# 2020 ANNUAL COMMUNITY REPORT

THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

## FACTS

A butterfly is sometimes used in reference to Lupus because of the butterfly -shaped rash that appears across the bridge of the nose of many Lupus patients.

1.5 million Americans and 5 million people worldwide have some type of Lupus.

Lupus patients often suffer from multiple autoimmune diseases.

Lupus is NOT contagious.

90 percent of people with Lupus are women.

Lupus is more prevalent among women of color – African Americans, Hispanics/Latinos, Asians, Alaska Natives, Native Hawaiians and other Pacific Islanders – than among Caucasian women.

Sunlight, infection, injury, stress or exhaustion can trigger "flares" (a more active state of the disease) in Lupus patients.

# TABLE OF CONTENTS

# From Your President

The first 6 months of Fiscal Year 2019-2020 carried on as usual with a successful golf tournament October 25, 2019, board meetings and support groups at the office, health fairs out in the community, and then, March 2020 happened. Along with the entire world, regular activities stopped. For us, this meant canceling all in-person meetings and events, with Tyler and I taking care not to be at the office at the same time and sanitizing everything we touched. We began Board Meetings and Support Groups on Zoom. City Parks and Recreation canceled all public events and closed the parks, due to the growing safety concerns surrounding the COVID 19 novel coronavirus, including the Annual Walk the Loop for Lupus scheduled for April 18, 2020. We hosted our first ever Virtual Walk July 18, 2020, which we deemed a success, even as we missed seeing each other at the park.

Fiscal Year 2019-2020 gave us pause to reflect on our programs, cut expenses as much as possible and make the best use of the resources at our disposal. We are grateful to the sponsors of the Walk and Golf Tournament, to individual donors and volunteers. Your time, talent and treasure brought in much needed donations. Thank you. We also applied for and received funds through the Payroll Protection Plan to help us manage this year. The needs of our patients do not stop. We received applications for the partial scholarship program as well as requests for help with medical and non-medical emergency needs through the LFSA Cares and Emergency Medical Funds. We were able to meet these needs. Thank you.

Lupus is one of the least known among autoimmune diseases, so another aspect of our mission is to raise awareness in the general and professional community. We managed to participate in a few Health Fairs and a health-related conference prior to March 2020, but all other public outreach for the rest of the year occurred through social media platforms, including an article published in the *Arizona Daily Star* prior to the Virtual Walk.

Please invite your peers and personal or professional business contacts to sponsor our events, to make a standing annual donation to our cause, to become a Board Member, and/or to attend our fundraising events.

The Lupus Foundation of Southern Arizona is here for people impacted by Lupus. Please stay in touch with us. Stop by the office, give us a call at 520-622-9006 or visit us on Facebook, Twitter or our website at www.lupus-az.org.

*Sharon Joseph*
*LFSA Board President*

# OUR MISSION STATEMENT

**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… to provide all possible support
to those dealing with the disease.

THE LUPUS
FOUNDATION
OF SOUTHERN ARIZONA

# 2020 ANNUAL REPORT TO THE COMMUNITY

## Fiscal Year October 1, 2019 - September 30, 2020

### INTRODUCTION

### BEGINNINGS

This organization began because of three women who were diagnosed with lupus. Along with their spouses and friends, they wanted a better understanding of the disease that was disrupting their lives and making them ill. They were looking for ways to live with lupus. They also wanted to support and educate other lupus sufferers, raise awareness among medical professionals and the greater community of Southern Arizona and help fund research that would someday lead to a cure.

Eventually, they decided to file Articles of Incorporation on October 9, 1984, and became the non-profit known as *Arizona Lupus Association*. After a few years, the Directors decided to join forces with the national lupus organization at the time and on January 14, 1989, became *Lupus Foundation of America, Inc. Southern Arizona Chapter.* They had access to training and education programs to offer to newly diagnosed patients as well as additional resources to enable their development as an organization. After almost 10 years as a local chapter, the Board of Directors withdrew from the national organization and on December 29, 1998, became the *Lupus Foundation of Southern Arizona, Inc.*, a separate entity to serve the needs of the people of Southern Arizona.

### TODAY

The foundation is dedicated to giving women and men, diagnosed with lupus, and living in Southern Arizona, an opportunity to come together to learn about their disease and to help each other live a quality life. We offer education and a supportive community, along with financial assistance programs for medical and non-medical emergency needs and partial scholarships.

LFSA is a nonprofit 501 c 3 serving people with lupus and their families in Pima, Pinal, Santa Cruz, Cochise and Graham Counties. A dedicated active Board of Directors leads the organization with laser focus on the LFSA mission. The mission ensures delivery of a program of general education to increase public awareness, disease knowledge and support for those with lupus and fosters the exchange of information among physicians and healthcare professionals.

## PATIENT DEMOGRAPHICS

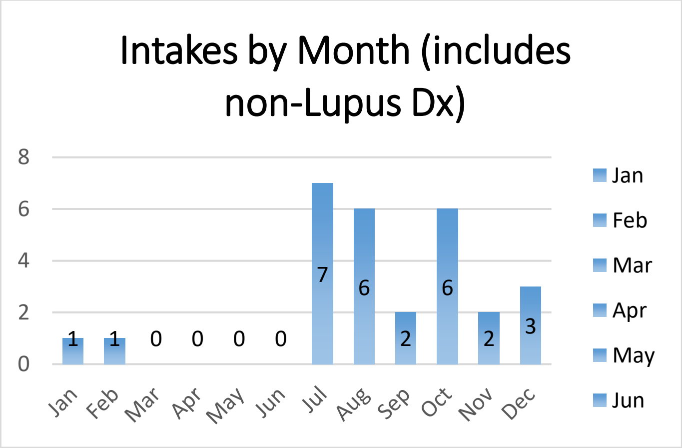
LFSA serves all people with lupus regardless of race, color, creed, age, gender or economic status. The foundation tracks its level of activity throughout the year from phone calls, walk-in patients, caregivers or interested persons making contact on behalf of a person with lupus.

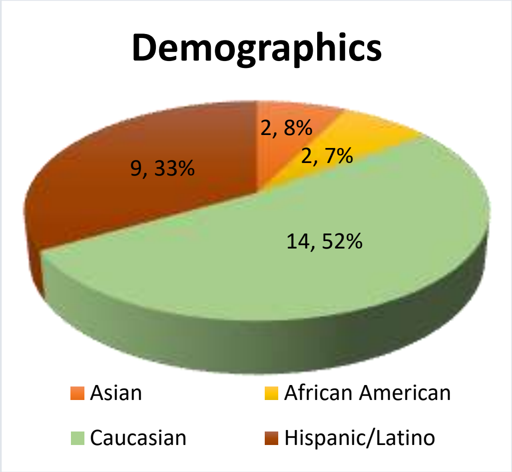
## INTAKES

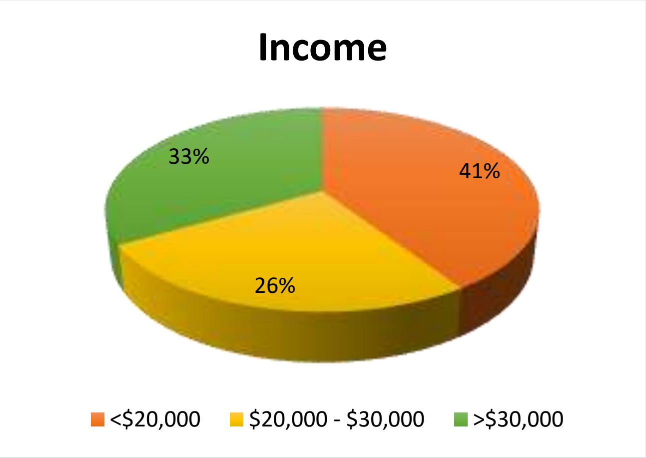
Intakes are designed to collect information about women and men with lupus who are served by LFSA. They are critical for tracking and encouraging patient participation and serve as an assessment tool for programs and community outreach.

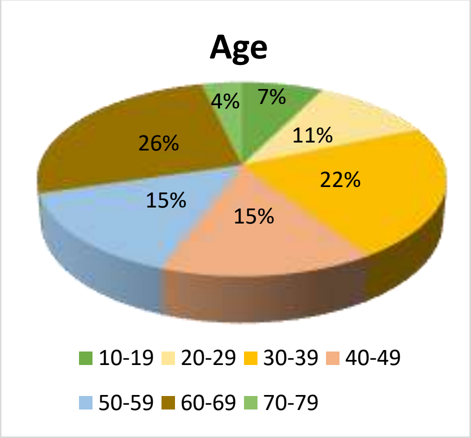
Intakes are completed in-person or by phone with the administrative associate. This year we introduced an online Intake Form which is accessed via the LFSA website. This form was already being developed prior to the COVID-19 pandemic and became indispensable after restrictions were placed on in-person contact and gatherings.

In 2020, 27 new intakes were completed, 25 through our new online form. We continue to raise awareness about lupus in the community and to improve our patient information tools, record keeping and procedures.









National data shows that 90% of people diagnosed with lupus are women. Intake information collected from the Southern Arizona region reveals that 96% of contacts who completed an intake and were informed of the services and programs offered by LFSA were women. Over 67% of the intakes in 2020 **earn less than $30,000 a year** and live **at or below the poverty level**. It is also important to note, that many of these patients **reported having lupus less than 3 months** and were receiving **government funded health insurance**.

## TOTAL TRAFFIC

LFSA maintains a traffic log of all walk-ins and phone calls during the year. In 2020, we logged more than 100 inquiries from callers and walk-ins and completed 27 intakes, all but two obtained using **our new online intake process.** It is significant that between March and June of 2020, we completed zero intakes, which tracks with the beginning of the COVID-19 pandemic and the creation of our new online intake form. This online form has changed the way we conduct intakes and may increase overall numbers as pandemic restrictions lift. In addition to intakes, we made 35 patient contacts and new patient calls as part of ongoing outreach efforts.

# LFSA MAJOR PROGRAMS

In 2020, LFSA continued the programming begun in 2015-2016, with a focus on support groups, educational attainment, retreats, emergency medical and non-medical assistance, and more!

## ***SCHOLARSHIPS***

The Scholarship Program is an academic study program to underwrite degree/vocational education of people with lupus. LFSA offers two 2-year scholarships per year. Applicants are voted on by the Board Officers. Applicants apply via the LFSA website. Scholarship recipients are enrolled in programs focusing on nursing, social work, business management, nutrition and art education. Students must maintain a minimum Grade Point Average (GPA) of 3.0 to qualify for this scholarship and most are achieving a GPA of 3.4 and above. Students are also required to volunteer ten hours of their time during each semester for which they have been funded.

***Outcomes:***

***We were able to fund two students with partial scholarships in 2020. Since its inception in 2015, the LFSA partial scholarship fund has awarded over $55,000 in partial scholarships.***

*I am currently a biomedical science major but am also interested in getting a second degree in neuroscience. I plan to go to medical school afterwards. From there, we'll see about a specialization. The scholarship has allowed me to pursue my education without having to work to help pay tuition. I've been able to focus on my studies while reducing my stress level. This has been really important for me and my family.*

-Selena Tang, LFSA Scholarship Recipient

## *LFSA EMERGENCY MEDICAL FUND*

For many people with lupus, the path to diagnosis can be long and arduous. Certain expenses are not covered by insurance and must be paid out of the insured person's pocket. This becomes a problem when the insured person is too ill to work, or until they begin to feel well enough to return to full time work or they may only be able to manage part time employment.

Once diagnosed with lupus, the journey becomes a life-long commitment to medical testing, pharmaceuticals, and medical related equipment (when required) and emergent procedures/surgeries. **There is no cure.** This important fund supports the health needs of our lupus patients by providing a one-time monetary wherewithal to get the medical services required, and directly benefits the patient's immediate needs. Patients must complete a qualification form, submit proof of a lupus diagnosis and provide an invoice for their request. Each case is considered and approved by the Board of Directors. Payments are sent directly to the vendor. This fund is promoted on the www.lupus-az.org website and with our focus on more community awareness of the programs of the foundation, it is beginning to attract those in need.

## *LFSA CARES ASSISTANCE FUND*

The LFSA Cares Assistance Fund provides funds to lupus patients for non-medical financial challenges on a one-time basis. Decisions are made by the Board of Directors. Patients must complete a qualification form, submit proof of a lupus diagnosis and provide an invoice for their request. Payment is made directly to the vendor.

***Outcomes:***

***This year we assisted a lupus patient who, due to complications from lupus, was hospitalized, resulting in outstanding medical bills. The Lupus Foundation of Southern Arizona was able to pay $1,100 worth of these outstanding bills, which helped this patient and her family meet their financial obligations.***

## ***RETREATS***

This program is a “close-in” forum at offsite locations for people with lupus, their spouses or significant others or caregivers. They are provided with a place to rest, relax and receive input concerning various topics such as: disease awareness, pain management, coping strategies, stress reduction, relaxation, exercise, diet and nutrition, caregiver/family awareness, etc. LFSA covers 100% of the cost for each attendee.

***Outcomes:***

***We were unable to host retreats during this fiscal year and look forward to resuming this program as soon as possible. Since the retreats began in the fall of 2015, the Lupus Foundation of Southern Arizona has hosted 84 participants at 9 retreats.***

## ***SUPPORT GROUPS***

Support Groups are for women and men with lupus, their families, and caregivers who come together for camaraderie, disease awareness, pain management, coping strategies, new treatments, etc. When a patient is having a painful day, is adjusting to new medications or maybe just does not know where to turn, attending a morning or evening group makes a difference.

Groups continued in person meetings as scheduled through March 2020, then assumed an online format with Zoom until further notice.

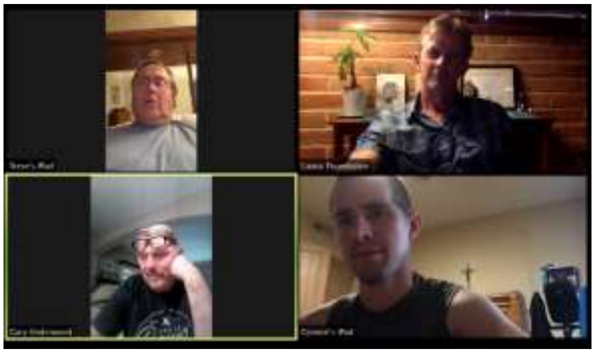
## *Coffee Talk*

*Coffee Talk* is on the 1st Wednesday of every month at 6 pm. Meetings are facilitated by Board Members and are designed to be open forum discussions.

## *Living with Lupus*

*Living with Lupus groups* are on the 3rd Wednesday of the month at 10 am. The morning group is topic oriented and is facilitated by Sharon Joseph, Board President. Guest speakers included healthcare practitioners, nutritionists, motivational speakers, Board Members, etc.

## *Lupus Men's Group*



*The Lupus Men's Group*, which meets every 3rd Wednesday of the month at 6 pm, started out as an online group. This group will likely transition to in-person meetings once circumstances allow.

### *Outcomes:*

***We received a grant from The Legacy Foundation of Southern Arizona to pay for one year of Zoom membership. Support group participation varies each month based on the individual's needs, the topic of the month and the demand for lupus disease education, quality of living and coping strategies. Participation in our online groups was lower than in-person participation. However, we now have a way to reach patients in remote locations once in-person restrictions lift. We expect to benefit from a hybrid support group strategy in the coming year, which will allow for both in-person and remote participation.***

# ~ Patient Testimonials ~

*“My financial crisis was resolved relatively quickly. I submitted my request for assistance and the Lupus Foundation handled the rest, by paying the full sum directly to the law firm involved in the dispute. Once that larger debt was settled, I was able to take care of other debts, which allowed me to get my life back on track.”* - Tori Micharski, LFSA Cares Recipient

* * *

*“I have had SLE and lupus nephritis since 2008. Recently, I was given a flyer with information about the Lupus Foundation’s group sessions. When I first attended the morning support group, I was nervous. However, I felt welcomed by Sharon and the other group members. In these group sessions, I learned new information about lupus and related chronic diseases. I also heard stories from other people with lupus, how they were diagnosed, and how they are managing their lupus. The group has helped me through my struggles of dealing with lupus while giving me love and support. I like to attend because I learn new things while meeting and connecting with new people! Thank you!”* - Courtney Harrison

* * *

*“When I was first diagnosed with lupus, it was sudden and unexpected. I had no idea what this diagnosis meant for my life and the life of my family. One of the first places we turned was the Lupus Foundation of Southern Arizona. Immediately they were there with phone numbers, resources, and practical suggestions about the path forward. They willingly answered our questions, listened to us, and gave us their perspectives navigating this disease, while providing the support we desperately needed in a frightening and uncertain time. I cannot convey how much they helped us. They showed us that there was a path forward and helped us to realize our own courage in walking it. I am deeply grateful for them and for everything they have done and continue to do for our community.”* - Amy Lacrosse

* * *

*“I was diagnosed with lupus October 18, 2018. I immediately became involved with the Lupus Foundation of Southern Arizona and was then invited to attend a couples’ retreat. This was an amazing experience. Not only was I able to meet people like me for the first time ever, but I was able to focus on my husband as well. This time was very special to me, and it is something that I will never forget. Thank you, Lupus Foundation of Southern Arizona. Thank you for all you do!”* - Marilyn Gentry

# ONGOING SERVICES

## ***RESOURCE KITS***

Resource Kits are available for men and women with lupus served by LFSA. Kits contain information about the foundation's programs, as well as items such as sunscreen, hand sanitizer, ice packs, lip balm, pill containers, etc., all useful tools for lupus patients.

***Outcomes***:

***We distributed two resource kits to new patients through March 2020. Patients who complete an Intake Form or attend a Coffee Talk or Living with Lupus Support Group for the first time receive a Welcome Resource Kit. Sadly, our inability to meet in-person prevented us from providing resource kits to nearly all our 2020 contacts.***

## ***AMY'S BLANKETS***

Amy's Blankets, provided by her family and embroidered by LFSA, are given to lupus patients in memory of Amy, a talented young woman from Bisbee, AZ, who was diagnosed with lupus as a young adult. One of the complications she endured was kidney failure, requiring chronic dialysis. She would comment to her family how cold she was during her treatments. In October 2013, after a 19-year battle with lupus, Amy died at the age of 40.

***Outcomes:***

***We distributed 3 blankets to patients who have been experiencing serious complications from their disease.***

## ***BILINGUAL SERVICES***

LFSA assists patients who speak Spanish on an individual basis. This service has provided bilingual program awareness and disease counseling to many patients who have requested the service or during a support group gathering. Information is disseminated to these patients in Spanish from the Lending Library and online. Spanish speaking assistance is available through volunteers whose contact information is located on our website at www.lupus-az.org.

## ***LENDING LIBRARY AND INFORMATION RESOURCES***

The Lending Library is available to all women and men with lupus upon completion of a Patient Intake Form. Staff members continue to research and distribute the most recently published articles on disease treatment, medication, recognizing symptoms and discoveries that bring hope to our patients. Upon request, a staff member will assist patients in researching any specific items of interest.

## ***ASSISTANCE AND REFERRAL***

LFSA Board Members who have lupus are available to provide disease counseling to all new walk-in and phone patients. The Patient Intake Form is sent to these Board Members. Within 24-48 hours, a patient receives a phone contact. If required, patients may be referred to other community assistance sources to address an immediate need. LFSA maintains referral sources to ensure patients receive the best community support possible.

**Lupus.**
**Learn about it.**

# COMMUNITY OUTREACH

LFSA utilized Health Fairs, the Lupus Foundation of Southern Arizona Magazine, the foundation website, Facebook, Instagram, Twitter, print brochures and Lunch & Learns for medical professionals and their staff, to reach a larger audience.

The use of social media such as our LFSA website at www.lupus-az.org and Facebook page at https://www.facebook.com/lupusarizona/ provides opportunities to reach a broad audience of people with lupus, community partners, supporters, the medical community, the Southern Arizona area and beyond. It also provides a platform for interaction between lupus patients on an everyday basis.

## ***HEALTH FAIRS***

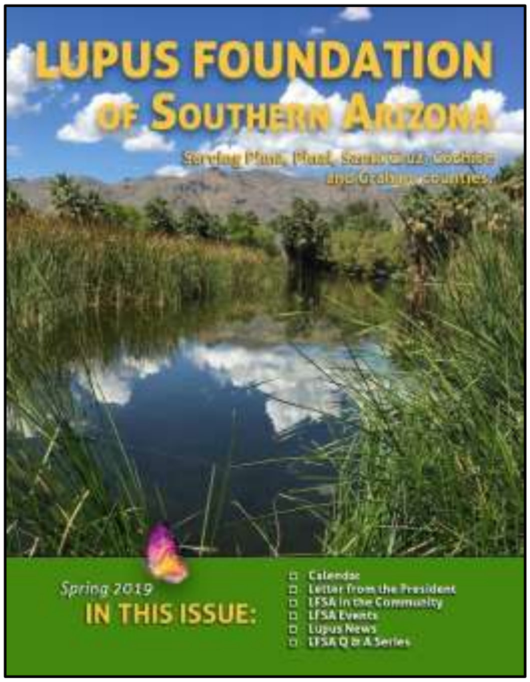
We participated in 4 Health Fairs in 2019 - 2020 at Saddlebrook, Tucson Estates, Sierra Vista and Green Valley and the UA Annual Arthritis Conference at Banner Health.  All other Health Fairs were cancelled due to COVID-19.

***Outcomes:***

***The total number of participants at the Health Fairs, Conference on Aging and the Arthritis Conference was approximately 1000 people.***

## ***LFSA MAGAZINE***

The Lupus Foundation magazine reaches an audience of several hundred lupus patients, families, supporters and physicians by email and direct mail. Each new issue can be found on our website, along with archived past issues.



# LFSA FUNDRAISING AND FINANCIAL REPORTS

The fiscal year began October 1, 2019 and ended September 30, 2020. All financial information is reviewed by a CPA throughout the year. The CPA prepares quarterly tax reports and the end-of-year IRS 990 tax return. Included in this Annual Report are LFSA Balance Sheets and Profit and Loss Statements for the 2020 fiscal year.

The Lupus Foundation of Southern Arizona is constantly growing its revenue stream through increasing public awareness, outreach to new sponsors, grant writing, major fundraising events and small outside fundraising efforts each year.

## ***MAJOR FUNDRAISING EVENTS***

Hit the Links for Lupus Golf - October 25th, 2019
Virtual Walk the Loop for Lupus - July 18th, 2020

## ***GRANTS***

Grant writing is ongoing during the Fiscal Year. The funds received from this endeavor keep our programs afloat and bring awareness to the larger community.

***Outcomes:***

***Grants received through applications and fundraising totaled $3,700.***

## ***OUTSIDE FUNDRAISING AND GENERAL DONATIONS***

Payroll planned giving programs and donations received through Network for Good and Amazon Smile comprised the outside funding sources in 2020, in addition to general donations from individuals, businesses and estates.

***Outcomes:***

***Ten payroll planned giving programs and Network for Good totaled of $9,962.99. Amazon Smile accounted for an additional $162.59. The annual general donations totaled $1,966.60.***

## ***MEMORIAL DONATIONS***

The foundation receives memorial donations from friends and family members of deceased loved ones who suffered from lupus.

# 2019 – 2020 BOARD OF DIRECTORS

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SHAUNNA SCHELIN-KOWALEWSKI – BOARD VICE PRESIDENT

SHERRI FRITZ – BOARD TREASURER

SHAIMA NAMAZIFARD, MBA – BOARD SECRETARY

JACQUELINE SHOPE – BOARD MEMBER

JOSHUA TAYLOR – BOARD MEMBER

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