

# LUPUS FOUNDATION OF SOUTHERN ARIZONA



*Fall 2016*  
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# CALENDAR

November

13<sup>th</sup>

## 2ND ANNUAL LFSA GALA

Join us at the Lodge at Ventana for the 2nd Annual LFSA Gala. Check our website for registration and additional information.

## 3<sup>RD</sup> 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.

## 1<sup>ST</sup> 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.

For more information, visit [www.lupus-az.org](http://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

REBECCA SHIELDS, PRESIDENT  
LANI BAKER, VICE PRESIDENT  
SHERRI FRITZ, TREASURER  
SHAUNNA KOWALEWSKI, SECRETARY

## BOARD MEMBERS

WENDY BLACK      DONNA MORTON  
SUE THOMAS      BILL MURPHY  
RICARDO HINDS      SHAIMA NAMAZIF  
LINDSEY EZELL

# LETTER FROM THE PRESIDENT



With the Holiday season right around the corner, I would like to take pause and thank everyone involved in our two very successful events this year. Our 15th Annual Walk-the-Loop-for-Lupus in April was a great success, as was our Hit-the-Links-for-Lupus in May. I would like to thank our sponsors, community partners, donors, members, walkers, golfers, and all who participated to generate resources for the organization this year. Our hearts at LFSA are warmed knowing that the community believes in our mission and cause in serving the Lupus community of southern Arizona.

It has been a busy 2016 for LFSA. Our very active Board continues to amaze – adding a new program this summer. Our first Couple's Retreat was held in July, and has been added to our already thriving programs: Women's Retreats, Camps for Kids, Emergency Medical Fund, the LFSA Scholarship program, LFSA Cares and LFSA for Kids. If you are interested in any of our programs, please visit our website at [www.lupus-az.org](http://www.lupus-az.org) for details.

LFSA's awareness campaign is in full-force as we continue our outreach throughout southern Arizona bringing awareness of Lupus and LFSA. Coffee Talk and Living with Lupus support group meetings continue to promote advocacy for the Lupus community, helping patients become more informed, and providing a safe and supportive forum for sharing. The calendar for these meetings are also posted on our website.

*"As LFSA continues to bring the Lupus community together, please know that you are not alone! You – the patient, caregiver, friend or relative are NOT ALONE!"*

We are delighted Glaxo-Smith-Kline and TMC are partnering to provide an informative presentation on Managing your Lupus on October 26th. And, please don't miss our 2nd Annual LFSA Gala on November 13th as we honor our founding members. Details for both events are posted on our website, or you can call our office at 520-622-9006.

As LFSA continues to bring the Lupus community together, please know that you are not alone! YOU – the patient, caregiver, friend, or relative are NOT ALONE! This disease impacts so many more lives than the patient, and the Foundation is here for all of you. Whether you are newly diagnosed, have had Lupus for some time, or are impacted by someone with Lupus, we implore you to reach out and stay in touch with us, either by phone or visit, through Facebook or on our website, as we welcome your input, your journey, your thoughts, and your needs.

*Rebecca Shields*, President

**Interested in attending an  
LFSA event as a PARTICIPANT OR  
a VOLUNTEER? CONTACT US AT  
520.622.9006**



## Support

- Monthly Support Meetings
- Resource Kits
- Counseling
- Retreats
- Emergency Funds
- Educational Scholarships
- Camp for Kids



## Awareness/Education

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



## Community Events

- Annual Walk the Loop for Lupus
- Hit the Links for Lupus Golf Tournament
- Annual LFSA Gala



# LFSA IN THE COMMUNITY

## LFSA THERAPEUTIC WOMEN'S RETREAT

In May 2016, LFSA held a therapeutic women's retreat. The event was held at the Omni Tucson National Resort.

The weekend included various activities such as a salsa making competition, journaling and vision board crafts, great food and conversations. Women's Retreats are held twice a year. Please let us know if you are interested in attending.



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*"Thank you for the chance of being able to join the Women's Retreat. It was a really fruitful experience. Glad to have known more wonderful women."* Dulce LFSA Retreat Participant

*"Thank you so much. I loved my time with the group!"* Melissa, LFSA Retreat Participant

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## LFSA THERAPEUTIC COUPLE'S RETREAT

In July 2016, LFSA held its first retreat for couples. Attendees included lupus patients and their significant others. The retreat was held at the Westward Look Resort. The weekend included various activities such as a sangria making challenge, vision boards, Reiki therapy, mediation and stress management sessions, great food and conversations. Please let us know if you are interested in attending.



*"Bob and I would like to thank you for including us in the Couple's Retreat. It was a wonderful time, and the resort was marvelous. We truly enjoyed every aspect of the activities. I especially enjoyed the Reiki session. To be able to meet others who are coping with Lupus, and to see the support that our spouses offer, makes it easier to know that we are not alone in this fight. We made some new friends and were able to spend time with old friends. What a*

*wonderful time, and I hope that the Foundation can continue to offer programs like this to others. Thank you again for including Bob and me, we had a wonderful time."* Terry & Bob LFSA Retreat Participants





# LFSA IN THE COMMUNITY

## LFSA CARES FINANCIAL HARDSHIP FUND

Dulce is involved in many of the programs that LFSA offers including the Living with Lupus Support Group and Therapeutic Retreats for Women. The well at Dulce's home has been in disrepair for the last four years. The LFSA Cares Financial Hardship Fund coordinated and paid for Dulce's well to be fixed so she can once again have running water.



For the past four years in South Tucson, Dulce has been living in a mobile home without running water



Starting in the summer of 2016, LFSA launched its Camp for Kids Scholarship program. The scholarship is available for kids who are impacted by lupus. The funds can be used for day camp, overnight camp, etc. for camps throughout the year - Summer Break, Fall Break, Winter Break, etc.

## LFSA CAMP FOR KIDS SCHOLARSHIP



### LFSA SUMMER CAMP SCHOLARSHIP

SUMMER CAMP FOR KIDS IMPACTED BY LUPUS



The Lupus Foundation of Southern Arizona is offering summer camp scholarships to kids who are impacted by lupus.

You pick the camp, we pay the cost up to \$150 per child.

\*Funds are limited, please contact us for more information.

Email: [info@lupus-az.org](mailto:info@lupus-az.org)  
Call: 520.622.9006





# LFSA IN THE COMMUNITY



## DID YOU KNOW?

- 2/3 of lupus patients experience sensitivity to UV light that can cause fever, debilitating fatigue, joint pain, rashes, and more.
- Factors that can trigger a lupus flare include stress, infection, UV light, and some medications.



## DID YOU KNOW?

- Lupus treatments can dramatically reduce a person's immune system and leave them prone to serious infections and illnesses.
- Infection is the second leading cause of death for lupus patients.



## DID YOU KNOW?

- 80% of those with lupus report experiences of debilitating fatigue, some to the point of forcing them to stop working.



## DID YOU KNOW?

- On average, people with lupus take 8 prescription drugs to manage their condition.
- Only 1 FDA approved drug has been developed to specifically treat lupus. It was approved in 2013.



## DID YOU KNOW?

- Many people with lupus suffer from joint and muscle pain.

## LFSA RESOURCE KITS

LFSA Resource Kits are available for lupus patients served by LFSA. Come into the office or join us for a Living with Lupus or Coffee Talk meeting to get your kit.



## AMY'S BLANKETS

Amy's Blankets are given to lupus patients to provide comfort and warmth. See more on Amy's story below.

### This blanket is in honor of Amy Ross.

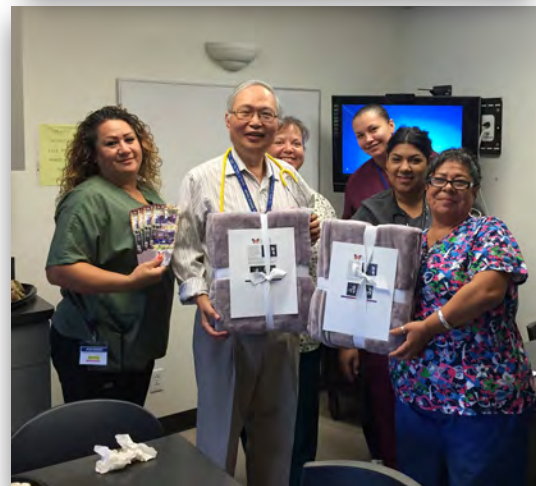
Amy and her husband, Derrick, performed as the musical folk duo "Nowhere Man and a Whiskey Girl". Amy and Derrick were married for 13 years and deeply in love. Amy was diagnosed with lupus as a young adult. One of the complications she endured was kidney failure, requiring chronic dialysis. In October 2013, after a 19-year battle with lupus, Amy passed away at the age of 40.



After her passing, Amy and Derrick's friends, family, and fans came together, and continue to do so every year, to bring awareness and raise funds for programs related to lupus.

During the many years of dialysis, Amy would comment to her family how cold she was during her treatments. With this in mind, LFSA designed a blanket for others who are undergoing lupus treatments to provide comfort and warmth. Through this, LFSA also wants to show how even the simplest gesture can have a meaningful impact on someone struggling with a chronic illness.

This blanket is provided to you by LFSA in honor of Amy's memory and the lasting effect she has had on the lupus community in southern Arizona.





# LFSAEVENTS



The Lupus Foundation of Southern Arizona's 15th Annual Walk the Loop for Lupus was a huge success with over 600 walkers. Thank you to everyone who participated!

The 2016 Walk the Loop for Lupus was presented by Miller Coors, a proud partner and supporter of the LFSA.



**Save the Date: 2017 Walk the Loop for Lupus April 22nd**



Thank you to all of the sponsors and golfers who participated in the 2016 Hit the Links for Lupus at Omni Tucson National. It was a fun day of golf and a great fundraiser that will help LFSA continue its mission of providing support, education, and partnership to those affected by Lupus.





## LUPUS AND ANXIETY: A DIFFICULT COMBINATION

New Life Outlook

Anxiety is inevitable. Virtually everyone that exists will experience some kind of anxiety at some point in his or her life. For some, it is the simple worries, whereas for others, it is more severe and can be crippling.

It seems lupus sufferers are prone to experience this unpleasant emotional state – and really it's no wonder those with chronic illness often suffer from generalized anxiety disorder in addition to their respective illness complications. Medical bills, doctor appointments, household tasks, family duties, livelihood, workload, and mortality may be some of the issues that weigh heavy on your mind.

Stress encourages and feeds lupus flare-ups, so learning how to control those anxious feelings is essential. I have learned through many years of trial and error how to get a handle on my anxiety when it strikes. Granted, I have not been able to alleviate it completely, but I have been successful at taming the beast, so to speak, when I know my health, happiness, and the well-being of my family depends on it.

### Prescription Medication

Relying on prescription medications to control anxiety is certainly appropriate, especially if your anxiety is severe. I have been prescribed a number of these medications throughout the years, and they have proven beneficial in my particular case.

However, you should exercise caution, as many of these medications are benzodiazepines, anticonvulsants, sedatives, or hypnotics. They may be effective, but the consequences that ensue may be less than desired, as many are habit forming and have unique consequences in your daily life. Other anti-anxiety medications are also anti-depressants, so if you suffer from both conditions, this could be a viable

option.

With the myriad of medications I already take to control lupus and related complications, I tend to reserve the anxiety medication (depending on severity) in times of absolute necessity. But don't fear the medication or feel ashamed if you have to take it!

Another excellent choice when battling anxiety is seeking professional assistance from a therapist. However, if

being sedentary most of the time, activity can help control anxiety.

**Say no to harmful substances.** Avoid alcohol, refrain from smoking, and cut back on caffeine as these substances can worsen anxiety. Furthermore, inappropriate drug use can intensify anxiousness.

**Get enough sleep.** If you are not sleeping properly, see your doctor. Lack of adequate rest can cause irritability, which promotes anxiety.

**Eat a healthy diet.** Some research indicates that eating whole foods such as vegetables, fruits, and whole grains contribute to anxiety reduction.

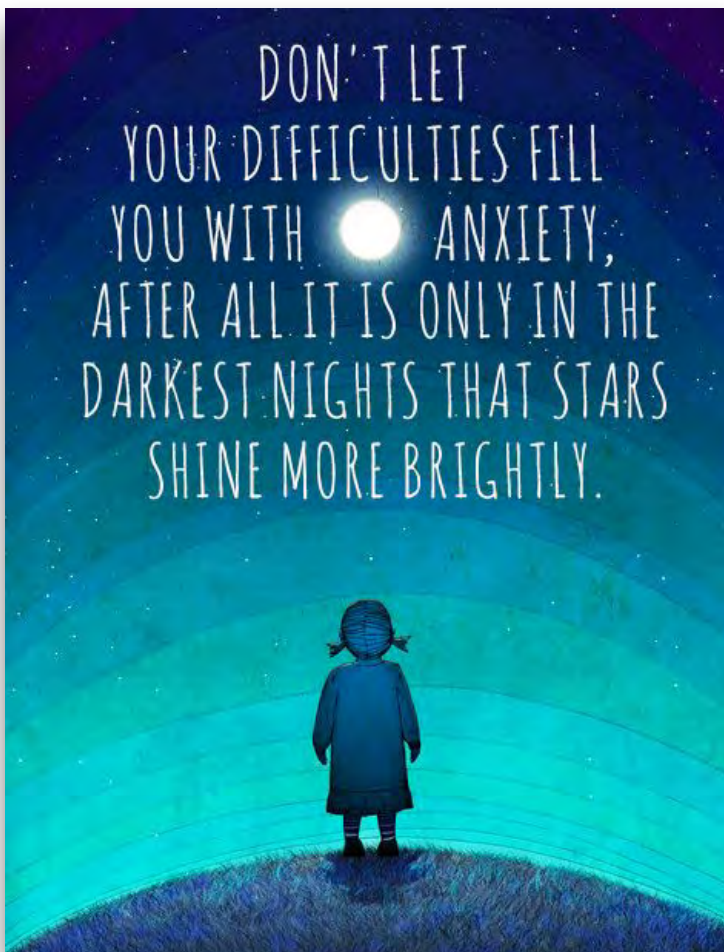
### Utilize relaxation techniques.

Meditation, yoga, and aromatherapy can ease your anxiety. I diffuse essential oils frequently. Lavender, ylang ylang, bergamot, and clary sage are excellent choices to boost your mood and reduce stress and anxiety. Add these oils to a bath to aid in relaxation. Additional "mood-boosting" oils include basil, lime, grapefruit, rose, orange, geranium, and sandalwood.

### Supplements

As with any supplement, consult a physician before adding alternatives to your regimen. Some seemingly helpful options can contribute to lupus complications or have adverse interactions with necessary medications.

**Vitamin B.** Thiamine (B1) promotes healthy cell growth and protects the immune system. Often referred to as "the anti-stress vitamin," Thiamine has a major impact on anxiety. Inositol (categorized as B8 in some research) is effective at treating anxiety without the side effects of some anti-anxiety medications. Pantothenic Acid (B5) promotes healthy skin, helps resist infection, and is widely known to help alleviate chronic anxiety. Because of the close link between anxiety and depression, Folic Acid (B9) and Cobalamin (B12) may be beneficial as well.



you are inundated with doctor appointments or homebound due to prolonged immunosuppression, this option may be "easier said than done."

### Lifestyle Changes

**Stay active!** This is not always an easy task when we consider the aches, pains, symptoms, and complications that come with lupus. However, physical activity reduces stress, improves your mood, and supports your health. Intense activity is not necessary – start slow, keep it simple, and increase gradually when you can. As long as you avoid



**Valerian** can help with stress and anxiety according to some studies, although there is a need for more research. Often taken to combat insomnia, small doses of this herb appear to be more effective when combined with lemon balm. However, this herb may have withdrawal symptoms, so tapering off is essential. **Theanine** is an amino acid found in green tea. Although there is not sufficient scientific evidence to show it helps treat anxiety, many who have taken it report feeling calmer. It reduces physiological responses to stress and raises levels of GABA, the calming neurotransmitter. **Magnesium** helps prevent anxiety, nervousness, restlessness, and irritability. It is a "calming" mineral and helps to nourish the nervous system and protect the heart and arteries. **Tryptophan** is an amino acid with a natural relaxation component that induces a calming effect when ingested (which is why you probably feel sleepy after eating turkey on Thanksgiving!) It helps control mood and plays an important role in maintaining serotonin levels, which aids in the prevention of anxiety, depression, and insomnia.

## Coping and Prevention

**Take action!** If you find your anxiety is frequent or severe, talk with your doctor to find out the source and get proper treatment. Certainly having a chronic illness plays into our feelings of

or involve yourself in social media, the more interactions you have with people the less likely the situation will disable you (unless they are the source of your anxiety, which in that case, be sure to make time for yourself!) Be open and honest with those closest to you and do something you enjoy that incites feelings of calm. **Break the cycle.** Journaling can be excellent therapy! Keep track of your personal thoughts and feelings. This can help you maintain a positive mental state. Taking a brisk walk or indulging in a hobby you enjoy can also be resourceful "cycle breaking" actions. Read self-help books or other genres you enjoy to get your mind on something else.

Remember that anticipation is often worse than the real thing, so do not let anxiety keep you from engaging in an activity you are thinking about trying.

**Remember the 90/10 principle!** We cannot control 10% of what happens to us – it is simply life and we have no control over it (a crowded waiting room, a traffic jam, etc.) However, the other 90% is completely within our control – it is how we react to the ten percent! When we react poorly, it can throw off our entire day and stimulate unnecessary stress and anxiety. Remain mindful of how you react to the situations in your life.

**Let it go!** Easier said than done, I know. However, dwelling on the past or attempting to predict the future can create unnecessary anxiety. We cannot change past events, so the "if-only" conversation has no positive value. If you do find yourself "expecting the

worst," at least "hope for the best!" Live in the moment, day-by-day, and deal with the punches life throws your way as they come with consciousness. Certainly change what you can in life, but allow the rest to take its course and handle it accordingly.

Anxiety may be inevitable, but we can maintain a positive state of mind if we commit to it and realize the value and purpose of the situation at hand. "Don't sweat the small stuff," is a wonderful motto to live by. Will problems arise? Of course, they will! However, we already know that — we deal with a chronic illness every single day, which is debilitating enough; couple that with anxiety, and a downward spiral may be hard to avoid.

Smile, breathe, go slowly — and remember — laughter really is the best medicine! I recently read a quote on Pinterest that said, "*Do not let the difficulties of life fill you with anxiety; after all it is only in the darkest nights that the stars shine more brightly.*" Recognize those bright stars and relish in the beauty of them!

## Anxiety a quick reference



Get outside and go for a walk. Soak up the sunshine!

Cut out refined sugar and caffeine. Eat sweet potatoes, whole grains, and leafy greens.



Do Emotional Freedom Technique video.

"Even though I feel this anxiety, I deeply and completely love and accept myself."



Take a deep breath, put your hand over your heart and repeat, "I have the ability to feel calm, no matter my circumstances. I welcome peace into every cell of my body now."



Bach Rescue Remedy - few drops under tongue

Diffuse Valor

Tranquil roll-on on back of neck

Hylands Nerve Tonic - a couple pellets under tongue.



**Bonus Tip:**

Observe when anxiety or fear hit. What were you thinking, doing, or feeling before the anxiety? Is there a way to simplify your life and cut out fear triggers?



anxiousness and therefore this emotional state cannot always be avoided, but allowing it to immobilize you will only add to the problem. If medication becomes necessary, be sure to take it regularly as prescribed! **Socialize.** Whether you spend time with family and friends, join a support group,



## LUPUS AND DEPRESSION - SELENA GOMEZ

Everyday Health 9.7.2016 Therese Boardchard



Twenty-four-year-old pop star Selena Gomez will be taking time off from her Revival world tour to take care of herself after experiencing some depression and anxiety related to her diagnosis with lupus.

She explained to *People* magazine recently that "anxiety, panic attacks, and depression can be side effects of lupus, which can present their own challenges."

A year ago, the singer and actress revealed to *Billboard* magazine that she had taken time off to undergo chemotherapy for lupus to prevent a stroke. Shortly after, Gomez told Matt Lauer and Hoda Kotb of the *Today* show that she was uncomfortable talking about the details of her personal story and diagnosis.

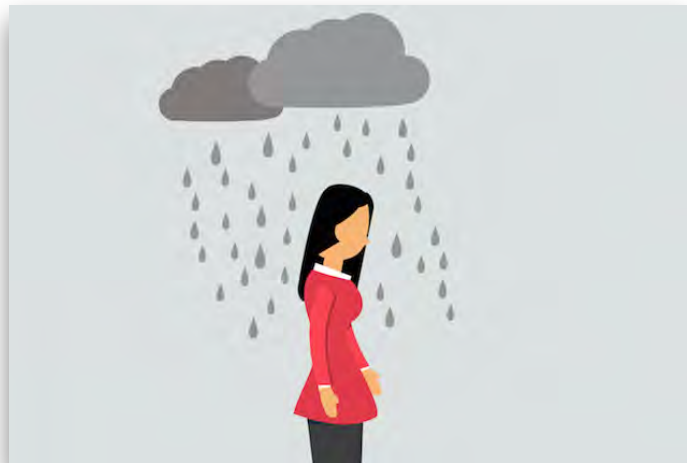
That seems to have changed in her recent statement to *People*, in which she says:

I want to be proactive and focus on maintaining my health and happiness and have decided that the best way forward is to take some time off. Thank you to all my fans for your support. You know how special you are to me,

but I need to face this head on to ensure I am doing everything possible to be my best. I know I am not alone by sharing this, I hope others will be encouraged to address their own issues.

Lupus is an autoimmune disease that affects five million people worldwide. It's a complex condition that takes various forms, the most common being systemic lupus erythematosus, or SLE. It occurs when too many antibodies are produced; these antibodies then attack and inflame healthy cells and organs. People with lupus often experience fevers, joint stiffness, weight changes, fatigue, Sjögren's syndrome (dry mouth and eyes), thyroid problems, gastrointestinal problems (heartburn or acid indigestion), osteoporosis, and, yep, depression and anxiety.

Like Selena, many people with chronic conditions will suffer from depression,



but with proper management of both illnesses, you can lessen the risk that either will get worse.

### Lupus and Depression: The Facts

According to The Johns Hopkins Lupus Center, approximately one-third of all people with lupus experience depression and anxiety. Why are the statistics so high? The Lupus Foundation of America compiled these and other helpful facts about lupus and depression:

Clinical depression may be a result of the ways in which lupus physically affects your body. Some of the medicines to treat lupus — especially corticosteroids such as prednisone (and at higher doses of 20 mg or more) — play a role in causing clinical depression. Clinical depression may be a result of the continuous series of emotional and psychological stressors associated with living with a chronic illness. Two common feelings associated with clinical depression [and lupus] are hopelessness and helplessness. People who feel hopeless believe that their distressing symptoms may never improve. People who feel helpless believe they are beyond help — that no one cares enough to help them or could succeed in helping, even if they tried.

## 350 million:

Number of people worldwide who suffer from depression.



## 16 million:

Number of U.S. adults who had at least one major depressive episode in 2012.

Women are more likely to be diagnosed with depression than men.







*LFSA is selling Apple Annie's Bread in December.*

*Please call the office at 520.622.9006 to place your order.*

## TOP FIVE LUPUS SYMPTOMS

Percent of MyLupusTeam members experiencing the following symptoms

97%  
Fatigue or  
Tiredness

92%  
Painful Swollen  
Joints

79%  
Pain  
(other than joint)

87%  
Problems  
with Sleep

Avid soccer player - (since age 5) - continues to play at night to avoid UV exposure

# Active

## Carolina

Daughter,  
Sister,  
Aunt,  
has two  
dogs,  
Harly &  
Tyson

## Young



Intelligent  
Diagnosed five years ago at the age of 18  
Native Tucsonan

Living  
with  
Lupus



Loves the outdoors  
Works full-time

The Lupus Foundation of Southern Arizona



## ARE FLU AND PNEUMONIA VACCINES SAFE IF I HAVE LUPUS?

Lupus.org

### Seasonal Flu Vaccine

*Is the flu vaccine safe?*

Overall, the flu shot is considered to be safe and effective for people with lupus. People with lupus generally do not have any side effects from the flu shot. When they do, their symptoms are usually mild, such as a local reaction with swelling of the arm at the site of the injection, a bit of low-grade fever and muscle aches. In general, the benefits of receiving the flu shot greatly outweigh the



medications.

*How does the flu shot work?*

**In general, the benefits of receiving the flu shot greatly outweigh the potential risks of experiencing a flare.**

potential risks of experiencing a flare. However, if you are pregnant or have had allergic reactions to these vaccines in the past, talk to your doctor before receiving one.

***You and your loved ones should get the flu shot, not the nasal spray.***



For most people with lupus, doctors recommend the flu shot every year.

The flu shot is a highly effective vaccine made from an inactivated (killed) virus. It is given once a year to people who are at risk for complications of influenza infection. About two weeks after vaccination, the body develops antibodies that provide protection against the influenza virus infection. If you're interested in learning more about the flu, and would like the most up to date information about the flu vaccine, visit the U.S. Department of Health & Human Service's website, [www.flu.gov](http://www.flu.gov).

### Pneumonia Vaccine

*The pneumonia vaccine is also recommended for people with lupus, and a second dose should be given five*

*years after the first dose.* This vaccine is given as a shot and can help to prevent most (but not all) kinds of pneumonia.

A new form of pneumonia vaccine called the prevnar13 was introduced in 2010 and covers more types of pneumonia. It is recommended that lupus patients also receive this vaccine, but at least one year apart from the pneumonia vaccine. The pneumonia vaccines, like the flu vaccine, can cause some mild symptoms of local swelling and inflammation in the arm, low grade fever and body aches.

*Dr. Costenbader, associate professor of medicine at Harvard Medical School, and a rheumatologist who co-directs the Lupus Center at the Brigham and Women's Hospital in Boston, Massachusetts.*

### RAFFLE BENEFITING TUCSON CHARITIES

100% FOR LOCAL CHARITIES

Win a NEW 2016 **FORD MUSTANG Shelby GT350!**

*Exclusive: Only 4,300 of these cars were made!*

**THE MILLIONS for TUCSON RAFFLE**

The Jim Click Automotive Team is presenting a new 2016 Ford Mustang Shelby GT350, to the entire community...to be used as the featured prize in our on-going effort to raise millions of dollars for non-profit organizations in Greater Tucson.

With your \$25 contribution (or 5 tickets for \$100) you could win a **2016 FORD MUSTANG SHELBY GT350!** The best part is that 100% of your contribution will support Greater Tucson charities - that keep all the proceeds from the maximum 100,000 tickets which will be sold. The drawing will be held on December 15, 2016. Entries must be received by December 9, 2016.

**TICKET PRICE**  
**\$25**  
OR 5 FOR \$100

**To purchase raffle tickets, contact us at 520.622.9006**

**\$25 per ticket  
\$100 for 5 tickets**



## AUTOIMMUNE DISEASE BIOMARKERS: NEW STUDY COULD PAVE THE WAY FOR LUPUS TREATMENT

Medical Daily 3.23.2016 Stephanie Castillo

Scientists are closing in on a possible biomarker for lupus and other autoimmune disorders.

Scientists believe women have a better immune system than men because the X chromosome has more immunity-related genes — and if you recall from your high school biology class, women have two and men have only one. But the double X may also increase women's risk for autoimmune disorders. Women account for 85 percent of lupus patients, and men born with an extra copy of the X chromosome, also known as Klinefelter's syndrome, are 14 times more likely to develop it too. A new study published in the *Proceedings of the National Academy of Science* may have figured out why.

The authors focused on X chromosome inactivation (XCI), a natural mechanism that silences one of the chromosomes to prevent women from having twice as many genes. Two active X's can be lethal, lead author Montserrat C. Anguera, an assistant professor in the department of biomedical studies at University of Pennsylvania's School of Veterinary Medicine, told *Medical Daily*. But in her research, Anguera found that XCI isn't as tight in white blood cells as it is in other cell types, such as those in muscles and the liver.

To find out why, she and her team isolated T and B cells from the blood of healthy mice and humans and

looked at the patterns of Xist, an RNA molecule that initiates and maintains XCI to silence a chromosome. "We like to call it a cloud," Anguera said. "It allows you to see where the RNA transcripts cluster around the chromosome" and shut it down.

Chromatin can also silence gene expression in female cells and often works with Xist to further reduce gene expression, Anguera said.

While there was Xist in the cells, Anguera was surprised to find that it was in the wrong place and the inactive chromosome was not completely silent. Silencing marks from chromatin were missing in T and B cells, too. Anguera and her team believe the cells lost both the patterns of Xist and chromatin, which partially triggered gene expression in the silent chromosome.

"This is super unusual to see because the XCI process happens early in embryo development, right as the embryo is implanted in the uterus," Anguera said. "That's when the decision is made to turn off the X from mom or dad. Once the decision is made, the cells maintain the memory."

If the silencing marks were lost, could you just reactivate them? That's very hard, Anguera said, and

**...doctors could use it to quickly identify people with lupus.**

when she and her team did it in some of the blood cells, only part of the Xist cloud reappeared.

Now the team is going to start looking at samples from lupus patients to see what XCI looks like in their cells. If they find a distinct pattern, doctors could use it to

quickly identify people with lupus.

"There are no good biomarkers for lupus and other disorders," she said. "There's a huge need for them since patients have to go through different types of tests before they get a diagnosis. Looking at an inactive X may be a fast and easy way to determine the severity or just the start of the disease."



There are about 80 autoimmune disorders, and 25 have a strong bias toward women, Anguera said.

This is the first study to find missing silencing marks from healthy female cells, according to the authors. It connects the immune system and silenced chromosomes in a new way and could soon reveal why women are predisposed to certain disorders.

"It's all very novel," Anguera said. "It could be the groundwork for something really cool and exciting."

Source: Wang J, Syrett CM, Basu A, Atchison ML, Anguera MC. Unusual maintenance of X chromosome inactivation predisposes female lymphocytes for increased expression from the inactive X. *Proceedings of the National Academy of Sciences*. 2016.



## LUPUS PATIENTS BEING ENROLLED IN PHASE 3 TRIAL OF ANIFROLUMAB

Lupus News Today 10.06.2016  
Carolina Henriques

Researchers at Temple University Hospital are taking part in a large, global Phase 3 clinical trial to evaluate whether a novel, investigational drug for systemic lupus erythematosus (SLE) is more effective than previously approved medications.

This trial (NCT02446912), one of several pivotal and ongoing studies of anifrolumab to treat moderately to severely active SLE, also referred to as lupus, is recruiting patients at nearly 160 sites across the U.S., Europe, Latin America and elsewhere, including at Temple.

Anifrolumab is being developed by AstraZeneca, and in previous studies it demonstrated an ability to reduce disease symptoms in over 50% of patients after one year of treatment. Patients receiving the drug also needed fewer corticosteroids to treat inflammation, common in lupus.

"The data from the Phase 2 trial was so promising that the FDA has granted fast-track approval for this new medication," Roberto Caricchio, MD, director of the Temple Lupus Clinic at the Lewis Katz School of Medicine at Temple and trial's primary investigator there, said in a press release. "That's excellent news because currently there are only four other drugs that have been approved to treat lupus, and only one of those was approved in the past 50 years. It is hoped that this treatment will help patients. However, this cannot be guaranteed."

Anifrolumab targets interferon type-1, a protein involved in the

inflammation known to play a key role in disease development.

"Interferon type-1 is a molecule called a cytokine, which activates a variety of immune cells in lupus and triggers flares," said Caricchio.

"Each immune cell has a 'lock' (receptor) that is opened by the 'key' interferon type-1. Once the lock is open the cell activates and so does the lupus. Previous lupus medications tried to block the interferon type-1 cytokine, but anifrolumab directly blocks the receptor (the lock) on the cell

...more effective than previously approved medications.

instead, making it more effective."

Adults (18 to 70 years old) with moderate-to-severe SLE, who are currently being treated with prescription medication, are being enrolled in this double-blind, placebo-controlled study, evaluating the efficacy and safety of two different doses of anifrolumab, a high and low dose administered intravenously, versus placebo. Treatment will be given in addition to currently prescribed medication. The study's primary goal is the number of treated patients who achieve an SLE Responder Index greater than or equal to 4 at week 52 (the index is a composite measure of disease activity). In total, the trial (NCT02446912) plans to enroll 450 people at its various sites; more information is available on the study's clinical trials.gov webpage.

At Temple, researchers are looking to enroll between 10 and 20 SLE patients for this study, which will last



one and a half years and require a total of 16 visits. Participants will be asked to fill regular questionnaires from home and submit them electronically. Those interested in enrolling at the Philadelphia-area site can contact the Temple Lupus Clinic directly at [attug24408@temple.edu](mailto:attug24408@temple.edu) or call 215-707-4479.

Two other Phase 3 trials assessing anifrolumab in lupus patients, one a long-term safety and tolerability study (NCT02794285) and the other an efficacy and safety study (NCT02446899), are also actively enrolling eligible patients. More information, including enrollment information, is available by clicking on each trial's identification number.

Lupus is a complex autoimmune disease and every patient experiences different symptoms — these may include joint pain, muscle pain, and fever or fatigue. To manage their symptoms, patients often use medications that are prescribed off-label, meaning that many of them have not been tested in lupus-specific clinical trials. Such use could lead to unwanted side effects, especially when the drugs are taken for longer periods of time.

"Lupus causes such a spectrum of manifestations ranging from mild to life-threatening and everything in between, which is why it's difficult to develop medications to treat it and to determine whether patients are responding to those medications," Caricchio said.



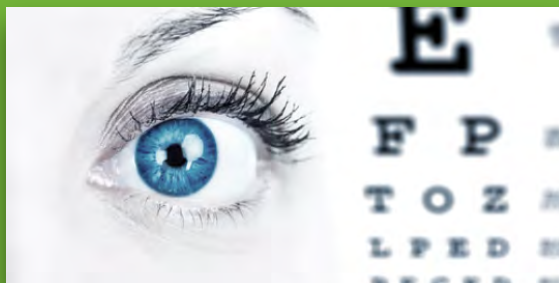


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The Lupus Foundation of Southern Arizona



**THE LUPUS  
FOUNDATION  
OF SOUTHERN ARIZONA**

### Awareness & Education

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

### Support

- Monthly Support Meetings
- Resource Kits
- Counseling
- Patient Retreats
- Emergency Medical Fund
- Education Scholarships
- Camp for Kids

### Community Events

- Annual Walk the Loop for Lupus
- Hit the Links for Lupus Golf Tournament
- Annual LFSA Gala

Lupus Foundation of Southern Arizona

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