THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

FACTS

The "Butterfly" is symbolic for the butterfly rash that commonly appears across the bridge of the nose of Lupus patients.

1.5 Million Americans and 5 Million worldwide have Lupus.

Lupus is more prevalent than AIDS, sickle cell anemia, muscular dystrophy, cerebral palsy, multiple sclerosis and cystic fibrosis COMBINED.

Lupus is NOT infectious, rare or cancerous.

Lupus affects 1 out of every 185 people; 90 percent of whom are women.

Lupus is more prevalent in African Americans, Latinos, Native Americans and Asian Americans.

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

Lupus is the least known of all major diseases.

TABLE OF CONTENTS

From Your President

What a successful 2016 for the Lupus Foundation of Southern Arizona!

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

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

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

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

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

Rebecca Shields

Our Mission Statement:

The purpose of the Foundation is to:

- Provide support, education, resources, and encouragement to lupus patients and their families
- Promote and develop programs at the local level to assist lupus patients and families better cope with Lupus
- Promote public education to increase knowledge and understanding of the disease and its ramifications
- Encourage and support pertinent research programs related to the diagnosis, treatment, cure and prevention of lupus
- Promote the exchange of information among health professionals and collaborate with the professional community to improve the standards of diagnosis, care and treatment of those affected by lupus

2016 ANNUAL REPORT TO THE COMMUNITY

Fiscal Year October 1, 2015 - September 30, 2016

INTRODUCTION

The Lupus Foundation of Southern Arizona Inc. (LFSA) was founded in 1978 by five people dedicated to giving Lupus patients an opportunity to come together, learn about the disease and how to live a quality life. Since then LFSA continues to serve Lupus patients in Southern Arizona with new and expanded programming designed with a quality of living focus in mind.

The LFSA is a nonprofit 501 c 3 serving the needs of Lupus patients in Pima, Pinal, Santa Cruz and Cochise Counties. A very active and strong Board of Directors leads the organization with purpose and focus on the LFSA mission. The mission ensures delivery of a program of general education to increase public awareness, disease knowledge and support for our Lupus patients, and fosters the exchange of information among physicians and healthcare professionals.

PATIENT DEMOGRAPHICS

LFSA serves all Lupus patients regardless of race, color, creed, age, gender or economic status. LFSA tracks its level of activity throughout the year whether from a phone call, a walk-in patient, caregiver or interested person on behalf of another Lupus patient.

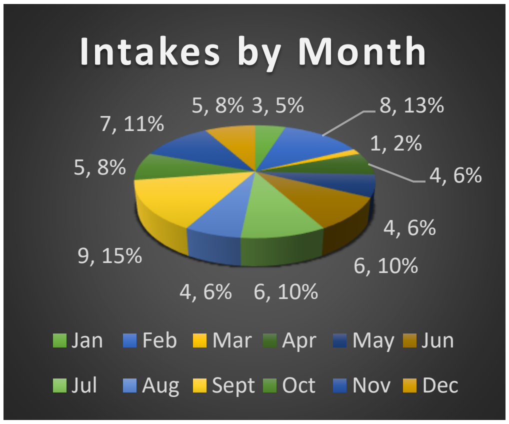
INTAKES

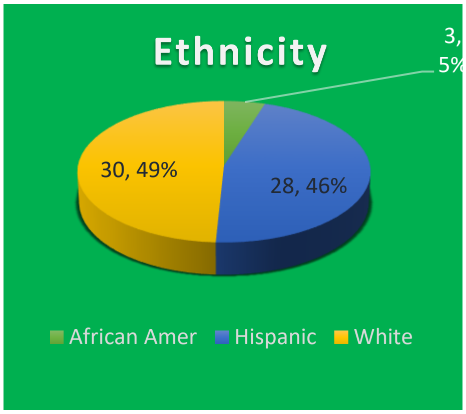
Intakes are designed to collect information about the patients served by the LFSA. Intakes are completed by the patient in person or a staff member completes the intake on the phone when a patient is not available. This information is critical to tracking patient activity.

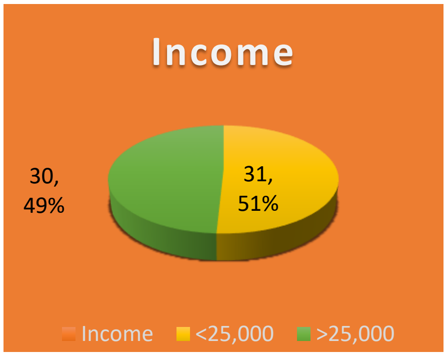
In 2016, a push to have the intakes completed by or on behalf of patients produced a 40% increase in intakes over 2015. This is due to increased community awareness, improved patient information tools, record keeping and procedure.

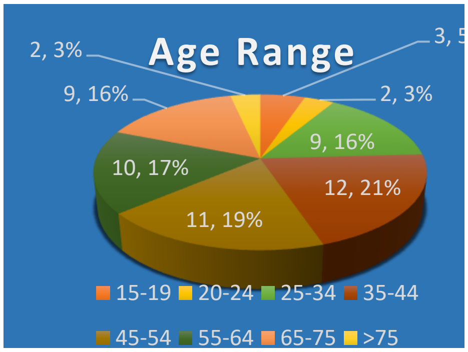
Below is a summary of important information collected from 2016 intakes:

46% Hispanic; 49% Caucasian; 5% African-American, Native-American & Asian-American. Patient gender served: Female 97%; Male 3% Patient Age Served: Ages 15-45-45%; Ages 45+ 54%.









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Data shows that 90% of patients diagnosed with Lupus are women. Intake information collected from the Southern Arizona region reveals that 97% of patients who completed an intake and were informed of the services and programs offered by the LFSA were women. 51.1% of the intakes **earn less than $25,000 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 staff maintains a traffic log of all walk-in and phone traffic in the year. It includes calls for general information, requests for Lupus chapters elsewhere in Arizona (Phoenix) and outside of Arizona; family caregivers seeking assistance for a family member with Lupus; those relocating to the Tucson area who are Lupus patients; Lupus patients seeking assistance with our scholarship program and other available programming and Lupus patients we are currently serving in our system. LFSA estimates a 45% increase in overall traffic over 2015.

LFSA COMMUNITY PROGRAMS

LFSA broadened its scope of work in Fiscal Year 2016 with new and expanded programming. These programs focus on educational attainment, retreats, camps for kids, and more!!

SCHOLARSHIP

The Scholarship Program is an academic study program to underwrite degree/vocational education of Lupus patients. LFSA offers 2-year scholarships up to $3,000 per year. Recipients are voted on by the board officers. Applicants apply via the LFSA website. Our current scholarship recipients are enrolled in programs with a focus on nursing, diet-nutrition and art. 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.

Outcomes:

No. of Students – Eight (8) from Pima County, Cochise County and Santa Cruz County maintaining GPA above the minimum requirement of 3.0.

> *Thank you for granting me financial support as I continue my studies at the University of Arizona. I will use this scholarship towards good use as I pursue my education in one of the medical fields. By awarding me with the (LFSA) scholarship, I will continue to strive and pursue every student's dream, which is a degree. Thank you for your financial generosity.*
>
> Carolina Hoyos 2016 LFSA Scholarship recipient

LFSA CARES EMERGENCY MEDICAL FUND

For many people with Lupus, the path to diagnosis can be long and arduous. It is not uncommon for health insurance plans to put a cap on the total amount of medical services covered annually. However, most plans also cap the amount of medical services covered over a lifetime. In both instances, expenses beyond the coverage caps must be paid out of the insured person's pocket.

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.** Once insurance coverage runs out along with other private funding (if there is any) there is no other option. This fundamental fund supports the health needs of our Lupus patients by providing the monetary wherewithal to get the medical services required directly to, and for the benefit of the patients. Patients must complete qualification form, submit proof of Lupus diagnosis & provide bill information. 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 more community awareness the fund is beginning to attract those in need.

Outcomes:

Two (2) patients were assisted: a wheelchair & health insurance premium. In each case the status of the medical condition of the applicant was serious and employment was not possible or insurance was in jeopardy because of a longer-term absence from work. The LFSA was happy to be a channel of support.

LFSA 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 Lupus diagnosis & provide bill information. Payment is made directly to the vendor.

Outcomes:

Three (3) Lupus patients were assisted.

RETREATS

This new program is a “close-in” forum at offsite locations for Lupus patients, caregivers & families where they can receive counselling and guidance with topics including: disease awareness, pain management, coping strategies, stress reduction, diet and nutrition, caregiver/family awareness, new treatments, etc. Implemented in 2016, retreats have been held for women and couples. LFSA covers 100% of the cost for each attendee.

Couples Retreat

2016 Women’s Retreat

Outcomes:

7 women	***White Stallion Ranch***	***Oct 2015***
9 women	***Omni Tucson***	***May 2016***
6 couples	***Westward Look***	***July 2016***

Retreats are facilitated by Board Members, facilitators and volunteers who have Lupus. In 2016 the LFSA delivered retreats for 6 couples and 16 women.

COFFEE TALK AND LIVING WITH LUPUS SUPPORT GROUPS

Coffee Talk

12 Coffee Talk groups were held at the LFSA office at 4602 E Grant Rd. facilitated by a Board Member on the 1st Wednesday of every month at 6pm. These group meetings are designed to be open forum discussions.

Outcomes:

In 2016 there were 63 attendees recorded for the year.

Living with Lupus AM Support Group

12 *Living with Lupus groups* were held at the LFSA office at 4602 E Grant Rd. facilitated by Rebecca Shields, Board President on the 3rd Wednesday of every month at 10 a.m. and are topic oriented.

Topics covered were:

Advocate for Your Own Medical Care
Interacting with your Pharmacist
Planning for Groups
Yoga & Meditation for Stress Reduction
Sun & Photosensitivity
Dr. Drew Kurtzman – Autoimmune & Connective & Tissue diseases

Managing your Care: Tracking your Labwork
Working with Your Physician
Pros & Cons of Vaccinations
Open Forum Discussion
Diet & Nutrition
Pain Management

Outcomes:

In 2016 there were 107 attendees recorded for the year. Another outcome of this group was to initiate a recipe book for Lupus patients. This idea surfaced at the Diet & Nutrition group that met in July 2016.

Support Groups are for Lupus patients, their families, and caregivers who come together for disease awareness, pain management, coping strategies, new treatments, etc.

Support group participation grew by 30% in 2016 due to increased demand for Lupus disease education, quality of living and coping strategies.

Dr. Drew Kurtzman MD of University of Arizona Cancer Center

<u>CAMPS FOR KIDS</u>

June 2016 was the launch of the “Camps for Kids” program. Applications can be submitted for children who are impacted by Lupus. Recipients receive up to $150 per child. LFSA sent 5 children of mothers with Lupus to summer camp. These children participated in programs in IT programming, Art, and Dance.

Camp Attendees

We wanted to thank the Lupus Foundation again for their generous scholarship so that my girls could attend dance camp. They had a blast!!! They learned new dances and made crafts, it was very special. We truly appreciated it!

RESOURCE KITS

LFSA Resource Kits are available for Lupus patients served by LFSA. Kits are available when you complete a patient intake or by attending a Coffee Talk or Living with Lupus support group.

AMY'S BLANKETS

Amy's Blankets are given to Lupus patients to provide comfort and warmth. Amy and her husband, Derrick, performed as a musical folk duo "Nowhere Man and a Whiskey Girl". Amy and Derrick were married for 13 years and deeply in love. Amy was diagnosed with Lupus as a young adult. One of the complications she endured was kidney failure, requiring chronic dialysis. In October 2013, after a 19-year battle with Lupus, Amy passed away at the age of 40. After her passing, Amy and Derrick's friends, family and fans came together and continue to do so year after year, to bring awareness and raise funds for programs related to Lupus.

During the many years of dialysis, Amy would comment to her family how cold she was during her treatments. LFSA designed a blanket for others who are undergoing Lupus treatments to provide comfort and warmth. This blanket is provided to Lupus patients in honor of Amy's memory and the lasting affect she has had on the Lupus community in Southern Arizona.

PUBLIC AWARENESS

The LFSA utilized Health Fairs, LFSA Lupus Foundation of Southern Arizona Magazine, brochures, radio spots, website, a Symposium and Facebook to reach its audience. There were 4 Health Fairs (City of Tucson Employees, Pima County employees, University of Arizona Arthritis Conference, Sierra Southwest Co-op Services that were attended in 2016. The "Lupus News" newsletter has transitioned to a semi-annual magazine publication reaching an audience of Lupus patients, families, and supporters, and physicians 500 large.

Website

The LFSA website presence at www.lupus-az.org along with the Facebook page at https://www.facebook.com/lupusarizona/ adds to the treasure chest of opportunities to get the LFSA message to its audience…Lupus patients, community partners, supporters, medical community and all of Southern Arizona.

LFSA Magazine & other community opportunities

In FY 2016, two editions of the semi-annual LFSA Lupus magazine with a print and email circulation of 500 were published. Marketing materials reached 5000 attendees through health fair participation and brochure distribution via events. There were two radio broadcasts and two print media interviews conducted.

LUPUS FOUNDATION
OF SOUTHERN ARIZONA

Spring 2016

IN THIS ISSUE

- ☐ Calendar
- ☐ Letter from the President
- ☐ LFSA in the Community
- ☐ LFSA Events
- ☐ Lupus News

SEE INSIDE FOR MORE INFORMATION ABOUT THE APRIL 23RD WALK THE LO FOR LUPUS

Symposium

A symposium for Lupus patients entitled, **“Managing your Lupus”** was held at Tucson Medical Center on October 26th, 2016 and co-sponsored by Glaxo Smith Kline and LFSA. Twenty (20) Lupus patients, caregivers and supporters were in attendance.

<u>BILINGUAL SERVICES</u>

The LFSA provides assistance in Spanish to our Lupus patients. This service has provided bilingual program awareness and disease counselling to many patients that have requested this service. After-hours assistance in Spanish is also available from our supporters by reaching the website at www.lupus-az.org.

OUTCOMES:

Ten Spanish speaking patients were welcomed to the LFSA by Spanish-speaking staff. Information was disseminated to these patients in Spanish from the Lending Library and On-Line.

<u>LUPUS INFORMATION AND RESOURCES</u>

The Lending Library is available to all Lupus patients who register with the LFSA by meeting with staff by phone or in person. In 2016 the library was enhanced with new Lupus publications such as, “The Lupus Encyclopedia,” and “Chronic Resilience”. Staff continues to collect and distribute the most recent published articles on disease treatment, medication, symptoms and discoveries that bring hope to our patients. Upon request, the staff will assist patients researching any specific items of interest.

OUTCOMES:

Staff conducted 30 on-line searches for the latest information on Lupus including published articles in Spanish. 10 books were checked out and returned.

<u>ASSISTANCE AND REFERRAL</u>

Three of LFSA's Board Members have Lupus and are available to provide disease counselling to all new walk-in and phone patients. An intake is completed and 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.

OUTCOMES:

A total of sixty-two (62) phone contacts were made to patients who completed an intake.

2016 Retreat for Couples

LFSA SUMMER CAMP SCHOLARSHIP

SUMMER CAMP FOR KIDS IMPACTED BY LUPUS

The Lupus Foundation of Southern Arizona is offering summer camp scholarships to kids who are impacted by lupus.

You pick the camp, we pay the cost up to $150 per child.

*Funds are limited, please contact us for more information.

THE LUPUS FOUNDATION OF SOUTHERN ARIZONA

Email: info@lupus-az.org
Call: 520.622.9006

FINANCIALS

LFSA financial year begins on October 1 and ends on September 30 2016. 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.

The LFSA is growing its revenue stream by increasing public awareness, grant writing, major fundraising events and small outside fundraising efforts each year.

Major fundraising events

Walk the Loop for Lupus - Annually in April

Hit the Links for Lupus Golf Tournament - Annually in May

Annual Gala - Annually in November

Other Outside Fundraising

In addition to the events above, small outside fundraising efforts are ongoing throughout the year such as the Amy & Derek Ross Concert, Jim Click Raffle, Apple Annie's Apple Bread sales and Eegee's Coin Campaign.

Grants

Four (4) grants were submitted in 2016 which resulted in $4,000 in grant awards. Grants were an important focus of the organization in 2016 and this effort is projected to expand in 2017.

Membership

Annually, the LFSA conducts a membership campaign to recruit and renew members. In FY 2016 there were 37 paid members; 62% are family memberships and 38% are individual members. Membership in the LFSA costs $20 for individual membership and $25 for family membership. The Board of Directors is committed to growing membership in FY 2017.

The members are invited every year to attend the Annual Meeting at which time this report is disseminated and those in attendance are invited to participate.

2016 BOARD MEMBERS

REBECCA SHIELDS, MBA – BOARD PRESIDENT
Director Corporate Philanthropy – Finley Distributing LLC

LANI BAKER, CPA, MBA – BOARD VICE-PRESIDENT
Vice President of Finance, Holualoa Companies

SHAUNNA SCHELIN-KOWALEWSKI – BOARD SECRETARY
Director Marketing Operations – Health South Rehab Hospital of So. Arizona

SHERRI FRITZ – BOARD TREASURER
Sales Representative – Young’s Market

WENDY BLACK
Assistant VP – Bank of America

LINDSEY EZELL

RICARDO HINDS
Sr. Customer Quality Engineer – Honeywell

DONNA MORTON
Director Development, Corporate Giving – TMC Foundation

BILL MURPHY
Health Care Information Tech. Spec.

SHAIMA NAMAZIFARD, MBA
Assistant VP – Wells Fargo Bank

SUE THOMAS
Skin Spectrum

MEDICAL ADVISORY BOARD

Bridget Walsh, DO, Rheumatology – Catalina Pointe
Mark Bradley, MD – Veteran’s Administration Hospital
Ernest Vina, MD, MS – University of Arizona Arthritis Center
Tracy Epstein, MS, NCC, LPC
Dr. Drew Kurtzman, MD, FASD, Asst. Professor Dermatology, Dir. Inflammatory Skin Disease Program – UMC Cancer Center
David Whittman, MD, FASN – Nephrology – Arizona Kidney Disease & Hypertension Centers

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PIMA COUNTY
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CELEBRATING 30 SEASONS
30
Apple Annie's
Taste the Country's Best!

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Cares
Foundation

derrick + amy ross foundation
NMWG.org
nowhere man and a whiskey girl