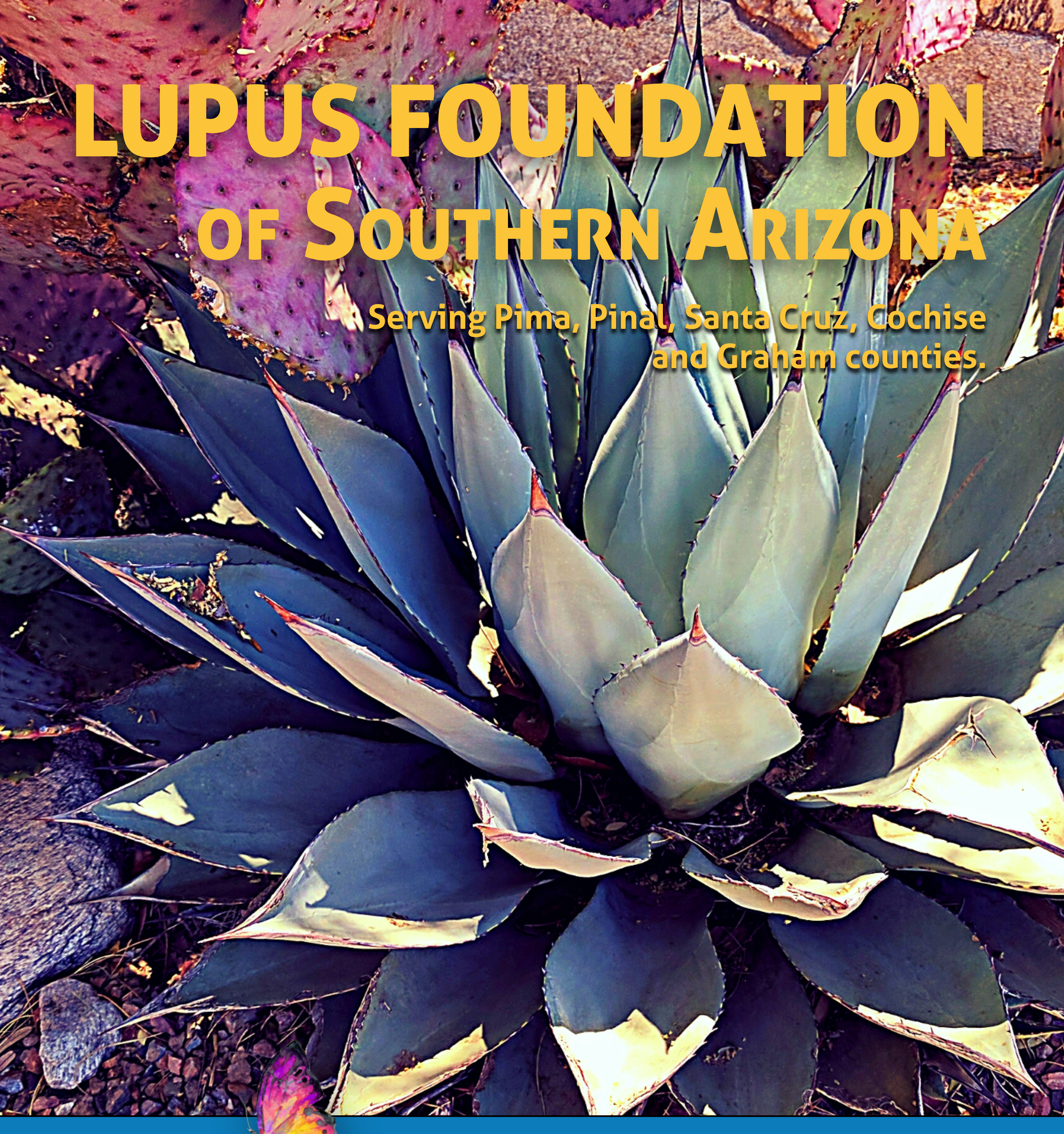
LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



Fall 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 - Tame the Flame!

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
Joan Redford

LETTER FROM THE PRESIDENT

As the Lupus Foundation of Southern Arizona begins another fiscal year and we all head into our wonderfully cooler weather, I want to take a moment to say thank you to our sponsors, community partners, donors, gala attendees, walkers and all who participated in our two major fundraising events during the 2017-2018 fiscal year: the October 15 Gala at Skyline Country Club and the April 14 Walk at Reid Park. The LFSA Board, along with our community of patients appreciates your generosity, support and belief in 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." We could not do all we do without you!

Since the inception of our partial Scholarship Program in 2015, twelve Lupus patients have attended classes and have been able to move on with their professional and personal lives. Through LFSA Cares and the LFSA Emergency Medical Fund, we have helped three individuals and families in need this year. With your support we service the needs of Lupus patients through phone calls, counseling, support groups and overnight retreats. We've been the "first other person with Lupus I've ever known or spoken to," for more than a few of our patients.

LFSA goals for this year include expanding our outreach to the larger community of southern Arizona through Lunch and Learn events, group presentations, health fairs and personal contacts, as well as the distribution of flyers at offices, libraries, campuses and other places of business. If you are an interested physician, ophthalmologist, business owner or individual, please contact our office to schedule a visit or an event. We will come to you!

We are "heating up" once again for another successful year, beginning with our November 4, 2018 "Tame the Flame" Gala at Skyline Country Club. Please join us as we honor Rebecca Shields, our immediate past President and Finley Distributing Co., our Title Sponsor. There's still time to purchase your tickets on our website or by calling Tyler, Administrative Associate, at 520-622-9006. Come out for a great cause and help us "Tame the Flame!"

Saturday, April 13, 2019 is the date for our Annual Walk the Loop for Lupus at Reid Park and, Hit the Links for Lupus is returning in 2019, so stay tuned for the date and details.

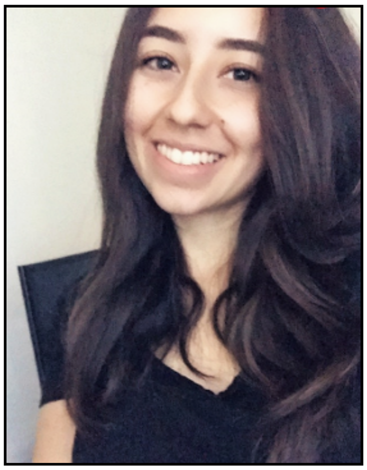
Thank you again, for caring. Know you are not alone in living with Lupus.

Peace,

Sharon Joseph, President

LFSA IN THE COMMUNITY

LFSA SCHOLARSHIPS - KATHERINE MARTIN



Katherine Martin

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

Recipient: I originally learned through my doctor's office. As I was checking out there was a poster about the scholarship program. It mentioned you would help any lupus patient going to school who maintained the required grade point average. I've always dreamt of being a dental hygienist. I was on a waiting list for the program and was finally accepted. The poster was a reminder that I wanted to do this and a way to make it work, financially speaking. I had been saving up since high school and I applied for the scholarship program to see if I could get some help.

LFSA: What are your academic goals?

Recipient: I'm in Pima Community College's dental hygiene program. It's a wonderful program and I am starting my second year. We have amazing faculty who care about the students. I've had tons of hands-on learning. We're given the opportunity to work with real patients in real office settings, some of them off-site, like the VA, Pascua Yaqui, and Saint Elizabeth's. Ultimately my goal is to graduate and give back to the community.

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

Recipient: In the beginning I was nervous. Most lupus patients have lots of medical appointments. I was able to work with my school schedule, still get to the doctor, and maintain my health while being in school full-time. I've done fairly well with my lupus but there are definitely days that are harder than others. I do my best to keep active and I keep up on my medications, and I always have a positive outlook and don't let my lupus stop me.

LFSA: How has the scholarship program helped you specifically?

Recipient: My dental hygiene program is fairly expensive. The LFSA scholarship has helped me with books and tuition, allowing me to spend money on other items required by my courses. It was nice to have the scholarship to fall back on. It was a weight lifted off my shoulders.

LFSA: Anything else you'd like to share with our readers?

Recipient: I'm grateful that I've had the support of the Lupus Foundation throughout my entire academic program. As anyone with lupus knows, some days are harder than others. You have to take the positive out of every day. Don't let the lupus take over your life, and if you have a goal, reach for it.

WOMEN'S
FOUNDATION
of Southern Arizona

Create change. Invest in women.

LFSA EMERGENCY MEDICAL FUND - DANIELLE DAVIS

Danielle Davis

LFSA: How did you first learn about the LFSA?

Recipient: When I was in the hospital, my grandmother heard about the Lupus Foundation from someone she met, who gave her your contact information. A week after I got out of the hospital, she took me to meet you. She's one of my biggest supporters. That's when I first learned about the Emergency Medical Fund. At the time I was still a little out of it so it didn't really register until I came to visit three months later. I came back and met with your staff, who told me about your programs and events. I decided to come to your Coffee Talk support group meetings. After my third Coffee Talk, I asked about the Emergency Medical Fund.

LFSA: That's when you applied for the program?

Recipient: Yes. I had several bills from my hospital stay and my in-patient rehab. Two more came from my outpatient rehab. These bills weren't covered by insurance and had to be paid out of pocket. I just didn't have the resources.

LFSA: Tell us more about Coffee Talk support group. How has that been helpful?

Recipient: At first I was afraid to attend because I thought everybody would be crying, but it's been informational. I get to hear about people's experiences, and it's been pretty positive for the most part. People still get a little depressed, but that's to be expected.

LFSA: We try hard to keep our support groups positive. Lupus patients are already struggling and the goal is to lift people up and give them the information they need to thrive in spite of their diagnosis. How has lupus impacted your life and ability to work?

Recipient: So far not too much. I'm hoping it stays that way. I'm now back working full time. I'm pretty much back to normal. I just got done with chemotherapy. Now I'm on maintenance. I'm trying to stay out of the sun. I'm very organized about my appointments. I'm taking Plaquenil to manage my lupus, and steroids. I plan on getting off the steroids in the near future if my doctors agree.

LFSA: What was your experience of the Emergency Medical Fund?

Recipient: I just graduated from college last year. I have student loans to pay. Then I got sick and ended up in the hospital. When I got out of the hospital I couldn't work as much as I wanted. So it was all this stuff crashing down on me at once. The LFSA Emergency Medical Fund basically paid all the outstanding bills not covered by insurance, which was really helpful. I'm also planning to get married soon.

LFSA: So are you planning your wedding?

Recipient: Yes. My fiancé and I are hoping to get married this Fall.

LFSA: That's exciting! It sounds like life really is getting back on track for you.

Recipient: Yes. I'm getting used to living with lupus, and being careful not to overdo it.

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

Recipient: Personally, if there was any way I could contribute to the Lupus Foundation, I'd be happy to. I volunteered during your last Walkathon and would do it again. Lupus should not be a life downer. I'm a very positive person, very optimistic. I like to encourage people to stay positive. It makes everything easier, including doctor's appointments!

LFSA: So staying positive is really important?

Recipient: Definitely!

TAME *the* FLAME

LFSA ANNUAL GALA

Presented By

Sunday

NOVEMBER 4, 2018
5:00-8:30 PM

Skyline Country Club
5200 East St. Andrews
Tucson, AZ

Honoring Rebecca Shields

$175 PER PERSON
$1,400 PER TABLE OF **8**

Featuring
Key Note Speaker
Cheryl Horvath
Tubac Fire District

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A POEM BY ALAYNA PALMER DROPE

The Silent Predator

I've watched this carnivore tear away pieces of my mother slowly over time.
He played with his food, enjoyed soaking his teeth into the victory of his hunt.
Bit by bit, he ripped away pieces of her flesh and blood.
With each gouge into her body, he feasts on part of her soul and heart.
This wolf ravenously mauled the woman I love.
Turned her heartwarming smile as rigid as a carcass
and her infectious laugh into a distant tweet in the woods.

Now, with his hungry gaze, he lunges toward me.
He scratches and snarls at the door;
His claws shred away splinters of my home.
His hot breath clouds the windows,
Making a cage of what once was a haven.

Instinct tells me to live and love normally,
But I see my reflection in his narrowed yellow gaze.
When stalked as game, normal means numbered days.
How do I not live as the prey I've become?
In fear and burdened with my broken wing for anyone who lets me in their flock.
The impending heartbreak of my struggle or loss for anyone who lets me in their nest.

I'm not afraid of the pain that slinks around the next tree.
But I ache for the next victim after my family lays my mutilated body to rest,
And the injuries inflicted on others while the predator prowls the terrain.
So I promise if the wolf catches me, it will be a battle not a slaughter.
And I won't stop pushing until I have no breath in my lungs.

I'm ready to live, ready to fight.
He might tear a bite out of me, but it will not end my course.
He thinks I'm the next meal, but I'm too much to chew, and have too many reasons to live.

Alayna Palmer Drope earned a B.A. in English from Missouri Valley College and a M.F.A. in Creative Writing from Spalding University. One of Alayna's short stories received Honorable Mention in the Writer's Digest 79th Annual Competition. Her work has been shortlisted and published in *The Masters Review*, appeared in *The Storyteller* and *The Number Eleven Magazine*. Currently residing in Arizona with her husband and three dogs, Alayna works as an IRA Specialist at Ascensus. In the evenings, Alayna continues to develop *Fault Line*, a collection of short stories set in a small community at the southern tip of Missouri, a setting in which the land's wide horizon dominates, where the land is essential to its inhabitants for a living. Characters come face to face with unexpected, life-altering events; they lose what can never be replaced, and they find ways to go on with their lives, sadder, wiser, and more open to compassion and love.

Feinstein Institute researchers find hypertension drugs could prevent memory loss in lupus patients

The Feinstein Institute for Medical Research 9/6/2018

The Feinstein Institute for Medical Research researchers published data yesterday in the Journal of Experimental Medicine that shows the class of drugs commonly used to treat hypertension, ACE inhibitors, can block cognitive decline in mice and might therefore be used to preserve the memory of patients living with lupus.

Lupus is a complex autoimmune disease that arises when the body starts to make antibodies that target its own, healthy cells, often specifically recognizing DNA. Patients can suffer a wide variety of symptoms, but as many as 90 percent develop neuropsychiatric lupus, which is often characterized by cognitive impairments such as memory loss or confusion.

After discovering that the activation of brain cells called microglia likely contributes to the memory loss and other cognitive impairments suffered by many patients with lupus, Betty Diamond, MD, and other Feinstein Institute colleagues wanted to find a way to block microglia. ACE inhibitors are known to block the activation of microglia. In their study with mice, Diamond and colleagues found that the ACE inhibitor captopril protected neurons against activated microglia, preserving their function and the cognitive performance of the mice.

"Our study suggests that ACE inhibitors are a promising class of therapeutics that can easily move into clinical trials aimed at mitigating the cognitive dysfunction associated with neuropsychiatric lupus," said Diamond, professor and head of the Center for Autoimmune, Musculoskeletal and Hematopoietic Diseases at the Feinstein Institute.

More details about the study:

Lupus patients experiencing memory loss often produce DNRAbs that recognize both DNA and a critical brain protein called the NMDA receptor, NMDAR. Antibodies are usually unable to enter the brain, but after injury or infection DNRAbs are thought to gain temporary access to the brain where they can target neurons expressing NMDAR. This causes the neurons to die or lose the synapses that connect them to neighboring nerve cells, resulting in memory loss or other cognitive defects. After suspecting that brain cells called microglia might be responsible for trimming the connections between neurons after exposure to DNRAbs, Diamond and colleagues analyzed mice that produce DNRAbs capable of penetrating the brain and inducing memory loss. The researchers found that microglia are activated when DNRAbs enter the brain and that a protein called C1q attracts microglia to the synapses of neurons targeted by these antibodies. Deleting the C1q protein, or depleting the microglial cells themselves, prevented neurons from losing their synapses after exposure to DNRA" "Betty Diamond is a leader in discovering novel therapeutics that will benefit generations of patients living with autoimmune disease," said Kevin J. Tracey, MD, president and CEO of the Feinstein Institute. "This paper is another important step in her approach to using basic science mechanisms to find future cures."

Dr.Betty Diamond, MD

In loving memory of Teresa Marrufo

Thank you to our Community Partners!

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DR. KENT KWOH, MD - UA ARTHRITIS CENTER

Dr. Kent Kwoh, MD

LFSA: Welcome back, Dr. Kwoh! Thanks for speaking with us again. Last time we spoke, you mentioned some of the studies being conducted by researchers at the University of Arizona. What research are you conducting at this time?

Dr. Kwoh: We have a number of experimental trials and are working with a number of different drug companies. We've studied a number of very exciting drugs and they are on various ways to approval. This is especially challenging for lupus drugs because there are so many ways to determine patient improvement. There are different drugs that target different parts of the immune system. We've made a lot of advances. Before we were working with a sledgehammer, like cyclophosphamide which wipes out your entire immune system or corticosteroids. They're very powerful but indiscriminate, and they have a lot of adverse affects. The idea is to have more target therapies so that we're doing fine manipulations, like going from a sledgehammer to a syringe with a needle where we're targeting specific parts of the immune system that may be abnormal or out of whack. The more targeted the therapy, the better the efficacy with fewer adverse events.

LFSA: You mentioned before you are studying the microbiome?

Dr. Kwoh: Yes, that's right. I mentioned the work being done by Joyce Wu, PhD., associate professor of immunobiology here at the University's College of Medicine. 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: What about probiotics?

Dr. Kwoh: I would caution patients though. There's been a lot of interest in probiotics but there really haven't been studies that show certain probiotics work. The other thing is knowing which probiotic to take, and whether you can take enough to really impact the immune system.

> *"The other thing is knowing which probiotic to take, and whether you can take enough to really impact the immune system."*

LFSA: Is anyone studying probiotics at this time?

Dr. Kwoh: There are studies underway, but we're not quite there. There's always the potential for adverse effects. You can't just introduce new bacteria to someone's gut without first considering adverse events.

LFSA: The microbiome seems very complicated.

Dr. Kwoh: It is. We're really just hitchhiking along. It's a little scary to think about how we're kind of in the minority when you consider all the microorganisms living in us and on us and around us.

LFSA: What other studies are you doing?

Dr. Kwoh: We're starting a new study that will involve enrolling patients to look at the natural history of disease, to identify biomarkers. There are certain tests out there now, but they're imperfect. The idea is that if we can get better biomarkers we might better understand disease and come up with potential targets for newer treatments.

LFSA: Which is why demographics are so important.

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Dr. Kwoh: Exactly. One study we are planning is looking at the issue of lupus disparities. Why do certain racial minorities do worse than other patients? And why do some patients overestimate the risks and underestimate the benefits of certain treatments? The key is patient education and helping people understand the risks, benefits, and tradeoffs. There is no safe medicine. I tell patients if they drink too much water that it's not good for you. And just because it's natural doesn't mean it's safe.

LFSA: It must come down to dosing on some level.

Dr. Kwoh: It does. You need to make sure you understand what you're getting, whether it's from a nutritional aspect or a supplement aspect or from a drug aspect and realizing that nutraceuticals and supplements aren't regulated the same way as drugs. You're not always sure what you're getting or if it might be contaminated.

LFSA: Our patients are desperate for answers. It's great to have all these ideas, but until the research is done and we really understand what is going on it's hard for anyone to say one way or the other what actually works.

Dr. Kwoh: Yes, I agree with you. When we have a disease as devastating as lupus and we don't have a cure, patients can become desperate. Unfortunately, people fall prey to practitioners who may not be as experienced or who may have less than perfect motives, so it's best to be cautious. That's why it's so great to have the Lupus Foundation as a source of trusted information. You're not biased, you're not selling anything specific. Patients have to be careful about practitioners who might be pushing one treatment to the exclusion of others.

LFSA: We couldn't agree more. Here at the Lupus Foundation we continue to be careful and fact-based. It's a huge benefit that we have a constructive relationship with the Arthritis Center and with people like yourself who continue to shed light on these situations.

Dr. Kwoh: We're happy to do it!

THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Arthritis Center

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The Spoon Theory by Christine Miserandino

Back by popular demand!

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

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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 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.

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

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 then others; some days I have more spoons then 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".

LFSA Q & A SERIES

Heidi Armand has attended numerous LFSA support groups. Here she shares some of her experiences trying to find balance as a working mother who also has lupus.

LFSA: When did you learn you had lupus?

Patient: Two years ago in November. My PCP suspected it for a while but the blood work kept testing negative. I just wasn't feeling well. My PCP suggested I test one more time and I got a positive ANA. He had told me a year earlier I was having a lot of IBS symptoms and joint pain I was just really sick, not absorbing any nutrients. He said if you don't destress, change your diet, you're heading down this path, this is the pattern I see in people with lupus.

LFSA: What have you done to manage your symptoms?

Patient: At the beginning it was changing my diet for the IBS and mal absorption, trying to heal that piece. I didn't realize at that time that it was the stress in my life. Since then I've begun to manage my stress better, exercise more, and I've cut back on my work hours. None of my labs are showing strong enough for my rheumatologist to treat me with lupus medications. My body doesn't react well to pharmaceuticals. Mostly its been supplements and stress management. I had a huge flare last April that lasted two months and they did put me on some steroids to manage that episode. Normally a lupus patient might stay on steroids long term but I was able to take a short burst and it worked. I've also had doctor support choosing and dosing my natural supplements which has been very helpful.

LFSA: Who are your biggest supporters?

Patient: My husband for sure. At first he had a hard time understanding my lupus. He actually came to a couple of your support groups. The women at your support group were really informative. They answered my husband's questions and since then he's been able to support me even more because now he gets it. It was hard for him before. He couldn't understand why I was laying around, resting so much. The women at the support group were so helpful. I also have a fantastic boss who's super supportive, very understanding. It's a small business so it's been possible to reduce my hours as needed and keep my job. It's hard for your friends to understand. I have one friend who tries but she grew up like I did, learning to just push through. My kids also try to understand. I have three daughters. The eldest has special needs so that adds to the stress. All in all the diagnosis was a good thing because we have some guidelines, but it's still really hard for them. I really worry about how it affects them. It's extremely challenging to get them to understand and have empathy. Kids are mostly all about themselves.

> *The women at your support group were really informative. They answered my husband's questions and since then he's been able to support me even more because now he gets it.*

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One thing that really helped when I first started going to the Lupus Foundation was learning about the Spoon Theory. My kids watched the video, and now they understand that I have only so many spoons to offer on a given day. The downside is I'm always talking about my health, always struggling. I try not to show them too much because they start looking at themselves, and I worry because I don't want them to have that mindset.

LFSA: People can't be inside your body, so you have to communicate your needs.

Patient: That's exactly what I'm talking about. I worry about them mimicking the behavior. The Spoon Theory helps, but the other day my girls were complaining about me not cleaning the bathroom enough. It was really tough to hear that. I had to explain how much it hurts for me to get down on the floor, to scrub the tub or toilet. I had to tell them how hurtful it was to hear that. So my lupus affects them. We've been talking a lot lately about normalizing my lupus lifestyle. No one sees me at my worst, only my husband, and most of the time I can hide what's going on. If I push through, and pretend I'm okay, I usually pay a price. The lupus is attacking me even when I feel good. If I can't see it or feel it, how can I expect anyone else to see it or feel it?

LFSA: So being a mom makes everything more challenging.

Patient: Absolutely. It's so hard being a mom with lupus. If I feel like crud, someone still has to take the kids to school and pick them up. I don't want their lives to stop because of me and that's the hardest thing, to fight that guilt and take care of myself. But at the same time I miss out on so much. Then you feel guilty and push through. As a mom I don't feel like I can slow down. I don't want the lupus to affect my kids' lives.

LFSA: That is so well-said and we've heard this from so many of our lupus patients, especially the ones with kids. Most parents push through and sacrifice, but if a lupus patient does that, he or she could end up in the hospital. You're fighting the needs of your family, but also social expectations that people without lupus are able to meet.

Patient: Exactly. How do we normalize this? It's so unpredictable. How do you run a household, raise kids, be a wife, work full time, and then manage your health on top of it? I'm overwhelmed every day. You wake up each day wondering if this is the day things will go bad. It's hard for me not to be scared all the time, and have that not affect my family.

LFSA: If there was one thing you would want to tell other lupus patients, what would it be?

Patient: What gets me through is my support system. The girls at the Lupus Foundation have been great. When I've been really low, they've lifted me back up, by saying I'm not alone and I can get through this. Those positive thoughts really help me through the dark times. Find yourself a good support system of people who understand lupus and who really care. When you can't be strong, they can be. The Lupus Foundation, my husband, my boss. They're all my cheerleaders. I thought I was alone and I thought I was crazy. Finding out I'm not alone or crazy, and that this is all very real, that really helps get me through the day.

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LFSA Bi-Annual Magazine
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Annual Walk the Loop for Lupus
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