2021 ANNUAL COMMUNITY REPORT



TABLE OF CONTENTS

LUPUS FACTS	President's Message	2
	Mission Statement	3
Lupus is an autoimmune disease, meaning the immune	Introduction	4
system attacks its own tissues.	Patient Demographics	5
Lupus (SLE) can affect the joints, skin, kidneys, blood cells, brain, heart and lungs.	Scholarships	6
Lupus is NOT contagious.	LFSA Cares	6
While there is no cure for	Retreats	7
lupus, current treatments focus on improving quality of life by	Support Groups	8
controlling symptoms and minimizing flare-ups.	Patient Testimonials	9
Sunlight, infection, injury,	Resource Kits	10
stress or exhaustion can trigger "flares" (a more active state of the disease) in Lupus patients.	Amy's Blankets	10
If you have lupus avoid	Bilingual Services	10
sunlight, sulfa antibiotics (Bactrim and Septra), garlic,	Information and Resources	10
alfalfa sprouts and echinacea. They stimulate the immune	Assistance and Referral	10
system and can cause flares.	Community Outreach	11
Lupus is more prevalent among these populations of women: African Americans, Asians,	Fundraising	12
Hispanics/Latinas, Alaska Natives, Native Hawaiians and	Board Members	13
other Pacific Islanders than in Caucasian women.	Community Partners	14
	Financials	15

LUPUS FACTS





Fiscal Year 2020-2021 was another year of working within the restrictions of the ongoing pandemic. We were able to host the Annual Hit the Links for Lupus Golf Tournament at the Omni on November 13, 2020. We are grateful to the sponsors, golfers and volunteers who helped us make this event a success. On April 17, 2021, we hosted our Second Virtual Walk at Barrio Charro. Thank

you to our faithful sponsors and those who participated in the Virtual Walk, those of you who sent photos of the murals they passed along the way, including participants who stopped by to say hello, purchase raffle tickets and take a walk on the nearby path.

Funds from the Payroll Protection Plan helped us again this year to retain staff during the pandemic. Major fundraisers, grants, donations from payroll programs and other charitable sources enabled us to fulfill applications for the partial scholarship program and request for aid through LFSA Cares and Emergency Medical Funds. We are grateful to these donors, often anonymous, for helping us maintain these programs during another difficult year.

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 hope the coming year will provide an opportunity to resume our public presence at various events and spread the word about the Lupus Foundation of Southern Arizona and the services we offer to people who have this disease.

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 member of the board, 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. Give us a call at 520-622-9006 or visit us on Facebook, Twitter or our website at <u>www.lupus-az.org</u>.

Sharon Joseph L7SA 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 support to those dealing with the disease.



2021 ANNUAL REPORT TO THE COMMUNITY Fiscal Year October 1, 2020 - September 30, 2021

The Lupus Foundation of America, Southern Arizona Chapter, began in 1978. Through the years it evolved in purpose and scope to its current form as the Lupus Foundation of Southern Arizona, Inc. The foundation gives people with lupus in the region 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.

The LFSA is a 501(c)(3) non-profit corporation serving people with lupus in Pima, Pinal, Santa Cruz, Cochise and Graham Counties. A dedicated Board of Directors leads the corporation with laser focus on the LFSA mission. The mission ensures the delivery of programs of support, disease knowledge and treatment options for people with lupus, awareness activities about lupus and the LFSA corporate mission to the public and presentations to raise awareness about lupus and the work of the foundation among physicians, healthcare professionals and various service organizations and communities.

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 by the number of phone calls, walk-ins, caregivers or interested persons making contact on behalf of a family member, significant other or friend with lupus.

INTAKES

Intakes are critical for tracking and encouraging patient participation and serve as an assessment tool for programs and community outreach. Individuals complete intakes online, inperson or by phone. In 2021, we received twenty new intakes. We continue to raise awareness about lupus in the community and to improve our 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 90% of contacts who completed intakes and were informed of the services and programs offered by LFSA were women. Over 50% of the intakes in 2021 <u>earn less than \$30,000 a year</u> and live <u>at or below the poverty level</u>. It is also important to note, that many of these patients <u>reported having lupus less than 3 months</u> and were receiving <u>government funded health insurance</u>.

TOTAL TRAFFIC

LFSA maintains a traffic log of all walk-ins and phone calls during the year. In 2021, we logged more than sixty inquiries from callers and walk-ins and completed twenty intakes and calls with current lupus contacts and newly diagnosed people as part of ongoing outreach efforts.

LFSA MAJOR PROGRAMS

In 2021, LFSA continued the programming begun in 2015-2016, with a focus on support groups, educational attainment, emergency medical and non-medical assistance, and more!

<u>SCHOLARSHIPS</u>

The partial Scholarship Program is an academic study program to underwrite degree/vocational education of people with lupus. LFSA offers two 2-year scholarships per year. Applications are reviewed and voted on by the Board of Directors. Information about applying is on the LFSA website. A survey of the areas of study pursued by recipients over the years, shows their interest in research, medicine, nursing, social work, business management, nutrition and education in various formats. 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. Recipients complete volunteer service hours as part of their requirements, which can include working at LFSA fundraisers.

Outcomes:

We were able to fund two students with partial scholarships in 2021. Since its inception, the LFSA partial scholarship fund has awarded over \$56,000 in partial scholarships.

LFSA CARES FUND

The LFSA Cares Fund supports the medical and non-medical financial challenges of people with lupus by providing one-time monetary assistance. Applicants must complete a qualification form, submit proof of a lupus diagnosis from a physician and provide an invoice for the financial request. Each case is presented to the Board of Directors for approval. Payments are sent directly to the vendor. Applications are on www.lupus-az.org or requested by phone or email.

For people with lupus, the path to diagnosis can be long and arduous. Science has made headway with more accurate testing, but sometimes years go by before a person receives a lupus diagnosis. Insurance does not cover all necessary medical expenses. This can be a financial hardship for an individual or family, especially when the person is too ill to work for significant periods of time, has lost their insurance due to illness, can only manage part time employment or attempting to complete a certificate or degree program and is unable to work and attend classes. Non-medical needs such as a mortgage or rent payment or household emergencies can occur while a person is in a disease state and often become emergencies because of the dilemma of being too sick to work. Once diagnosed with lupus, the journey becomes a life-long financial and personal commitment to medical testing, pharmaceuticals, and medical related equipment (when required) and emergent procedures/surgeries. In addition to lupus, a person may require the services of a rheumatologist, cardiologist, nephrologist, neurologist, pulmonologist, dermatologist, therapist, orthopedic doctor, physical therapist and a primary care physician. Research and clinical trials have produced new medications to help a person live with lupus, but currently there is no cure for this terrible disease.

Outcomes: Four applicants received rent, mortgage and medical bill payments to help them meet their financial obligations.



<u>RETREATS</u>



This program is a "close-in" forum at offsite locations for people with lupus. Participants can get away from their daily responsibilities to rest, relax, have fun and receive input about disease awareness, pain management, coping strategies, stress reduction, relaxation, exercise, diet and nutrition, caregiver/family awareness and other relevant topics. LFSA covers 100% of the cost for each attendee.

Outcomes:

The Lupus Foundation of Southern Arizona has hosted eighty-four participants at 9 retreats since 2015. We hope to resume this valuable support system soon.

SUPPORT GROUPS

Support Groups are for people with lupus, their families, and caregivers who come together for camaraderie, disease awareness, pain management, coping strategies and to discuss potential new treatments, other alternatives or to just know they are not alone. When a person with lupus is having a painful day, is adjusting to new medications or just does not know where to turn, attending a morning or evening group makes a difference.

Coffee Talk



Coffee Talk support groups are on the 1st Wednesday of the month at 6 pm online.

Living with Lupus

Living with Lupus groups are on the 3rd Wednesday and moved to the 2nd Thursday of the month online.

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 transition to in-person meetings once circumstances allow.

Outcomes:

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. The number of attendees in online groups is lower than in-person participation. However, online groups benefit people in remote locations. 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 ~

"The Lupus Foundation of Southern Arizona helped me in my time of need. I was behind on two bills due to being out of work because of my Lupus. The Lupus Foundation of Arizona helped to take the stress out of the situation so I could focus on my health instead of focusing on everything else in my life that was going wrong. This assistance meant the world to me. I'm usually not someone who asks people for help. The Lupus Foundation made me feel like I was important, cared for, and looked after. I am so happy that the Lupus Foundation was there for me, and for so many others in their time of need." -Amanda Walden



"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

The Lupus Foundation of Southern Arizona supplies Resource Kits to newcomers with lupus who participate in support groups. Kits contain information about the foundation's programs, as well as items such as sunscreen, hand sanitizer, ice packs, lip balm, pill containers, and t-shirts when available, all useful tools for people with lupus.

AMY'S BLANKETS

Amy's Blankets, provided by her family and embroidered by LFSA, are given by the foundation to people with lupus in memory of Amy, a talented young woman from Bisbee, AZ, 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 forty.

BILINGUAL SERVICES

LFSA assists Spanish speaking people who have lupus on an individual basis. We are available to answer questions about the disease, direct them to bilingual service providers and offer a support system. Information is available in Spanish from the Lending Library and other online resources. Spanish speaking assistance is available through volunteers whose contact information is located on our website at <u>www.lupus-az.org</u>.

LENDING LIBRARY AND INFORMATION RESOURCES

The Lending Library is available to all people with lupus upon completion of an Intake Form. Staff members continue to research and post links to recently published articles on disease treatment, medication, recognizing symptoms and new discoveries. They also assist people who are searching for books about a specific item of interest.

ASSISTANCE AND REFERRAL

We offer support, provide lupus resources and lists of area providers and other issues to people who have lupus. They receive return calls within 24-48 hours of receiving the completed Intake Form or phone message. If required, referrals are made to other community assistance sources to address an immediate need. LFSA maintains updated referral sources to ensure the best possible community support.

Lupus. Learn about it.

COMMUNITY OUTREACH

The Lupus Foundation of Southern Arizona's focus on community outreach is the way we let people know we are here to be a source of support and provide services to people with lupus. We are available to speak to large or small groups, to physicians and staff, in health care centers, schools, church groups, assistance centers, health fairs and anyone else who wants to know about lupus and how we can be of help. We believe people reach out to those they trust. If someone tells you they have lupus and they could use help, we want them to know we exist. To refer people to us, join a support group, receive emergency assistance or schedule a meeting for your group, call us at 520-622-9006.

1.5 million people in the US have lupus. Yet we meet people who have never heard of it or the Lupus Foundation of Southern Arizona! We distribute brochures, produce an annual magazine for people with lupus and post archived issues on the foundation website.

The use of social media such as our LFSA website at <u>www.lupus-az.org</u> and Facebook page at <u>https://www.facebook.com/lupusarizona</u> provide opportunities to reach a broad audience of people with lupus, community partners, supporters, the medical community in the Southern Arizona area and beyond. It also provides a platform for interaction among people with lupus on an everyday basis. A private Facebook group, Southern Arizona Lupus Warriors, can be found at <u>https://www.facebook.com/groups/221865599545348</u> for people with lupus and family members looking to support each other in a confidential, online environment.

LFSA FUNDRAISING AND FINANCIAL REPORTS

All financial information from the foundation is reviewed by a CPA throughout the year. The CPA prepares State and Federal financial reports, including the Arizona quarterly tax returns, Corporation Commission Annual Business Account Report, Pima County Non-Profit Exemption Status, Federal IRS 990, W9s and all other required federal forms. Included with this Annual Report is the Statement of Financial Position for the fiscal year October 1, 2020 – September 30, 2021.

The Lupus Foundation of Southern Arizona is constantly working to grow 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 – November 13, 2020 2nd Virtual Walk the Loop for Lupus - April 17th, 2021

GRANTS

Grant writing is ongoing throughout the fiscal year. These funds support our programs and help usdevelop relationships with the philanthropic community.

Outcomes:

Grants received through applications and fundraising totaled \$2500.

OUTSIDE FUNDRAISING AND GENERAL DONATIONS

Payroll planned giving programs and donations received through Network for Good, Amazon Smile, Benevity Fund, comprised the outside funding sources in 2021, in addition to general donations from individuals, businesses and estates.

Outcomes:

Ten payroll planned giving programs and Network for Good totaled \$6,201.06. Amazon Smile accounted for an additional \$483.00. The annual general donations totaled \$17,892.70 which included a generous donation of \$14,474.85 from Holualoa Companies. This special donation, along with \$3,996.00 in payroll protection (PPP loans) allowed the Foundation to remain financially stable during the second year of the COVID-19 pandemic.



2020 – 2021 BOARD OF DIRECTORS

SHARON JOSEPH, MCSp – BOARD PRESIDENT

SHAUNNA SCHELIN-KOWALEWSKI – BOARD VICE PRESIDENT

SHERRI FRITZ – BOARD TREASURER

SHAIMA NAMAZIFARD, MBA – BOARD SECRETARY

JACQUELINE SHOPE – BOARD MEMBER

JOSHUA TAYLOR – BOARD MEMBER

PRESIDENT'S COUNCIL

Rebecca Shields, MBA Director Corporate Philanthropy – Finley Distributing LLC

Special Thanks to our Community Partners!



































Statement of Financial Position

As of September 30, 2021

	TOTAL
ASSETS	
Current Assets	
Bank Accounts	
Checking Account	10,214.81
Investment Account	22,721.73
Paypal Account	0.00
Savings Account	2,220.79
Square Inc.	0.00
Total Bank Accounts	\$35,157.33
Accounts Receivable	
Accounts Receivable	0.00
Total Accounts Receivable	\$0.00
Other Current Assets	
Deposits	0.00
Inventory	0.00
Petty Cash	0.00
Prepaid Expenses	0.00
Prepaid Expenses - Gala	0.00
Uncategorized Asset	0.00
Total Other Current Assets	\$0.00
Total Current Assets	\$35,157.33
Fixed Assets	
A/A Website Development	-6,912.00
Accum/Dep Equipment	-3,984.00
Accum/Dep Leasehold Improvemnts	-3,144.95
Equipment (office furn/equip)	3,984.00
Leasehold Improvements	3,144.95
Website Development	6,912.00
Total Fixed Assets	\$0.00
TOTAL ASSETS	\$35,157.33

Statement of Financial Position As of September 30, 2021

	TOTAL
LIABILITIES AND EQUITY	
Liabilities	
Current Liabilities	
Other Current Liabilities	
Accrued Expenses	0.00
Deferred Revenue - Gala	0.00
Payroll Liabilities	0.00
941 Taxes Payable	0.00
AZ Income Tax	35.52
AZ Unemployment Tax	0.00
Federal Taxes (941/944)	704.94
Fica Payable	0.00
FIT Payable	0.00
SIT Payable	0.00
Total Payroll Liabilities	740.46
Unearned or Deferred Revenue	0.00
Total Other Current Liabilities	\$740.46
Total Current Liabilities	\$740.46
Total Liabilities	\$740.46
Equity	
Fund Balance Restricted	0.00
Fund Balance Unrestricted	36,866.79
Unrestricted Net Assets	0.00
Net Revenue	-2,449.92
Total Equity	\$34,416.87
TOTAL LIABILITIES AND EQUITY	\$35,157.33

Statement of Activity

October 2020 - September 2021

	TOTAL
Revenue	
Direct Public Grants	
Corporate and Business Grants	4.94
Total Direct Public Grants	4.94
General Donations	417.85
Apple Annies	1,000.00
Dr. Kwoh	500.00
Holualoa	14,474.85
Laura Bosworth	500.00
TASL	1,000.00
Total General Donations	17,892.70
Golf Tournament Revenue	
Birdease Payments	6,573.24
Individual/Non-sponsor/Foursome	1,740.00
Frank Jones	1,000.00
Total Individual/Non-sponsor/Foursome	2,740.00
Sponsorship (event)	4,942.47
Square Payments	541.38
Total Golf Tournament Revenue	14,797.09
Grant Awards	
PhRMA	2,500.00
Total Grant Awards	2,500.00
Interest Income	850.17
Other Outside Funding	
Amazon Smile	483.00
Arizona Community Foundation	70.00
Arizona Gives	236.23
Blackbaud Giving Fund	13.00
Network For good	3,922.18
Total Other Outside Funding	4,724.41
Paycheck Protection Program	3,996.00
Payroll Plan Donations	186.89
Benevity Community Impact	627.39
City of Tucson (Untd Way)	81.55
Frontstream	355.00
Pima County (Untd Way)	668.17
United Way of Tucson and Southern Arizona	40.65
Total Payroll Plan Donations	1,959.65

Statement of Activity

October 2020 - September 2021

	TOTAL
Walkathon Fundraiser	
Individual	632.00
Sponsorships (event)	8,179.85
Square	187.57
Stripe Transfer Walkathon	4,163.04
Total Walkathon Fundraiser	13,162.46
Total Revenue	\$59,887.42
Cost of Goods Sold	
Golf Tournament Expenses	
Birdease	299.00
Facilities	6,014.00
Giveaways	1,761.82
Golf Awards	497.58
Other	12.98
Printing	174.24
Social Media	65.24
Total Golf Tournament Expenses	8,824.86
Walkathon Expenses	
Facebook/Social Media	166.00
Raffles	345.00
Total Walkathon Expenses	511.00
Total Cost of Goods Sold	\$9,335.86
GROSS PROFIT	\$50,551.56
Expenditures	
Adver/Promo-Community Awareness	
Magazine	830.41
Total Adver/Promo-Community Awareness	830.41
Bank Fees - Svc Chrgs	31.00
Business Expenses	
Taxes - Not UBIT	10.00
Total Business Expenses	10.00
Contract Services	
Accounting Fees	500.00
Sharon Joseph	9,300.00
Total Contract Services	9,800.00
Insurance	
Business Owners Pers Prop/Liab	475.00
Director's Officers Liability	1,069.00
	511.00
Worker's Comp Total Insurance	2,055.00

Statement of Activity

October 2020 - September 2021

	TOTAL
Meals	
Exec Planning Sessions	96.73
Marketing/Promo	42.00
Total Meals	138.73
Office Expenses	9.77
Computers/IT	2,378.34
Offsite Storage	1,375.38
Supplies	119.12
Total Office Expenses	3,882.61
Operations	
Telephone, Telecommunications	2,098.71
Total Operations	2,098.71
Patient Programs	
LFSA Cares - Assistance Program	2,729.50
Scholarships	1,200.00
Support Groups	
Paid Guests	75.00
Total Support Groups	75.00
Total Patient Programs	4,004.50
Payroll Expenses	
Payroll Tax Expense	809.49
Taxes	0.00
Wages	17,460.00
Total Payroll Expenses	18,269.49
Postage-Office	38.80
Bulk Mail	245.00
Total Postage-Office	283.80
Rent	8,614.80
Utilities - water, gas, electri	2,982.43
Total Expenditures	\$53,001.48
NET OPERATING REVENUE	\$ -2,449.92
NET REVENUE	\$ -2,449.92