal, which is rarer and doesn't have a fixed percentage.



Do you take Hydroxychloroquine to treat your RA or Lupus?



See your optometrist every 6 months.

One of the potential side effects of Hydroxychloroquine is permanent vision loss.

Epstein-Barr virus protein can “switch on” risk genes for autoimmune diseases

EBV may trigger some cases of lupus, say NIH-supported researchers.

National Institutes of Health - 4/16/2018

Infection with Epstein-Barr virus (EBV), the cause of infectious mononucleosis, has been associated with subsequent development of systemic lupus erythematosus and other chronic autoimmune illnesses, but the mechanisms behind this association have been unclear. Now, a novel computational method shows that a viral protein found in EBV-infected human cells may activate genes associated with increased risk for autoimmunity. Scientists supported by the National Institute of Allergy and Infectious Diseases report their findings today in *Nature Genetics*.

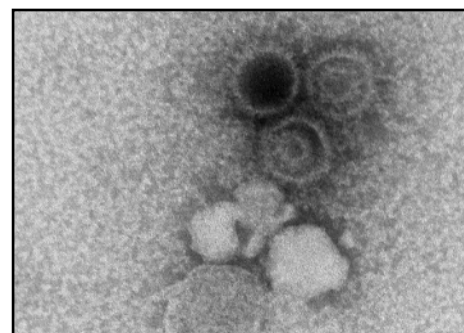
“Many cases of autoimmune illness are difficult to treat and can result in debilitating symptoms. Studies like this are allowing us to untangle environmental and genetic factors that may cause the body’s immune system to attack its own tissues,” said NIAID Director Anthony S. Fauci, M.D. “A better understanding of the complex causes of autoimmunity promises to lead

to better treatment and prevention options.”

EBV infection is nearly ubiquitous in the human population worldwide. Most people acquire EBV in early childhood, experience no symptoms or only a brief, mild cold-like illness, and remain infected throughout their lives while remaining asymptomatic. When infection first occurs in adolescence or young adulthood, EBV can lead to a syndrome of infectious mononucleosis characterized by prolonged fever, sore throat, swollen lymph nodes and fatigue. This syndrome, also known as “mono” or the “kissing disease,” generally resolves with rest and only rarely causes serious complications.

When EBV infects human immune cells, a protein produced by the virus — EBNA2 — recruits human proteins called transcription factors to bind to regions of both the EBV genome and the cell’s own genome. Together, EBNA2 and the human transcription factors change the expression of neighboring viral genes.

In the current study, the researchers found that EBNA2 and its related transcription factors activate some of the human genes associated with the risk for lupus and several other autoimmune diseases, including multiple sclerosis, rheumatoid arthritis, inflammatory bowel disease, type 1 diabetes, juvenile idiopathic arthritis and celiac disease.



An electron microscopy image showing three Epstein-Barr virions. NIAID

Previous studies suggested that EBV infection may result in autoimmune diseases, particularly lupus. In the current work, researchers led by John B. Harley, M.D., Ph.D., director of the Center for Autoimmune Genomics and Etiology (CAGE) at Cincinnati Children’s Hospital Medical Center, with his colleagues Matthew T. Weirauch, Ph.D., and Leah C. Kottyan, Ph.D., also of CAGE, wondered whether genetic analysis could further explain the relationship between EBV infection and lupus. Their team developed a new computational and biochemical technique known as the Regulatory Element Locus Intersection algorithm, or RELI. Sifting through and comparing a large collection of genetic and protein data from healthy individuals and those with autoimmune diseases, the team used RELI to identify regulatory regions in genes associated with the risk of developing lupus that also bound EBNA2 and its related transcription factors.

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"We were surprised to see that nearly half of the locations on the human genome known to contribute to lupus risk were also binding sites for EBNA2," said Dr. Harley. "These findings suggest that EBV infection in cells can actually drive the activation of these genes and contribute to an individual's risk of developing the disease."

In follow-up analyses, the investigators used RELI to probe regulatory genes associated with other autoimmune diseases and found that EBNA2 bound to genes associated with the risk for multiple sclerosis, rheumatoid arthritis, inflammatory bowel disease, type 1 diabetes, juvenile idiopathic arthritis and celiac disease.

"Because EBV is most often encountered in early childhood, avoiding infection is practically impossible," said Daniel Rotrosen, M.D., director of the Division of Allergy, Immunology and Transplantation at NIAID. "However, now that we understand how EBV infection may contribute to autoimmune diseases in some people, researchers may be able to develop therapies that interrupt or reverse this process."

Researchers note that EBV infection is not the only factor that contributes to the development of the seven autoimmune conditions discussed in the paper. Many of the regulatory genes that contribute to lupus and other autoimmune disorders did not interact with EBNA2, and some individuals with activated

regulatory genes associated with disease risk do not develop disease.

Study suggests altering gut bacteria may put lupus into remission

Michael Jurgelewicz DC DACBN
DCBCN - 11/3/2014

The connection between the gut and autoimmune disease is in the news once again. Just this past month a journal article was published on the changes in intestinal barrier function (leaky gut) with multiple sclerosis. Researchers suggested that future drugs to treat MS should not only focus on the central nervous system but also on the intestines by repairing and restoring the intestinal barrier. It's important to remember that the gastrointestinal tract is 80% of our immune system. Whenever inflammation is present the tight junctions and intestinal mucosa can become damaged causing gaps or pores in the lining of the GI tract. Then toxic byproducts in the digestive tract can be absorbed into the bloodstream and transported to the liver. The molecules of food and toxins are leaked through the GI lining and eventually they affect systems throughout the body causing joint inflammation toxins expressed in skin disorders autoimmune conditions and food

sensitivities.

There has been a sharp increase in the incidence of autoimmune disorders over the past several decades. Why is this occurring? The answers may be found in the current medical research but you would probably never know it by visiting a doctor. The above mentioned study is a perfect example between the big disconnect between medical research which is often outstanding and the practice of traditional medicine which often leaves quite a bit to be desired when it comes to the management of chronic disorders.



The typical allopathic clinical approach to autoimmune diseases focuses on the management of symptoms with various anti-inflammatory medications chemotherapeutics and also very potent immunosuppressive agents with serious potential side-effects like leukemia and lymphoma. These approaches certainly can provide substantial relief to the patient but they do not really get to the cause of these conditions and some research suggests that these approaches may result in a furthering of the pathological process.

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Gut bacteria has been identified as an important environmental factor in overall health and autoimmune disease. A recent study demonstrated the role of the gut microbiota in lupus. According to research published in *Applied and Environmental Microbiology* *Lactobacillus* species were shown to reduce the severity of lupus symptoms while *Lachnospiraceae* a type of *Clostridia* correlated with a worsening of symptoms.

In this study researchers presented that mouse models of lupus had higher levels of *Lachnospiraceae* and lower *Lactobacillus* than control mice. In addition they compared male and female mice and found that the differences were present only in females. These results suggest that the gut bacteria may contribute to lupus a disease which is much more common in women. Also the gut microbiota was monitored over time in both lupus and control mice. As a result they found that *Clostridia* was increased in both early and late stages of the disease.

In further experiments the team treated the symptoms in the lupus mice with either retinoic acid alone or vitamin A with retinoic acid. The latter worsened the symptoms which was surprising since it had been expected to reduce them. In these mice *Clostridia* increased and *Lactobacillus* decreased. However retinoic acid alone did improve the symptoms and the dysbiosis.

The research suggests that altering the gut microbiota

could help lead to a remission of lupus. Thus patients with lupus should consume *Lactobacillus*-containing probiotics to aid in reducing lupus exacerbations. The use of probiotics prebiotics and antimicrobials can improve the microbiota and reduce lupus symptoms.

The team was inspired to perform this research based upon a study where type 1 diabetes was found to be dependent on gut microbiota. Type 1 diabetes and lupus are different diseases but all autoimmunity has the same common environmental triggers. It would be beneficial if every patient with autoimmune disorders underwent a comprehensive digestive stool analysis (in my opinion and which modern research supports). There are several other factors to consider that play a role in autoimmunity such as gluten intolerance food sensitivities gastrointestinal infections heavy metal toxicity and vitamin D deficiency.



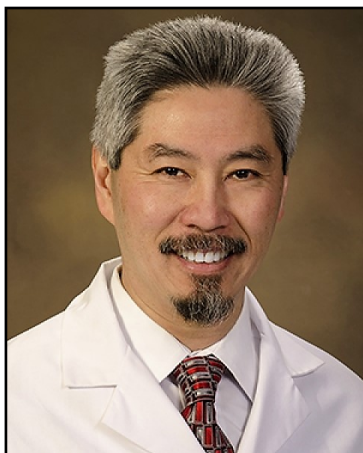
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DR. KENT KWOH, MD - UA ARTHRITIS CENTER



Dr. Kent Kwoh, MD

LFSA: Why is lupus so difficult to diagnose?

Dr. Kwoh: Lupus is difficult to diagnose because it has so many different manifestations. Many different organs can be involved and that involvement may be mild or severe.

Common manifestations are

often non-specific. Joint pain, fatigue, weight loss and anorexia are seen in many different diseases and are not specific to lupus. Another problem is there is no single test to diagnose lupus. The ANA is often used but is non-specific and can read positive for other diseases besides lupus. A variety of other tests can also be performed, but again these tests are not specific to lupus. There are classification criteria for lupus, but those criteria are most commonly used in clinical trials. They aren't typically used in doctors' offices to diagnose lupus.

LFSA: Is there a specific protocol or best practice for working with a patient who might have lupus?

Dr. Kwoh: A good medical history and solid physical exam are important. Gathering data about different systems is critical. This data might point toward lupus or some other connective tissue disease. It's also important to understand that there are patients who may not meet typical lupus criteria. We sometimes diagnose these patients as having undifferentiated connective tissue disease. We also want to make sure patients don't have other connective tissue diseases like Sjogren's Syndrome or rheumatoid arthritis. There are patients who have what's known as mixed connective tissue disease that has its own ANA markers. There's even an entity called 'rhupus' where the patient manifests symptoms of both rheumatoid arthritis and lupus. What's important here is that we are treating people, not blood tests.

LFSA: What are the connections between lupus, rheumatoid arthritis and other autoimmune diseases?

Dr. Kwoh: These diseases are multi-factorial, meaning that the pathogenesis has many different causes. There's often a genetic feature but these are polygenic disorders involving multiple genetic markers. And the same genetic markers may show up differently in different individuals. There are also environmental factors. Sun exposure is problem for lupus patients who are not able to process damage from the sun, causing their bodies to produce antibodies. This is why sun protection is so important for lupus patients. In addition there is growing evidence that the microbiome is important in people struggling with autoimmune disease.

LFSA: It's interesting that you mention the microbiome. We've been hearing more and more about this in the popular press.

Dr. Kwoh: The microbiome is increasingly being recognized as an important factor in terms of the pathogenesis or cause of many different diseases. The microbiome is an incredibly complex system. People are aware that there are bacteria in our mouth and colon, but actually there are bacteria all over our bodies, as well as viruses and fungi, some living in places people aren't commonly aware of. When we look at the DNA in our own cells versus the microbiome, our own genetics comprise only a tiny fraction of the overall picture. It's a little mind boggling. Going forward, it's important that we recognize which parts of the microbiome are involved in disease creation, and which ones aren't.

LFSA: Is the Arthritis Center involved in any research related to the human microbiome?

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LFSA Q & A SERIES

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Dr. Kwoh: Joyce Wu, PhD., associate professor of immunobiology here at the University's College of Medicine, has done some important work in this area. She has observed a specific type of bacteria triggering immune cells in the gut that can lead to systemic manifestations. We're planning a series of studies to look at this in more detail, starting with studies in lupus mouse models, then progressing to studies in human patients. We're hoping to identify differences in human immune systems that may be triggered by the microbiome. This in turn could lead to exciting new therapies designed to target these disruptions.

LFSA: That's very exciting! It sounds like the human microbiome might one day be the key to unlocking many health problems.

Dr. Kwoh: I would caution patients about the microbiome. There's a lot of interest in probiotics and how they affect the microbiome. However, there really haven't been any studies that show that certain probiotics work. The other problem is knowing what probiotic to take and how much might be beneficial. There are studies underway but it's still too early to claim anything definitive.

LFSA: We hear stories from lupus patients about doctors who don't listen, or who say a person's symptoms are 'all in their head'. What advice do you have for doctors working with lupus patients?

Dr. Kwoh: It's very important to listen to your patients and keep an open mind. The manifestations of disease may not be obvious or straight forward. It's not always what the doctor can see. It's more about what the patient is experiencing. Symptoms can manifest in a variety of ways and in varying levels of severity. Often times it's very subtle, and what looks like lupus today can look like something else tomorrow. That's where an experienced practitioner can really be of service. It's like putting together a puzzle. The different manifestations can occur over time and may not be present all at once, so a good history is critical to proper diagnosis and treatment. It's really like a tapestry. You need to see the whole picture in order to appreciate what's actually going on. Another factor is that

patients with lupus can have fragmented care. They often see multiple doctors with different specializations. It's important for these doctors to communicate and for patients to advocate for this to happen.

LFSA: That's a great answer to a complicated question. And it's basically how we counsel patients here at the Foundation.

Dr. Kwoh: It's great that the Lupus Foundation exists to educate lupus patients and others in the community about lupus.

LFSA: The UA Arthritis Center has been very helpful in providing support in that area. We look forward to asking additional questions about the Center and its research in a follow up interview. Thank you so much for speaking with us today, Dr. Kwoh. Perhaps we'll see you at our upcoming Gala in November?

Dr. Kwoh: I'm looking forward to attending!



THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON

Arthritis Center

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

Esperanza Nuñez has been involved with the Lupus Foundation of Southern Arizona for over five years and has attended numerous LFSA events. Here she shares some of her experiences as a lupus patient.



Esperanza Nuñez

LFSA: When did you first find out you had lupus?

Patient: I first learned I had lupus when I was living in Italy. My ex-husband and I were living there when he was stationed in the military. I woke up one morning and couldn't move from my neck down. It took me a few

months to finally get a diagnosis. I saw a nephrologist, a cardiologist and finally a rheumatologist who diagnosed me. This was in April of 2012. After that we moved back to the United States for treatment.

LFSA: How did you first react when you received your lupus diagnosis?

Patient: I was relieved to learn I had lupus and not something that couldn't be treated. I had some experience with lupus because my sister-in-law was diagnosed with it too, so I knew what to expect. The hardest part was that I didn't tell my mom, and she passed away two days after I was diagnosed. I was still in Italy and she was here in Tucson, so I didn't get a chance to tell her. I found out I had lupus, then my mom passed away, and a month later my husband filed for divorce. A lot of difficult things happened in one month.

LFSA: Any one of those things would be tough all by itself. Who helped you through that difficult time?

Patient: My dad, who lives here in Tucson, has been my biggest supporter. He's kind of my rock. My nephew, who I've helped raise, has also been a huge support. He's been here for me, giving me a reason to keep going. He's nine years old. I'm really the only mother figure in his life since his

mother is estranged from the family. It's been great to have such strong family support since my diagnosis.

LFSA: Family support is one of the things we encourage here at the Foundation.

Patient: Some families struggle more than others, but mine has been a little more understanding since they've seen everything I've gone through. My dad knows I can't always get up and walk around. He'll help me run errands and things like that. My family members are pretty well educated about lupus and I'm always willing to answer their questions.

LFSA: What treatments have you tried to help manage your lupus symptoms?

I was relieved to learn I had lupus and not something that couldn't be treated.

Patient: I was on prednisone a long time, resulting in joint deterioration and hip replacement surgery. I had my left hip replaced in 2016. Right now what's working best is Benlysta. I've been receiving Benlysta infusions for almost two years, and it's kind of my wonder drug. Benlysta has allowed me to get off prednisone and meloxicam (a non-steroidal anti-inflammatory) and balance out my lupus. I still take plaquenil, and thankfully haven't experienced any side effects related to that medication.

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LFSA: Benlysta seems to be helping a lot of lupus patients these days.

Patient: It's really good if your body tolerates it. Some people try it for a year and it doesn't do anything. Sometimes it takes six, seven months, sometimes longer for your body to start to feel the effects. I'm now able to work, reduce my joint pain, go out and play in the park. I'm currently working full time in the front office of a physical therapy business. My boss is very understanding about my lupus and helps me when I need it.

LFSA: You just attended one of our women's retreats, didn't you?

Patient: That's right. I got to meet some new people and spend time with a few I've known from previous Lupus Foundation events. It was relaxing and informational. People came in and shared their stories. I really enjoyed it. And the food was amazing! We had great dinner conversations. It's nice sometimes to not talk about lupus, and just feel normal.

LFSA: We try to make our retreats as comfortable as possible. We're glad you were able to attend.

Patient: I love participating in your events. I'm attending the evening support group right now. I like how the evening meetings are a little less structured than the morning ones, which are usually about a certain topic. In the evening group we are able to talk freely about whatever we want. I think when you're newly diagnosed the morning group is great because you're learning about your illness. You have nurses and other professionals coming in, teaching you things. That gives you a direction. The evening group is great once you have a sense of your illness and what it means to be living with lupus.

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

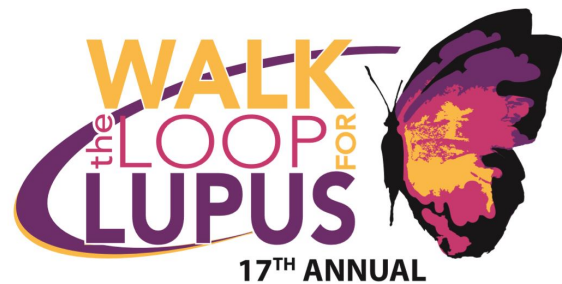
Patient: Be your own advocate. It's not always what the doctors say, it's how you feel. It might feel like you're in the deepest, darkest hole, but things do get better. It just takes time.

LFSA: So plenty of patience with the process?

Patient: Oh yes, definitely.

LFSA: Anything else before we let you go?

Patient: I just want to say thank you to the Lupus Foundation for hosting support groups for people like me. Being able to talk to other lupus patients, to have a support system, is very much appreciated.



We have t-shirts for sale! Contact the LFSA at 520-622-9006 or by email at info@lupus-az.org to get yours today!



THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



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

***Annual Walk the Loop for
Lupus***
Annual LFSA Gala
LFSA Golf Tournament



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