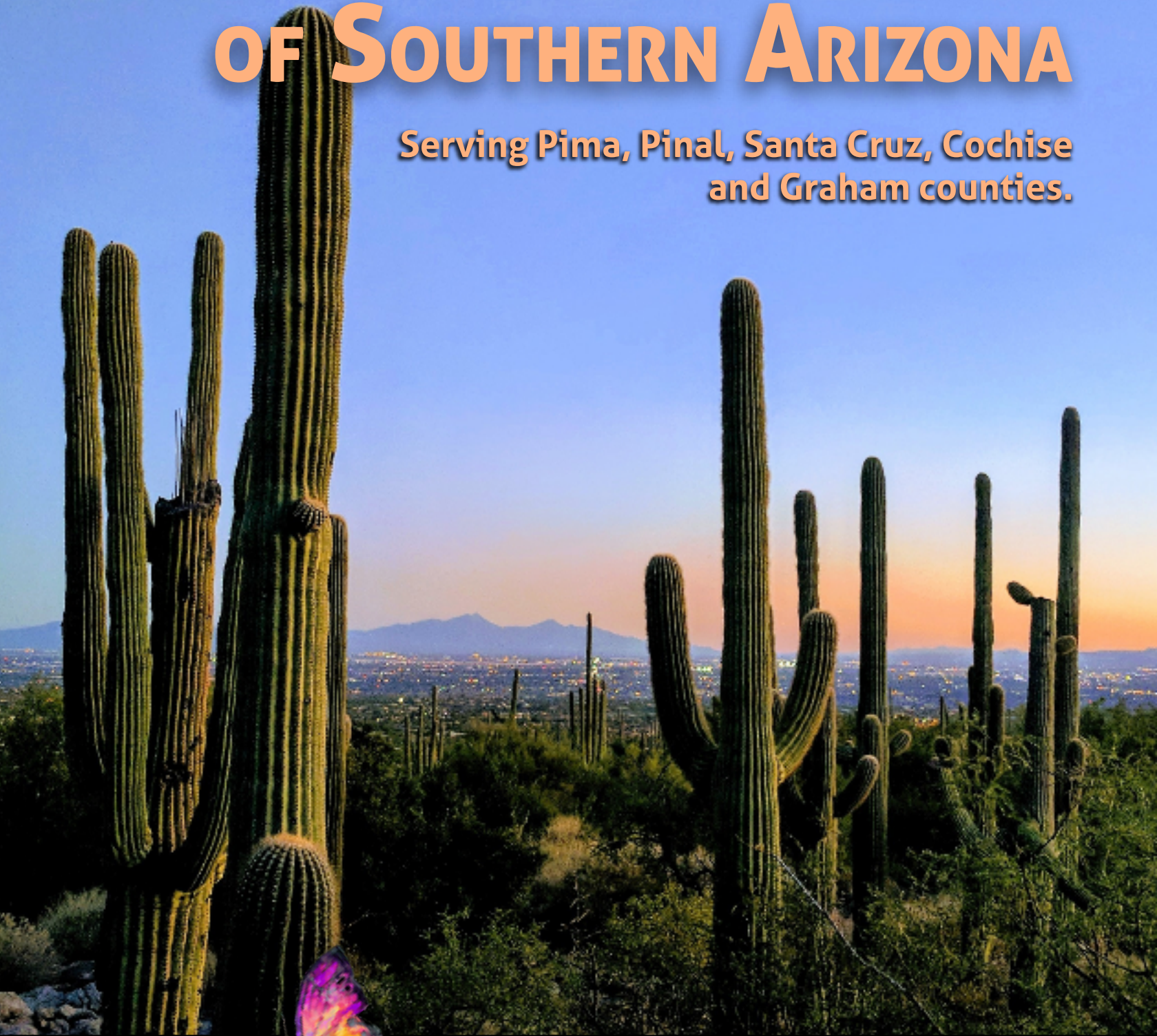


LUPUS FOUNDATION OF SOUTHERN ARIZONA

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



Fall 2017

IN THIS ISSUE:

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

CALENDAR

March

7TH

LFSA Annual Meeting

Join us at 4602 East Grant Road for our Annual Meeting. This meeting is for anyone who wants to learn more about what's going on at the Lupus Foundation of Southern Arizona.

April

14th

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.

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

Sharon Joseph, President

Shaunna Kowalewski, Vice President

Lani Baker, Treasurer

Shaima Namazifard, Secretary

BOARD MEMBERS

Wendy Black

Sherri Fritz

Abigail Garcia

Ricardo Hinds

Donna Morton

LETTER FROM THE PRESIDENT



The year 2017 is another successful year for the Lupus Foundation of Southern Arizona. As we enter the holiday season I want to thank our sponsors, community partners, donors, members, event attendees, volunteers and all who help us raise funds to fulfill our mission. The LFSA "exists for one reason only ... and that is to provide all possible support to those dealing with the disease" of Lupus. We could not do this important work without the help of each one of you. And we want to continue this work with you and the countless additional helpers we will recruit to join us in this most necessary and meaningful mission.

As I begin my work as President of the Foundation, I am grateful for the support and vote of confidence I have already received from many of you. I am most grateful to Rebecca Shields, for her energy, vision and guidance to myself and the Members of the Board of Directors. Rebecca served on the Board 4 years, 3 of them as President. We can only build on the programs she and the Members

of the Board have put into motion and draw on the examples of their hard work and dedication.

Our 16th annual Walk the Loop for Lupus on April 22nd at Reid Park was a great success and turned out an enthusiastic crowd of walkers. It was followed on May 17th by another amazingly successful and fun Hit-the-Links for Lupus annual golf tournament at the Omni Tucson National. The 3rd Annual Gala on October 15th was a beautiful evening with friends at the Skyline Country Club and brought our three major annual events to a close, successfully raising funds to further our programs of service.

Through your generosity, we provided funds to 9 different partial scholarship recipients this year, 2 of whom have graduated. We recorded 155 walk-ins and calls from those making inquiries. We offered two Retreats for Women, continued the well-attended monthly Living with Lupus mornings and Coffee Talk evenings and provided support to Lupus patients through LFSA Cares and the Emergency Medical Fund.

There's still a lot of work to do. Our goals of greater community awareness, education and partnership with organizations and individuals throughout the counties of Southern Arizona, spur us on.

The Lupus Foundation of Southern Arizona is here for ALL impacted by Lupus. Remember you are NOT ALONE! Reach out to us by phone or visit, through Facebook or our website. We welcome your input, your journey, your thoughts and your needs. Be well!

Sharon Joseph, President

Through your generosity, we provided funds to 9 different partial scholarship recipients this year, 2 of whom have graduated.

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 SCHOLARSHIPS - HALEY ANDERSON



LFSA: How did you learn about LFSA?

Recipient: I found out from my doctor. I came up for a visit and saw your poster on the wall. Before that I hadn't heard of LFSA.

LFSA: How did you learn about the scholarship program?

Recipient: I checked out your website. I called your office and the rest is history.

LFSA: What are your academic goals?

Recipient: My first goal is to get my associate's degree. Currently I'm working on a degree in business administration at Cochise College. I may then go on to a university for a four year degree.

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

Recipient: Having Lupus is a challenge. I had taken a break from school to set aside money, but then I got sick. I had to use that money for medical bills, and was living paycheck to paycheck. I used to work two jobs but Lupus has made that harder. I wasn't sure how I would do going back to school. It's been almost ten years since I've been in school, so I was a little nervous trying to balance a full-time job and go to school full-time. But it worked out. I completed my first semester with a 4.0 grade average. I'm proud of that!

LFSA: How specifically has the scholarship program helped?

Recipient: I didn't have the money to go back to school, and it's hard to go into debt. I was hesitant to take out a loan. Learning that there was financial help was great. The LFSA scholarship covers the semester and I only have to pay for the books. The scholarship has made it affordable for me to attend school.

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

Recipient: I would like to say thank you to the Foundation. You guys have been awesome! In addition to the scholarship, I recently attended one of your retreats. It was the first time I had a chance to talk to anyone else who had Lupus. I've had Lupus for five years. At first I didn't expect anything good to come from my Lupus diagnosis, but after getting in touch with the Lupus Foundation I finally feel like I'm stepping in the right direction.



LFSA IN THE COMMUNITY

LFSA WOMEN'S RETREATS



This year the Lupus Foundation of Southern Arizona hosted two overnight women's retreats. Participants were able to take time out to unwind, relax and engage with other Lupus patients in fun and informative activities. The first retreat was held in June at White Stallion Ranch and included a late afternoon horseback ride. The second retreat was held in November at La Posada. The Foundation hopes to offer retreats for Couples and Women in 2018.



LUPUS FOUNDATION OF SOUTHERN ARIZONA'S 16TH ANNUAL WALK THE LOOP FOR LUPUS

The Lupus Foundation of Southern Arizona's 16th Annual Walk the Loop for Lupus was a huge success with over 600 walkers attending. Thanks to everyone who participated!

The 2017 Walk the Loop for Lupus was presented by Miller Coors, a proud



partner and supporter of the LFSA.

Save the Date! The next Walk the Loop for Lupus will be April 14th, 2018.

We hope to see you there!



LUPUS FOUNDATION OF SOUTHERN ARIZONA'S ANNUAL HIT THE LINKS FOR LUPUS GOLF TOURNAMENT



Thank you to all of the sponsors and golfers who participated in the 2017 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 FOUNDATION OF SOUTHERN ARIZONA 3RD ANNUAL GALA



Dr. Ernest Vina

The Lupus Foundation of Southern Arizona 2017 Annual Gala was a huge success! We would like to thank our title sponsor, HealthSouth Hospitals of Tucson, as well as all the evening's sponsors and attendees. Dr. Ernest Vina from the University of Arizona's Arthritis Center gave a talk on Current Pharmacologic and Non-Pharmacologic Treatments for Lupus. Mr. Stanley Lehman, who has provided years of support to the LFSA, was our guest of honor. More than 120 guests were hosted to a fabulous silent auction and dual course meal. During the meal, guests watched a new promotional video about the LFSA. 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!



HealthSouth receives title sponsor award



Mr. Stanley Lehman

Rebecca Shields

LFSA Board President

2014-2017

*Thank you, Rebecca,
for your service and dedication to the
Lupus Foundation of Southern Arizona!*



Silent Auction

A EULOGY FOR THE PERSON I WAS BEFORE I GOT SICK BY LARA PARKER

It was 5:43 a.m. As I stared at the time on my phone, I realized that the pain I was feeling hadn't been a dream. I could feel the tightness in my stomach and the cramping in my back. I wondered how long I had before the pain would make me vomit. I wished I could just fall back asleep. I rolled over to grab the heating pad that I always keep by the side of my bed. And then I tried to brace myself for the immense pain I knew was coming.

I no longer remember what it's like not to be in pain. I don't remember what it's like to not have a stabbing pain in my abdomen wake me up every morning. And it's been years since I could take my dog for a walk without my vagina burning with each step I take. It rarely surprises me anymore. Having these aches and pains doesn't necessarily feel different or out of the ordinary; it just feels normal. I don't know anything else at this point, and the days when I did are long gone. Sometimes, I wonder if those days ever even existed at all. For the most part, I feel like I've come to terms with the pain. I've accepted it as part of my life. But then, out of the blue, I'll start my morning and the pain will be unexpectedly fierce. It'll be sharper than usual; it'll wake me up in the middle of the night. I will feel heavy and weighed down. I'll be forced to stay in bed for 14 hours straight. And I'll forget that I ever came close to accepting this at all.

I've been living with chronic pain since I was around 15 years old. It was less severe back then — more of an occasional distraction compared to what it is now. It seemed easier to deal with; I think I still believed that I would grow out of it. Now, at 26, it is

always with me. The pain causes me to miss work, to miss friends' birthday celebrations... even to miss my own. But it isn't just the physical pain that I'm dealing with. After 10-plus years of this, it's the mental aspect of living with chronic pain that really tests my limits. Living in constant pain has drained me. Because living like this means trying to find a way to accept that this is my life now, and that this is who I am now. I have to do this every single day, over and over again. And after 10 years, I'm still not that great at it.



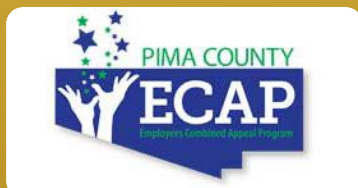
Living with chronic pain feels like you're constantly at war. Each day is a small battle. Sometimes, the battles are easily won, and sometimes... they're not. But beyond fighting with your own body to ease the physical pain, you're fighting a battle to maintain who you are. Chronic pain eats away at you. Some days I feel like my chronic pain is making me lose my mind. I feel unhinged. The persistent discomfort causes me to be irrationally angry, and to lash out at those around me. It gives me immense anxiety, which has led to severe depression. It has taken everyday things like waiting in line or going for a walk and turned them into challenges. When you're at war with your own body, small things become

amplified. Suddenly that person cutting in front of you in line is your worst enemy. The coworker complaining of the hangover they have from the night before is the rudest person you've ever met. And the girl running outside your apartment window is there just to taunt you. It's not rational. But neither is being in pain every day.

Trying to hold on to the person I am without my pain is the hardest battle I've ever fought. I feel like the person I could've been has died, and I must grieve for her day after day. I think about this a lot — the idea that I might be a totally different person if I weren't in pain. I like to think I'd be one of those carefree girls who laughs easily and is always down for an adventure. I imagine myself smiling more often. I think I would have an easier time connecting with people, and people would be drawn to my energy instead of scared away by it. College definitely would have been a different experience. Instead of lying in bed with my heating pad wondering what the hell was wrong with me, I might've attended house parties or gone out to bars until 3 a.m. I might have traveled the world by now, or moved to Australia on a whim. Maybe I'd work on a luxury yacht. I like to think that I'd spend less time in bed watching TV and more time out in the world hiking, biking, and exploring new places. I yearn for simple things — like eating a donut without stomach pain, or being able to attend SoulCycle classes. I'd even settle for just being able to go on a run. Really, I just want to live my life. But I can't do that with my conditions — not in the way that I want to, anyway.

(continued on next page)

Thank you to our Community Partners!



(continued from previous page)

I distinctly remember being a young girl and thinking about my future. I, like most people, often wondered what I would be like when I got older. I had it all planned out. I would go to college with a scholarship to play basketball. Once there, I would study to become a marine biologist, or maybe start my own ad agency — all while attending fabulous parties and dating multiple cute boys. I loved to think about who I would be when I graduated from college — what job I would have, and the exciting life I would lead as a twentysomething. I saw it all — the parties, the dinners out with friends, the vacations. I dreamed about several different scenarios, but none of them included me stuck in bed with a chronic illness.

As much as I want to be free of this disease, I can no longer spend my time endlessly searching for a cure. I don't want to spend hours reading message boards, and I don't want to continue spending thousands of dollars on specialized doctor visits. I want to allow myself time to grieve for the life I didn't get to have... and then I want to move on. The time has come to get to know the new Lara — the one who has chronic pain, and might still have it 20 years from now. I want to get to know what this Lara is capable of, and I want to dream new dreams of where this Lara's life will take her. Admitting this doesn't mean that I'm giving up — quite the opposite, actually. It means I'm finally allowing myself to be free. I won't stop taking my supplements or attending physical therapy. I might even still get a crystal healing now and again. I will never stop fighting back against the illnesses that have taken so much from me. But I cannot keep existing in this in-between — this place where I'm convinced that

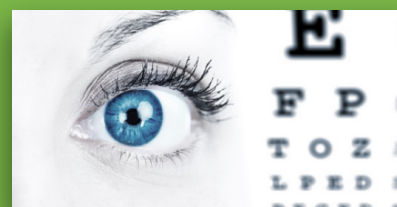
there *is* a cure out there somewhere, but I'm just not working hard enough to get there. I can't live in the past anymore, yearning for a life I can barely even remember. I need to exist in the present, where I know that I am sick, and where I also know that I've done and am doing everything in my power to fix it.

Sometimes, I'm not sure who I am anymore. It's hard to find the words to explain what it feels like to have your life stolen from you by an illness. One day, you feel familiar with your body and think you have an idea of what's happening inside of it. And then suddenly everything is out of your control, and no matter how badly you want to fix it, you can't.

There are different versions of Lara now. There's good-pain-day Lara, and there's bad-pain-day Lara. There's "I'm Going to Fight This Shit and Actually Win" Lara, and then there's "I Am Tired of Fighting, I Just Want to Sleep" Lara. I never know which Lara I'm going to get. But no matter which Lara it is, it's never the one I thought it would be, all those years ago. And for the first time in a long time, that's ok.



**Do you take
Hydroxychloroquine to
treat your RA or Lupus?**



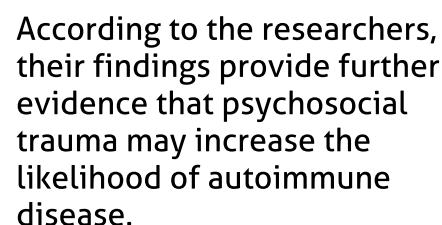
**See your optometrist
every 6 months.**

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

What is more, researchers found that exposure to any traumatic event - even in the absence of post-traumatic stress disorder (PTSD) may increase Lupus risk.

PTSD is a mental health condition that may arise after witnessing or being involved in a traumatic incident, such as a

According to Lupus Research Alliance, there are around 1.5 million people in the U.S. living with Lupus, with more than 90 percent of cases arising in women aged between 15 and 44 years.



FDA APPROVES INJECTABLE DRUG FOR SYSTEMIC LUPUS ERYTHEMATOSUS

Specialty Pharmacy Times -
7/24/2017

GlaxoSmithKline (GSK) recently announced that the FDA has approved belimumab (Benlysta) in a subcutaneous formulation for the treatment of patients with active, autoantibody-positive systemic lupus erythematosus (SLE), according to a press release.

Belimumab is the first self-injectable drug approved for the treatment of patients with SLE.

SLE is an autoimmune disease that causes the body to produce autoantibodies that attack nearly all systems in the body. SLE is the most common form of Lupus and there is currently no cure for the disease.

Belimumab is a human monoclonal antibody that binds to BlyS. Since the drug does not bind B cells directly, it inhibits the survival of the cells. Additionally, it lessens the differentiation of B cells into immunoglobulin-producing plasma cells, according to the release.

Belimumab is the first self-injectable drug approved for the treatment of patients with SLE.

After receiving proper training from their healthcare provider, patients will have the ability to self-administer the 200-mg injection once per week. Belimumab will be available as a single-dose prefilled syringe or a single-dose autoinjector, GSK reported.

The new approval is based on positive data from the BLISS-SC phase 3 clinical trial, which included more than 800 patients with SLE, according to the release. The study examined reduced disease activity after 52 weeks of treatment with belimumab plus standard care or placebo plus standard care.

GSK reports that this is the second formulation of belimumab to receive FDA approval to treat patients with SLE. The intravenous formulation was approved in 2011, and is administered by a healthcare professional as a weight-based dose of 10-mg/kg. The infusion formulation must be administered every 4 weeks in a 1-hour session at a hospital or clinic, according to the release.

Subcutaneous belimumab will save patients time and money, as it can be self-injected, according to a press release. The drug will be available at

specialty pharmacies in August 2017, GSK wrote.

Additional regulatory submissions for the novel formulation of the drug are currently under review or planned to be submitted this year.



"We are delighted with today's decision. Lupus can impact the lives of patients in many different ways with varied and often unpredictable symptoms," said Vlad Hogenhuis, senior vice president, head of Specialty Care at GSK. "Since it launched in its IV form, thousands of patients worldwide have received treatment with Benlysta. The approval of the new injectable formulation will now provide an additional choice for patients, allowing them to self-administer their medicine at home rather than going to hospitals or clinics for their infusions."



WELCOME TO HOLLAND

"Holland!?" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy." But there's been a change in the flight plan. You have landed in Holland. And there you must stay.

The important thing is that it is just a different place. You must buy new guidebooks. You must learn a whole new language. And, you will meet a whole new group of people you would not otherwise have met. It is slower paced than Italy, less flashy than Italy. But after you've been there awhile, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.



So, welcome to Holland. Along with the patient in your life, you have landed in an unexpected destination. You have experienced the loss of a dream and are challenged to adjust to a different type of life than you had planned. You have probably lost some companionship and, instead, may have taken on new responsibilities. But, you have a choice to dwell on what you have lost or to seek out new possibilities.

-Anonymous Patient

In Memoriam

~

Alicia Merrill

Jon Depka

Allen Teasley

LFSA Q & A SERIES

Pam Anderson is an administrative associate at the LFSA office. Here we learn how she was diagnosed with Lupus, and how modifying her diet brought unexpected benefits.



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

Patient: I was diagnosed with Lupus in 1993, but I've probably had it since I was a teenager. I was on a rafting trip in the Grand Canyon and developed sun poisoning. It was so severe that I was almost evacuated by helicopter and ended up in a hospital in northern Arizona for a week. After that I began having problems with swallowing properly. My gastroenterologist thought anxiety might be the cause. This condition continued for 13 years before the doctors finally scoped my esophagus and found all the damage. I wish I would have been diagnosed sooner. I began having other problems, including the swelling of my knees, TMJ, feeling tired and additional aches and pains. Some people think these symptoms are all in your head, which was psychologically

damaging to me at the time. When you go to the doctor and they can't find anything wrong, your family is like, "Let's get on with it. There's nothing wrong with you." It's difficult not having a diagnosis, not knowing whether or not it's all in your head.

LFSA: A lot of our patients have shared similar stories about not being taken seriously.

Patient: That's true. It took persistence on my part to obtain a diagnosis, since my family was unable to advocate for me at the time. There are doctors in my family and if they're right, you're wrong. I just kept going from one doctor to another. Rheumatologists, cardiologists, gastroenterologists, dermatologists and primary care doctors. After a while, things were beginning to add up. I found out I was pregnant and my gynecologist figured that I probably had Lupus.

LFSA: That sounds like an odd way to learn you had Lupus.

Patient: He said I had vasculitis and people with Lupus can develop this problem. I was referred to a rheumatologist who put all my symptoms together. He diagnosed me with a form of Lupus that is chronic but not severe because I didn't have kidney involvement. I then looked for doctors who worked with Lupus patients and found Dr. Yoakam at the University of Arizona, who finally gave me the full diagnosis.

LFSA: So it took a long time and a team of doctors to get to the diagnosis.

Patient: That's right.

(continued on next page)

(continued from previous page)

LFSA: Tell us about the medications you've taken.

Patient: After the diagnosis, I was given Plaquenil, which I took for several years but couldn't see that it was helping me. The medication that helped the most was probably Prednisone. The pain and inflammation in my joints died down. I had energy. The fatigue went away. But the Prednisone led to osteoporosis and increased blood pressure. It eventually caused a serious infection that I barely survived due to my immune system being suppressed. But the worst thing was probably the weight gain. I gained over 150 pounds.

LFSA: That's when you started the diet you're on now?

Patient: I tried so many diets but I usually gained the weight back. My rheumatologist didn't want me to go on a low-carb diet since it might affect my kidneys. Then about two years ago my health was about the worst it has ever been. I had cerebral hypertension and vomiting. I began seeing Dr. Gann at the Diet of Hope. The diet had lot of restrictions. Within six weeks I had lost a lot of weight and I was starting to get off some of my blood pressure medications. I was feeling better, healthier. My joint pain went away. My acid reflux started to go away for the first time ever. As of today, it's been almost a year and I've lost 103 pounds total.

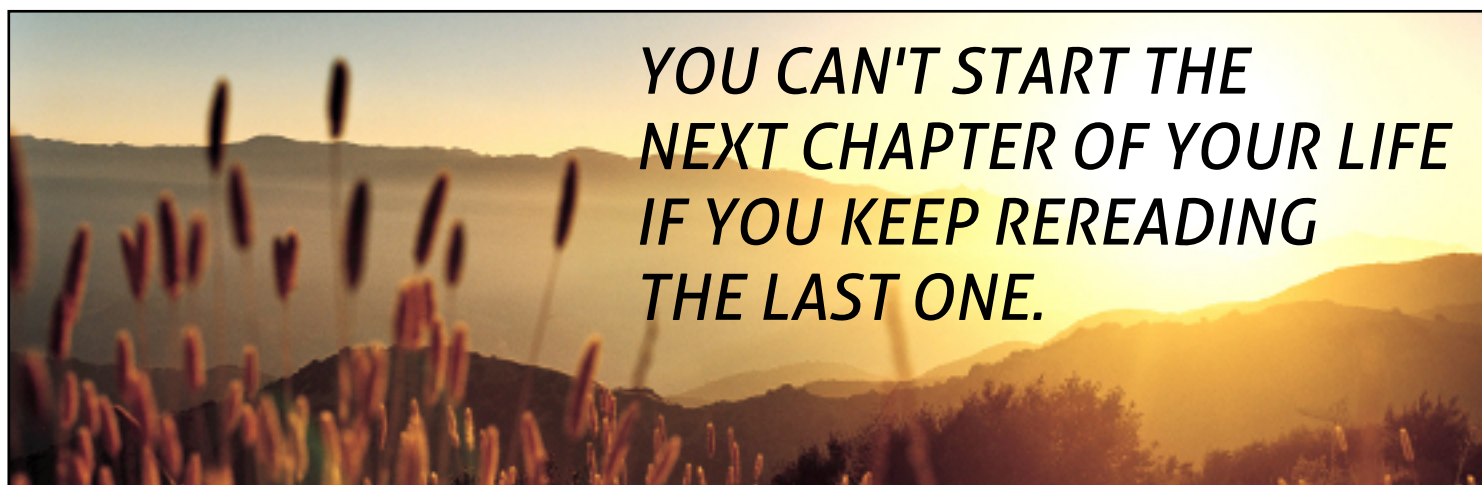
LFSA: That's an impressive turn around!

Patient: I think I'm either in remission or there's something that I'm eating or not eating that has to do with my improved health. Dr. Gann believes it is the things I'm not eating, like grains, sugar and other carbs, that might have been causing my inflammation. The healthy things I am eating, more vegetables and healthy fats, are helping to control my other symptoms. I am currently off all my blood pressure medications which I've taken since 1983. Of course I'm watching all my levels very carefully.

LFSA: So it's good to work with a doctor when making changes to your diet.

Patient: Yes. The diet I'm on is a medically-supervised weight loss diet. It's all-natural and healthy for me. But I wouldn't want to recommend anything that might cause liver or kidney problems for someone else.

LFSA: It's remarkable how well this particular diet worked for you. We hope our readers understand the importance of being closely monitored when making dietary changes.





THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

Community Education

LFSA Bi-Annual Magazine

Lending Library

Living with Lupus Campaign

Health Fairs



Monthly Support Meetings

Resource Kits

Counseling

Patient Retreats

Emergency Medical Fund

Education Scholarships

Camps for Kids

***Annual Walk the Loop for
Lupus***

***Hit the Links for Lupus Golf
Tournament***

Annual LFSA Gala



Lupus Foundation of Southern Arizona

4602 East Grant Road

Tucson, Arizona 85712