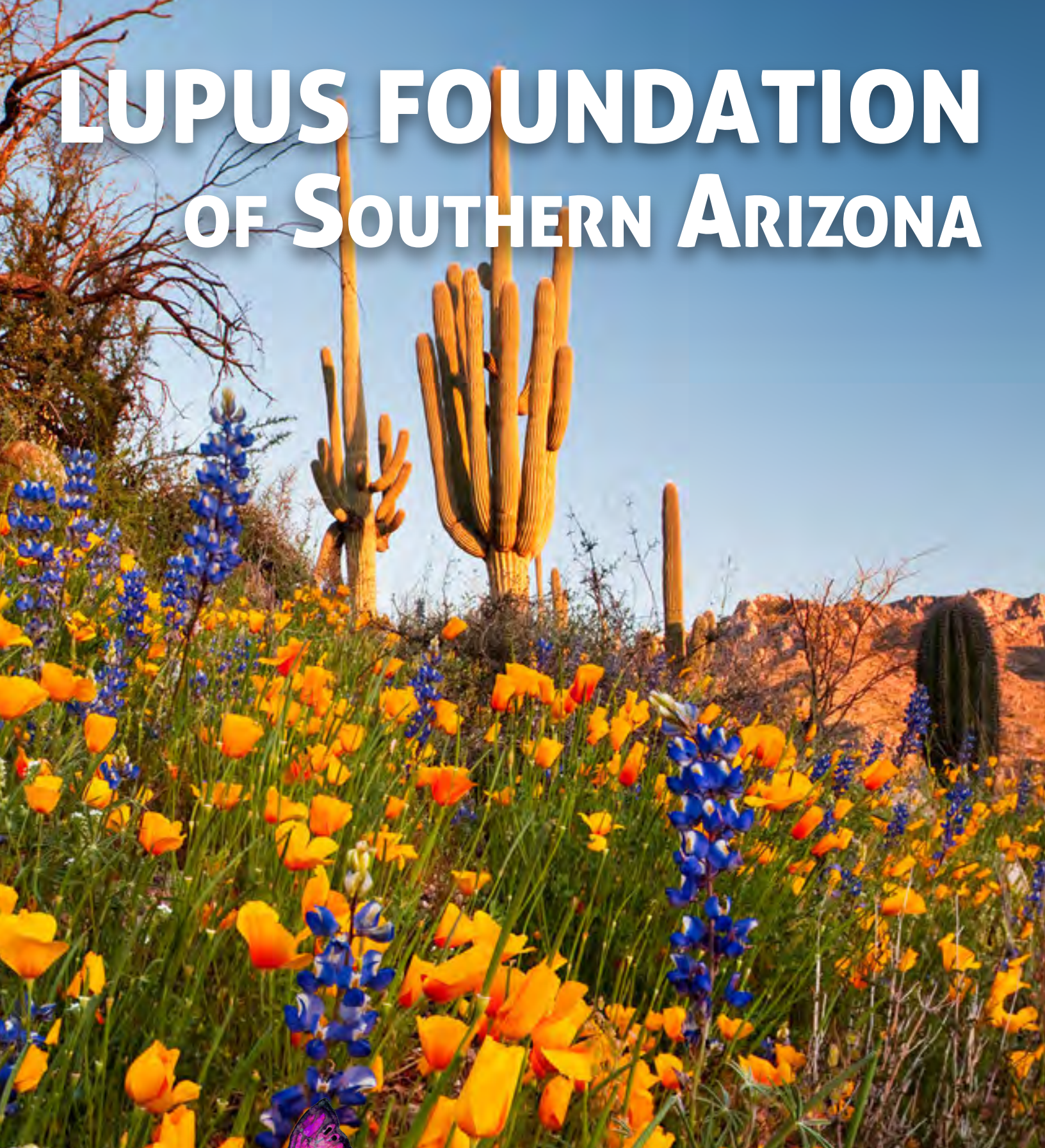


LUPUS FOUNDATION OF SOUTHERN ARIZONA



Spring 2017

IN THIS ISSUE:

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

CALENDAR

April

22nd

Walk-the-Loop-for-Lupus

Join us at Reid Park for the 17th annual Walk the Loop for Lupus. Check our website for registration and additional information.

May

19TH

Hit the Links for Lupus Golf Tournament

Join us at Omni Tucson National for the Hit the Links for Lupus Golf Tournament. Check our website for registration and additional information.

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.

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.

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

Rebecca Shields, President
Lani Baker, Vice President
Sherrl Fritz, Treasurer
Shaunna Kowalewski, Secretary

BOARD MEMBERS

Wendy Black
Lindsey Ezell
Abigail Garcia
Ricardo Hinds
Donna Morton
Shaima Namazifard

LETTER FROM THE PRESIDENT



What a successful 2016 for the Lupus Foundation of Southern Arizona! The Foundation set out to build on its existing programs implemented in early 2015 while launching two new programs. The Awareness Campaign has helped to drive an increase in LFSA traffic 40% from its previous year and we have increased our Medical Advisory Board to a complement of six to provide a more comprehensive patient advisory panel.

The LFSA Board was also as active as ever. Our committed Board members had three very successful events in 2016. Our 16th Walk-the-Loop-for-Lupus, always held in April each year, had one of its highest turnouts yet. May's Hit-the-Links-for-Lupus held at Omni Tucson National netted our largest revenues to date for a golfing fundraiser, and the LFSA 2nd Annual Gala exceeded previous year's expectations in revenues and turnout. Additionally, LFSA had the privilege to honor its Founding Members – Catherine Meyer, Jon and Lilly Depka, and Gerry and Alicia Merrill. If it were not for these five remarkable individuals, the Foundation would not be thriving today.

Our programs are all being utilized and are growing.

We are proud to have awarded eight scholarship awards in two years and look forward to awarding 2017's recipients. LFSA Cares and the Emergency Medical Fund continue to aid those financially impacted by this devastating illness. In addition to the 2016 Women's Retreats, LFSA held its first Couples Retreat in July. Camps for Kids was launched as well. Both new programs are a testimonial to LFSA's commitment to provide support to everyone in families impacted by Lupus.

We invite you to join LFSA as a Member. With your membership of only \$20 (\$25 for family memberships), you will not only help to support our programs, but you will receive our email updates and our bi-annual LFSA Magazine, which focuses on medical updates and information on Lupus and LFSA's events, programs and community news. You can become a member by visiting our website at www.lupus-az.org or by calling our office at 520-622-9006.

Please join us for our 16th Annual Walk-the-Loop-for-Lupus on April 22nd at Reid Park – Ramada 10 and our Hit-the-Links-for-Lupus Golf Tournament at Omni Tucson National on May 19th. Golf is \$100 including lunch! You can either go online or call our office for details and registration.

The Lupus Foundation of Southern Arizona is here for ALL impacted by Lupus. So, please stay in touch with us, either by phone or visit, or through Facebook on our website, as we welcome your input, your journey, your thoughts, and your needs. Be well!

Rebecca Shields, President

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

"We are proud to have awarded eight scholarship awards in two years and look forward to awarding 2017's recipients. LFSA Cares and the Emergency Medical Fund continue to aid those financially impacted by this devastating illness."



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 ANNUAL MEMBER MEETING

The LFSA Annual Member Meeting was well-attended by both new and returning members. It was a great opportunity to update the members on LFSA's programs while allowing members to sign up for committees, raffle prizes and more. Several attendees learned about the meeting through social media. LFSA has increased its social media outreach over the last year and will continue to do so in the future.



LFSA KIDS CAMP SCHOLARSHIP

CAMP FOR KIDS IMPACTED BY LUPUS



**COMPUTER
PROGRAMMING**

ART

SPORTS

Dance

HIKING

SCOUTS

The Lupus Foundation of Southern Arizona is offering 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
Call: 520.622.9006



APRIL 22ND @ REID PARK



REGISTER TODAY!

Register online at www.lupus-az.org

Call (520) 622.9006 for more information

HEALTHSOUTH
Rehabilitation Hospital of Southern Arizona

Agero

LUPUS FOUNDATION OF SOUTHERN ARIZONA GALA

LFSA's 2nd Annual Gala was a huge success in honoring the LFSA Founders, who started the Tucson Foundation in 1983. The LFSA would like to thank the Gala's Title Sponsor, New Belgium Brewing, as well as all the evening sponsors and attendees. Our special thanks go out to Frank and Margaret Jones and their entire family for their continued support of 25 years of LFSA. Over 150 guests were hosted to a fabulous silent auction and dual course entrees. Dr. and Mrs. John Finley won the live auction bid on the Lodge at Ventana Canyon's kindly donated Baked Alaska dessert. Fun 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!



The LFSA Board of Directors



Frank and Margaret Jones



Honored Guests and Founders: Jon Depka, Catherine Meyer and Lilly Depka



(seated L-R) Founders: Jon Depka, Lilly Depka, Catherine Meyer, (back row L-R) Launa Odom, Guest Speaker Samantha Davis, Paul and Sharon Joseph.



SUN SAFETY

SUMMER SKIN PROTECTION



DRINK WATER



STICK TO THE SHADE



MOISTURIZERS



PROTECTIVE
CLOTHING



WEAR SUNGLASSES
AND HAT



AVOID PEAK
HOURS



SUNSCREEN



PAIN RELIEVERS



PROTECT SKIN

Lisa, Theresa, & Bonnie



**Sisters
Mother
Daughter**

Lisa: Loves to swim and camp

Bonnie: Loves reading. Loves to camp.

*Living
with
Lupus*



Theresa: Passion for Life, Loving Family, Proud Mother, Strong and Persevering, "Giving up is NOT an option", Enjoys helping others navigate the disease.

The Lupus Foundation of Southern Arizona

THE SPOON THEORY BY CHRISTINE MISERANDINO

My best friend and I were in the diner, talking. As usual, it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember

thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.



At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "Here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands.

I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a "loss" of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

She grabbed the spoons with

excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become?

I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of "spoons". But when you have to now plan your day, you need to know exactly how many "spoons" you are starting with. It doesn't

guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As, she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said "No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make your self something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today

(continued on next page)

and tomorrow too." I quickly took away a spoon and she realized she hasn't even gotten dressed yet. Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay

"...the difference in being sick and being healthy is having to make choices...when the rest of the world doesn't have to."

warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone. Sometimes you can borrow against tomorrow's "spoons", but just think how hard tomorrow will be with less "spoons". I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on "spoons", because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn't even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a

little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared."

It's hard, the hardest thing I ever had to learn is to slow down, and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful

ability to not think and just do. I miss that freedom. I miss never having to count "spoons".

After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word, when I do anything. It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them, because they have one of my "spoons".



VITAMIN D LEVELS LOW IN PEOPLE WITH SEVERE LUPUS, STUDY SHOWS

Lupus News Today - 1/23/2017

Those with severe cases of systemic lupus erythematosus (SLE) have low levels of vitamin D, according to new research.

Vitamin D deficiency is common in SLE patients. Because they are sensitive to light, they avoid exposure to the sun, which helps create vitamin D through the skin. The SLE medications glucocorticoids



protein binds to 25(OH)D, regulating its stability and delivery to tissues.

Results showed that 25(OH)D serum concentrations were significantly lower in SLE patients than in 150 healthy volunteers. In the

patient cohort studied, 142 or 71.4% had 25(OH)D serum concentrations below 30 ng/mL. The researchers categorized vitamin D deficiency as a 25(OH)D level lower than 20 ng/mL, and vitamin D insufficiency as a 25(OH)D level lower than 30 ng/mL.

When the team looked for associations between 25(OH)D serum concentrations and disease activity, they discovered the concentrations were lower in patients with severe activity — those with SLEDAI scores of 20 or more — but not in patients with milder cases of the disease — those with SLEDAI scores of 1–5. They found no correlation between DBP blood levels and disease activity.

Researchers said it is possible that vitamin D deficiency alters the immune system in ways that lead to SLE. The deficiency may be a consequence of the disease, they said.

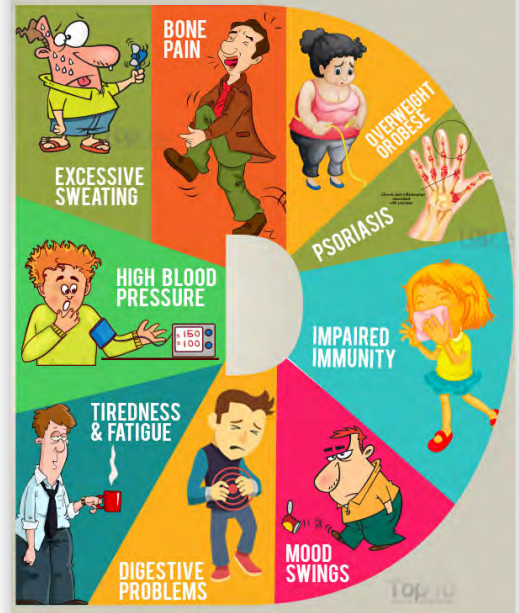
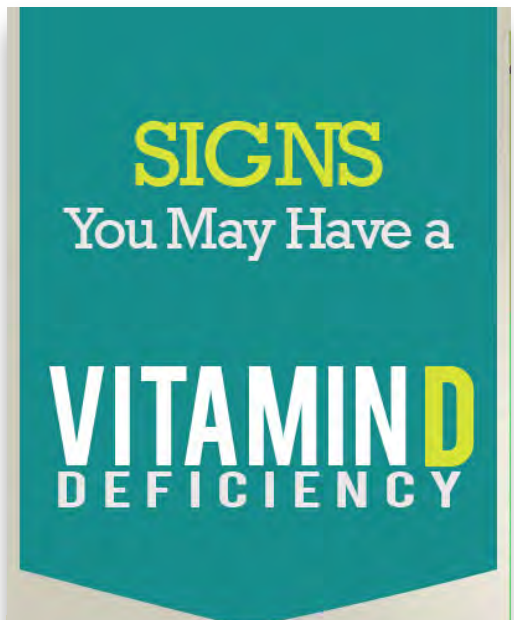
The team wrote that it was unable to “establish a causal relationship

The deficiency may be a consequence of the disease.

and hydroxychloroquine may also reduce vitamin D levels in blood.

Researchers evaluated the disease activity of 199 SLE patients using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI). They also collected blood samples to determine the patients' vitamin D levels.

The team measured the blood levels of 25-hydroxyvitamin D [25(OH)D], a circulating form of vitamin D, and of vitamin D binding protein (DBP). The



between vitamin D serum concentration and disease activity in SLE patients.” Whether “low vitamin D serum concentrations are a causal co-factor in the immunological disturbances that characterize SLE, or if, on the contrary, the inflammatory disease process and low sun exposure causes reduction in vitamin D serum concentrations,” will require additional research, the authors added.

They called for a study that tracks vitamin D levels in SLE development over time.



DNA, RNA TARGETED IN LUPUS PATIENTS MAY DECREASE CHRONIC INFLAMMATION, DISEASE SEVERITY

Lupus News Today - 8/22/2016

Improper clearing of dying cells and elevated levels of RNA and DNA in serum are connected to increased chronic inflammation in autoimmune diseases. In a recent study, researchers at Duke University showed that scavenger molecules that feed on the nucleic acids not only reduce chronic inflammation in mice with lupus, but also increase their ability to fight flu.



The study, "Scavenging nucleic acid debris to combat autoimmunity and infectious disease," published in Proceedings of the National Academy of Sciences, suggests that the clean-up molecules may offer a promising treatment for lupus patients.

"This debris left by dead cells can mistakenly signal to the body that

there is an infection that warrants immune action, triggering the innate immune system," Bruce A. Sullenger, PhD, director of the Duke Translational Research Institute, said in a press release. "By

...may offer a promising treatment for Lupus patients.

selectively targeting the source of the immune activation rather than shutting off the innate immune system downstream, these nucleic acid scavengers are able to limit pathological inflammation without compromising one's ability to fight a viral infection."

Autoimmune disorders such as systemic lupus erythematosus (SLE) are characterized by increased production of antibodies against the self-nucleic acids DNA and RNA and their associated proteins, which results in the activation of inflammatory pathways. Current therapies focus on impeding the overactive immune cells but patients become more vulnerable to severe opportunistic infections.

Targeting the free-circulating RNA and DNA using enzymes that degrade the molecules can dampen inappropriate immune activation and improve disease outcome.

In the recent study, researchers assessed whether nucleic acid-binding polymers that can act as scavengers could limit the autoimmune-associated inflammation.

The research team observed dramatic therapeutic benefits in mice with cutaneous (skin) and

systemic lupus erythematosus upon cutaneous and systemic application of the scavenger polymers, respectively. Then they tested mice to see if the approach also compromised their ability to fight outside infections.

Results revealed that the mice exposed to doses of influenza recovered better than healthy mice that had not undergone nucleic acid scavenger treatment.

"This approach has the potential to treat a wide range of inflammatory conditions – from lupus to diabetes to even obesity," said Sullenger.



Do you take Hydroxychloroquine to treat your RA or Lupus?

**REMINDER:
See your optometrist every 6 months.**



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

HIT THE LINKS FOR LUPUS 2017 GOLF TOURNAMENT

FRIDAY – MAY 19, 2017

@ OMNI TUCSON NATIONAL



Lunch

Trophies



Goody
Bags

Raffle
Prizes



HIT THE LINKS
FOR LUPUS
GOLF TOURNAMENT



Sponsorship Opportunities Available

Register online at <http://birdeasepro.com/HitTheLinksForLupus>

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 instead, making it more effective."

...more effective than previously approved medications.

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 clinicaltrials.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 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.



LFSA Q & A SERIES

*LFSA is pleased to announce our new **Question and Answer Series**. Here we'll ask Lupus patients and people affected by Lupus about their real-life experiences. This issue's Q & A features Terry Davis and her experience with Benlysta.*



Terry Davis

LFSA: Thank you for taking the time to participate in our Q & A series. First off, tell us a little about yourself: where you are from, what you do for a living and any personal information you would like to share.

Patient: My name is Terry Davis. I moved from Massachusetts over forty years ago and have lived in Tucson ever since. I'm a site manager for a petroleum distributor. I'm married, I have two step-children and three grandchildren. My mother died from Lupus in 1981 at age 46, so receiving my own diagnosis was terrifying. I thought I was going to die.



LFSA: When were you diagnosed with Lupus and what were your symptoms at the time?

Patient: I was diagnosed in August of 2014 at the age of 54. At the time I couldn't move. I hurt in every joint of my body. My hair, my eyelids, everything all over was hurting. It took a lot of effort to get out of bed, to complete everyday tasks that you take for granted: showering, brushing

my hair, putting on socks, that type of thing. That was in February of 2014, and by the beginning of March I was convinced I needed to see a doctor. I went with my husband to see my primary care doctor. My PCP was great. She convinced me my Lupus could be treated. By April I met with a fantastic rheumatologist, and three months later I had my first appointment to start Benlysta.

LFSA: What other treatments did you try prior to trying Benlysta?

Patient: I tried several other treatments but didn't respond well to any of them. I took methotrexate, I took prednisone and a whole plethora of other medications. I knew they weren't working. So I did some research and found out about Benlysta. You have to have the right markers and you have to have the right relationship with your doctor. You have to be proactive in your treatment, because if you aren't you're not going to get the treatment you need. Benlysta was the only drug that I chose to take.

LFSA: When did you start Benlysta and what was your overall experience?

Patient: At first my rheumatologist said I didn't qualify for Benlysta. I told her the methotrexate almost killed me, please see what you can do. A week later I started my first round of Benlysta. It took about twelve months for the medication to kick in, to where I was feeling half-way normal. I still got tired and I still had to watch what I was doing to avoid over doing it. I did a lot of research on what I should eat, how I should exercise and how to remain stress free. I warned my children and grandchildren that if they got sick, not to come visit grandma. It took a while, but with the help of my rheumatologist and my PCP we got things under control, and in January of 2017 my Lupus was in remission. At this time I'm no longer on Benlysta or any other Lupus medication.

LFSA: That's fantastic! It sounds like you had excellent support and the right attitude.

(continued on next page)

"You have to be proactive in your treatment, because if you aren't you're not going to get the treatment you need."

Thank you to our Community Partners!

(continued from previous page)

Patient: It's all about attitude. In the beginning I had the denial, the anger, all kinds of emotions. Then I woke up one morning and I realized 'this is your new normal so get used to it, or fight it' and I woke up fighting. I've had a full-time job through this whole ordeal. I get up every day, I throw my legs over the side of the bed and say 'here we are, give me what you've got, because I'm not giving up'. I knew the minute I laid down my head and said 'I'm giving up' I'd be dead. You have to be honest with yourself and with the people around you. My job and my family are what fuel me, and if I can't function for them then I'm not functioning for myself.

LISA: It's like when you're on an airplane and they tell you to put your mask on first before your child.

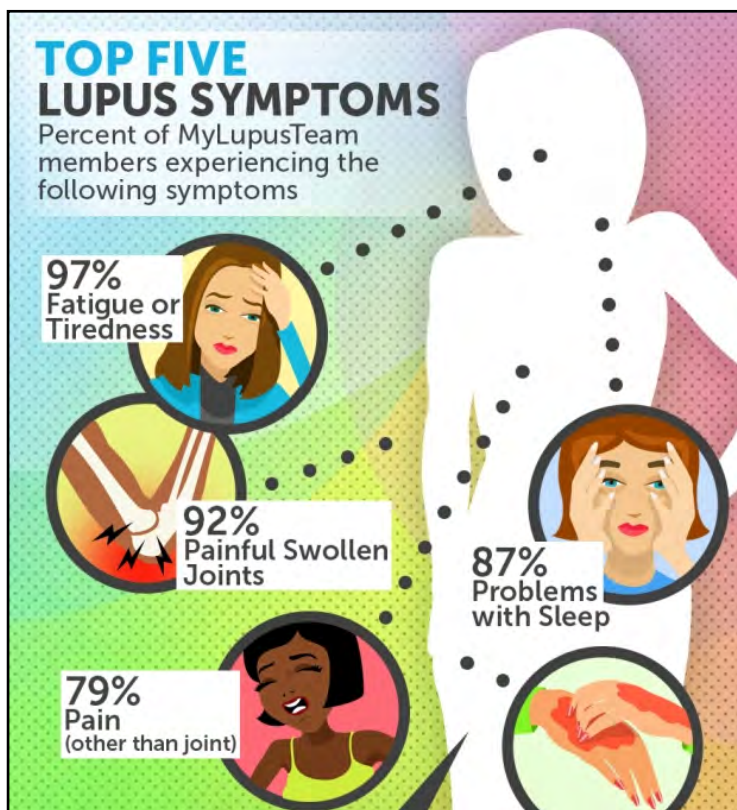
Patient: Yes. Put your mask on first, then help the people around you.

LISA: Did you have any difficulties or negative experiences during the time you were on Benlysta?

Patient: I had an allergic reaction to one of the pre-medications I was taking. I was taking Claritin or Benadryl prior to treatments, and one time my throat swelled up. My doctor made some adjustments and I was fine. It wasn't the Benlysta.

LISA: Is there anything else you'd like to let our readers know about your Lupus treatment?

Patient: Do your own research. Be your own advocate. Speak up. Ask questions, and do not leave without the answers. Also, you have to give your treatment time. And the more you help it by changing your diet and lifestyle, the easier it gets. Above all, don't depend on others to give you strength, find it within yourself. 🦋



Favorite quote "If the situation is inevitable, proceed as if you chose it"

Works full time as a Registered Nurse

Extremely active - gym rat, motorcycle enthusiast

George

Loves
loud
and
fast
hobbies



Living
with
Lupus



Native Tucsonan

Devoted dad to a son and a daughter

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

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