

The Butterfly Effect

A Publication of the Lupus Society of Illinois

SPRING 2023



VOL. 1, 2023

We're Turning 50!

Celebrate with us!



In 1973 a group of volunteers joined forces to create an organization dedicated to supporting the lupus community and educating the public about lupus.

Over the past 50 years, that organization has grown to what we now know as the Lupus Society of Illinois!

For fifty years we've served the lupus community with financial assistance, educational events, support groups, advocacy efforts, research funding, navigator programs and more.

For fifty years, we've provided access to reliable information about lupus and treatments to anyone who requested it.

For fifty years, we've been the first point of contact for people with lupus and those who care about them.

We're proud of what we've been able to achieve – together.

We'll be celebrating all year and we invite you to celebrate with us!

See page 3 for more details!

Mission Statement

The Lupus Society of Illinois promotes lupus awareness and complements the work of health care professionals by providing personalized resources for the lupus community while supporting research.

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info@lupusil.org
www.lupusil.org

Letter from the Board Chair

Dear Friends,

It's the 50th anniversary of the Lupus Society of Illinois. The Lupus Society has performed an important function in being there to support our lupus patients and their families.

For many years, people did not understand lupus. They still do not, to a large extent, but there is a great deal of information that is available now online and through information such as the Lupus Society of Illinois' website. The Lupus Society stands at the forefront of providing accurate information about the illness.

There has been a great deal of progress so that lupus can often be made to go into remission. Many autoimmune antibodies have been discovered, and their connection with active lupus has been evaluated. Research has allowed the approval of various medications used to treat lupus rashes, joint pain, pleurisy and chest congestion, brain disease, and kidney disease.

Newer medications and solutions are still coming along, though there has been a lot of progress made.

We appreciate your support for the Lupus Society. We will always try to help you.

Sincerely,

Dr. Robert Katz

Chairman of the Board of Directors
Lupus Society of Illinois



Workplace Giving

Matching Gifts Program

Many corporations have matching gift programs.

Contact us to complete the paperwork so your gift can be doubled or tripled! Questions? Contact Kelli at 312-542-0002 or email kelli@lupusil.org.

Payroll Donations

Combined Federal Campaign (LSI code is 21759)

Community Health Charities

We receive donations from payroll deductions designated by Community Health Charities. Please remember to designate Lupus Society of Illinois as your charity.

Disclaimer The LSI Butterfly Effect Newsletter is published three times per year – spring, summer, and fall – by the Lupus Society of Illinois (LSI). A complementary subscription to The LSI Butterfly Effect Newsletter is included with membership or a donation of \$50 to the Lupus Society of Illinois. Call, email or write the LSI for more information. The opinions and statements expressed by the authors or contributors to this publication do not necessarily reflect the opinions or position of the LSI Butterfly Effect Newsletter or the LSI. All rights reserved. No material in this publication may be copied or published without the express written consent of the LSI.

50th Anniversary Special Activities

Share your memories on our website or post to social media with #LSI50 and we'll add them to our celebration page! We are accepting memories, stories, congratulations and photos!

Jayne's Shared Memories

"The LSI has been a big part of my Lupus journey. Through fundraising, education seminars, having family & friends join my team for over 10 years of Lupus walks, being a walk ambassador, going to their award luncheons, speaking downtown for world lupus day and meeting & making friends in the lupus community I have so many memories. I'll share a few of probably hundreds of pics"

-Jayne



Sharonna's Shared Memories



May is Lupus Awareness Month

Lupus Awareness Month is the time of year when the lupus community takes time to educate their families, workplaces, and neighborhoods about lupus. Education can be as modest as sending an email to your friends and family about lupus to organizing a Lupus Awareness Day at your office. We encourage you to get creative as you raise awareness about this often-misunderstood disease.

Please let us know what you're up to – you may inspire others in the lupus community to act!

Email mary@lupusil.org or call Mary at 312-648-6053.

Membership

"Membership is open to everyone and lasts all year"

Living with lupus can be isolating and the best defense against isolation is building community. A community of individuals who share values, experiences and a commitment to supporting others.

We work hard to make the Lupus Society of Illinois a vehicle for building your lupus community. And now we're introducing a membership program to make that sense of community stronger.

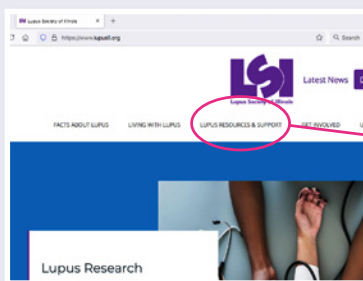
Membership is open to everyone and lasts all year.

Your donation of \$50 will add you to the roster of lupus supporters who come together to build the lupus community. Funds raised will go toward our mission in Illinois – funding educational events, patient navigator assistance, financial assistance, support groups and more.

lupusil.org/membership

Did you know?

Did you know that LSI records our webinars and posts them to our website and YouTube pages?



Use drop down menu to access "Past Educational Events"



Mari Gonzalez is LSI's New Lupus Community Navigator!

Mari is new to her role but not to the LSI. Mari was diagnosed with lupus in 2012 and her life has never been the same. Due to lupus and its side effects, the single mom had to quit a job she loved and fell into a depression. "I didn't have a purpose since I couldn't use my education that I worked so hard to obtain."

Mari's education and experience make her qualified for her new role. Mari has worked as a navigator in the past and her years of living with lupus,

leading lupus support groups and serving the community make her well suited to her role.

Mari's goals are the same as the LSI: to help people live better with lupus. Whether it's finding a rheumatologist, learning about disability or trying to connect with others in the lupus community, Mari is ready to help.

To contact Mari, email her at mari@lupusil.org or call 312-542-0005.

Mark Your Calendars

Illinois Lupus Walks

**Western Suburbs
Naperville Riverwalk, Naperville**
August 12, 2023
Fun Starts: 9am
Walk Starts: 10am
Register at www.lupuswalkil.org
or call 312-542-0002

**Chicago Lupus Walk & Fun Run
Lincoln Park, Chicago**
September 30, 2023
Fun Starts: 8:30am
Run Starts: 9:45am
Walk starts: 10am
Register at www.lupuswalkil.org
or call 312-542-0002

Fundraising Events

**Bank of America Chicago Marathon
Grant Park, Chicago**
October 8, 2023
LSI has guaranteed spots!
Contact us to find out more

Educational Events

**Spanish Language
Educational Event**
July 15, 2023 | 6pm
Casa Michoacán
1638 S. Blue Island Ave.
Chicago, IL 60608
Register at lupusiled.org or
call 312-542-0002

Facebook Live Events

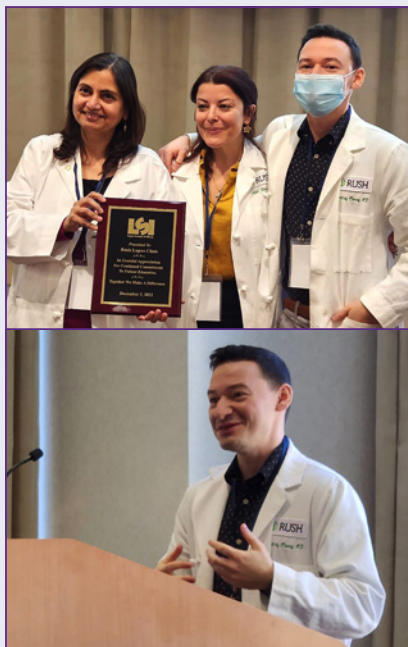
**Building Resilience in the
Lupus Community**
May 9, 2023 | 6pm
Presented by Rev. Shirley Brummell, Ph.D.

**Rush Lupus Clinic
Questions & Answers**
May 23, 2023 | 6pm
Featuring the Rush Lupus Clinic Doctors

**Resources for the
Lupus Community**
May 30, 2023 | 6pm
Presented by Mari Gonzalez,
Lupus Community Navigator for LSI

2022 Educational Events

The Annual Rush Lupus Clinic & LSI Educational Event



The Annual Rush Lupus Clinic & LSI Educational Event was an educational and important occasion.

This year, the Rush Lupus Clinic team received a plaque in recognition of their outstanding contribution to lupus education. LSI is honored to have a close partnership with a leading lupus clinic in metro Chicago.

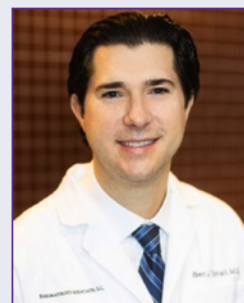
In addition, Stacy Jaimes, MD & LaShon Gurrola, BSN, RN, two health care professionals with lupus, shared their stories – and received recognition for their ongoing commitment to service to the lupus community.

Congratulations to everyone involved in making this a special event! We look forward to seeing you all next year!



Educational Webinars

Some of our web presentations from 2022 that are online



Lupus, Anxiety & Depression

Presented by:

Dr. Ben Small

Date: October 13, 2022

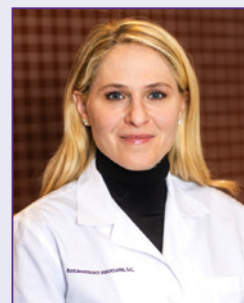
Empowering Lupus Patient Educational Event



On Saturday, April 23, 2022, LSI hosted its first live educational event since COVID-19 began in 2020. Coincidentally, the Empowering Lupus Patient Educational Event was the last live educational event in February 2020, hosted prior to the shut down.

The event included presentation on Lupus & Kidney Health presented by Emily Littlejohn, DO, MPH. Followed by a moving presentation by Tonya Rhodan, a living kidney donor.

The final presentation was a panel discussion featuring lupus warriors who are battling or have battled lupus nephritis or their caregivers. The event was touching and illuminating.



Lupus & Fibromyalgia

Presented by:

Dr. Alexandra Katz Small

Date: November 10, 2022

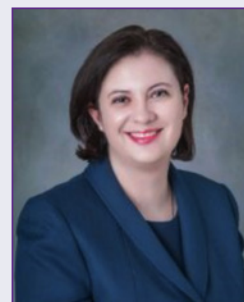
Spanish Language Educational Event



On June 21, 2022 the LSI hosted its annual Spanish Language Educational Event. This year's event was in Pilsen at Casa Michoacán. The event included a presentation by Patricia Canessa, Ph.D.

Dr. Canessa's talk included general lupus information and an extensive question and answer session. The event included time for participants to network and meet one another.

This year's Spanish Language Educational Event will be on June 15, 2023.
For more information contact Mari@lupusil.org or call 312-542-0005.



Lupus & Covid 19 Understanding Vaccines, Boosters & Treatments

Presented by:

Dr. Karen Mancera Cuevas

Date: March 10, 2022

Thank you to all of our wonderful
2022 Illinois Lupus Walk
Supporters!

Top Sponsors!

- Lakeshore Recycling Systems
- GSK Pharmaceuticals
- Horizon Therapeutics
- Pepsi
- Much Shelist
- Huntington Bank
- Cottingham & Butler
- Natalie Navarro
- WHFH 88.5FM
- Delta Life Fitness
- Aurinia Pharmaceuticals

Top Walkers!

Top Teams:

K's Hope for a Cure \$4,582
(Southern Suburbs)

Team Vail \$2,825
(Western Suburbs)

Rush'ing Stars \$6,769
(Chicago)

Top Fundraisers

Regina Casto \$2,552
(Southern Suburbs)

Jackie Kolar \$2,026
(Western Suburbs)

LaShon Gurrola \$5,834
(Chicago)

Largest Team

K's Hope for a Cure
47 members (Southern Suburbs)

Team Vail
20 members (Western Suburbs)

DAZZLING LUPUSLICIOUS DIVA
27 members (Chicago)

Thanks to our Walk Committees
and volunteers who make our
events successful.

2022 Illinois Lupus Walks were a HUGE success!

Thanks to the hundreds of walkers
who helped raise thousands of dollars
for our mission!



Like years past, the LSI has the team
t-shirt contest, DJ Rick, raffle, face
painting and family fun!

A special thank you to our Lupus Walk Ambassadors –
read their stories on our website.



Gloria Veal
Walk Ambassador
Southern Suburbs



Cheryl Vail
Walk Ambassador
Western Suburbs



Mari Gonzales
Walk Ambassador
Chicago Walk



Don't miss the
2023 Illinois Lupus Walk
celebrating our
50th Anniversary!

Western Suburbs

Saturday August 12, 2023
Naperville Riverwalk,
Grand Pavilion

Chicago - Lincoln Park

Saturday, September 30, 2023
Lincoln Park,
Chicago

Register at www.lupuswalkil.org or call 312-542-0002.

Fun Fundraisers 2022

Alan Handley & the Annual Lakeshore Recycling Systems, Inc. Golf Outing

Alan Handley and the team at Lakeshore Recycling Systems, Inc. hosted an amazing and successful Golf Outing benefitting the LSI.

We are honored to be the recipient of their generosity again. The event brought in over \$100,000 for LSI's mission – which means that LSI will continue to provide resources and services to YOU and the entire lupus community.

Below are some photos from the event.



Thank you again to Alan, the Handley Family and the amazing team at Lakeshore Recycling Systems for all they do for the lupus community!

Kendra Scott Jewelry

Thanks to everyone at **Kendra Scott Jewelry** for hosting shopping weekends to raise awareness and funds for the LSI!



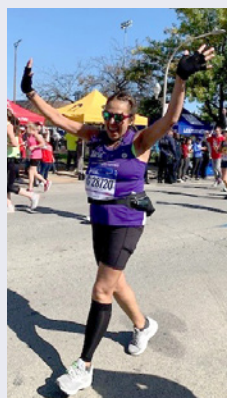
Don't miss Kendra Scott Jewelry's upcoming shopping event this May!

Bank of America Chicago Marathon

Of the 40,000 runners in the 2022 Bank of America Chicago Marathon, 26 participated as Lupus Charity Runners. Participants came from across the US and Mexico and were bound by their dedication to raising awareness and funds for the LSI.

Lupus Charity Runners has had a team in the Chicago Marathon since 2007 and are honored to be an official charity of the event.

If you are interested in learning more about Lupus Charity Runners, please contact mary@lupusil.org or call 312-542-0002.



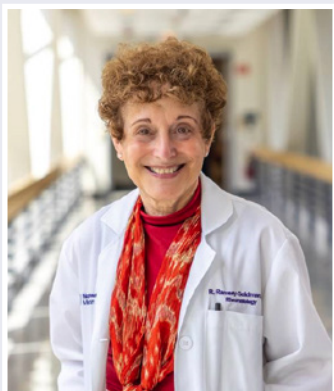
Deadlifts for Lupus

Thanks to the UIC fraternity Theta Lambda Beta for hosting it's annual Deadlifts for Lupus event! This fun, friendly fundraiser raises money and awareness about lupus.

Thank you for all you do!



LUPUS & FATIGUE



Reviewed by Dr. Rosalind Ramsey-Goldman, LSI Medical Advisory Board Member

Chronic fatigue is a common problem and a burden for persons with inflammatory rheumatic diseases. Fatigue can persist even if there are no longer signs of inflammation while taking standard of care medications. A recent study conducted in Europe examined non-medication interventions to lessen fatigue using telephone-based counseling to change physical activity in the setting of

psychosocial support. Most participants had arthritis (not lupus), and the investigators noted a significant improvement in fatigue in the group that received remote counseling. They called their study Lessening the Impact of Fatigue in Inflammatory Rheumatic Disease Trial, LIFT. This important study was one of the first to examine strategies to help lessen fatigue symptoms.

»

Associate Board



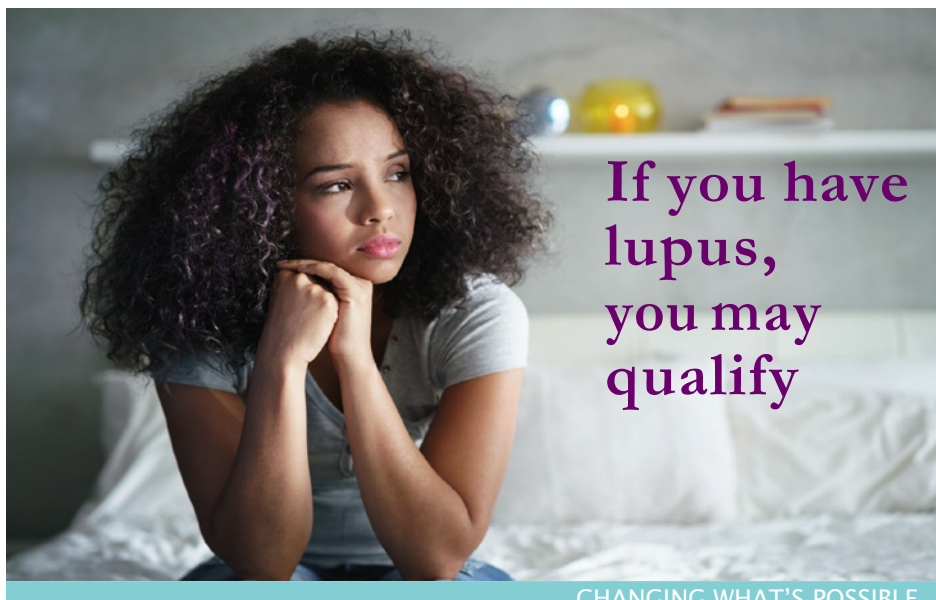
Are you over 21, friendly and looking to get more involved in the lupus community? Then you should know about the LSI's Associate Board!

Associate Board members serve as ambassadors for the younger generation by promoting the Lupus Society of Illinois' programs and services. The Associate Board is made up of individuals aged 21+ who want to have fun while raising awareness of lupus. Their main objective is to promote the mission of LSI by engaging youth through social, volunteer and fundraising activities.

If you would like to know more about LSI's Associate Board please email lisa@lupusil.org or call 312-542-0002.



Research Opportunities



If you have lupus, you may qualify

CHANGING WHAT'S POSSIBLE

Clinical research opportunity

- Do you have **active lupus** that is not responding to your current medications?
- Are you between the ages of 18-65?

If so, you may be eligible to participate in a clinical trial testing if a **new type of cellular therapy** is effective and safe in treating active lupus.

If you qualify, you will receive the study therapy or placebo (inactive product), medical exams, and compensation for your time and effort.

Research Study: Mesenchymal Stem Cells in Systemic Lupus Erythematosus

Principal Investigator: Dr. Rosalind Ramsey-Goldman, Northwestern University

For more information, please contact:

**Holly Milaeger at
312-503-0251**

IRB Number: STU00201326
21 July 2021



« LUPUS & FATIGUE Continued

You can read more about this study at ClinicalTrials.gov, NCT03248518, or *Lancet Rheumatology* 2022, published online June 27, 2022 (1).

These results are very encouraging and support the strategy for the ongoing study at Northwestern University, called the Lupus Intervention Fatigue Trial (LIFT), which is specifically designed to help persons with lupus reduce fatigue using non-medication remote interventions. In addition, the

counseling includes how to improve diet quality which was not included in the study from Europe. If you are interested in participating in LIFT, you can read more about this study at ClinicalTrials.gov, NCT02653287, and our protocol paper published earlier this year (2). This is the link to the Lupus Intervention Fatigue Trial.

Find out about more clinical trials here: clinicaltrials.gov

(1) Remotely delivered cognitive-behavioural and personalized exercise interventions to lessen the impact of fatigue: a qualitative evaluation. Bennett SE, Almeida C, Bachmair EM, Gray SR, Lovell K, Paul L, Wearden A, Macfarlane GJ, Basu N, Dures E; LIFT study team. *Rheumatol Adv Pract.* 2022 Jun 25;6(2):rkac051. eCollection 2022.

(2) Motivational interviewing intervention for increasing physical activity and improving dietary behaviors: The Lupus Intervention Fatigue Trial protocol. Kinnett-Hopkins D, Ehrlich-Jones L, Chmiel JS, Chung A, Erickson D, Semanik P, Spring B, Rothrock NE, Ramsey-Goldman R. *Contemp Clin Trials.* 2022 Mar;114:106690. doi: 10.1016/j.cct.2022.106690.

Research Opportunities



If you have **lupus** and suffer from **low energy** or you **feel tired often**, you may qualify for the Lupus Intervention Fatigue Trial (LIFT) - a study being done to test two treatment programs to help people with lupus better manage their fatigue.

You may qualify if you:

- Are at least **18 years old**
- Have lupus
- Are able to participate in physical activity
- Will be in Chicago area for next 12 months

You will be asked to participate in:

- » A one year program including 4 visits to Northwestern Memorial Hospital in downtown Chicago
- » 4 individual phone calls and/or counseling sessions

INTERESTED OR HAVE QUESTIONS?



Holly Milaeger: holly.milaeger@northwestern.edu | Phone: (312)503-0251

IRB ID#: STU00201960
Department of Medicine, Division of Rheumatology
Principal Investigators: Rosalind Ramsey-Goldman, MD, DrPH
& Linda Ehrlich-Jones, PhD, RN

Northwestern Medicine
Feinberg School of Medicine

Lupus Wednesday Warrior!

The Lupus Wednesday Warrior is a series of articles on lupus fighters and champions in our community. We are always looking to meet warriors and share their stories!

Contact Lisa Klaslo at lisa@lupusil.org for more.

Here's an example of one of our amazing Lupus Wednesday Warriors!

Lupus Society of Illinois LUPUS WARRIOR WEDNESDAY

June 8, 2022

My name is LaShon Gurrola, lupus warrior, Registered Nurse, and an LSI support group leader. I was diagnosed with lupus in 2011. I was introduced to LSI by my colleague and friend, Dr. Jolly.



Shortly after the introduction, I started an LSI support group at Rush University Medical Center, with the support of the Rush Lupus Clinic. With the support of a few dear people, I was able to start a second support group at Elmhurst Edwards Hospital. I keep myself very busy working full time, going to school to become a Family Nurse Practitioner, facilitating the two support groups, and I am also a founding member of Gamma Pi Rho Lupus Sorority Inc. And if that isn't enough to tire you out, I am the mother to 3 beautiful and smart daughters and 2 cutie pie grandbabies.

I am an educator, advocate, and friend to all those living with lupus.

Support Group Meetings

A support group is run by and for people with a common life situation and comprised of people willing to talk freely and to trust openly in the good will of other group members. A support group provides a source of information, a place to be yourself and is open to the public.

A support group is not a professional counseling or therapy session, a 12-step program, a substitute for medical treatment or health counseling, a replacement for family, friends or other close relationships, or a cure.

For more information about this or any support group, please contact Lisa Klaslo at 312-542-0006.

Meeting dates and times are subject to change and notifications will be provided by the volunteer support group leader directly to participants.

CHICAGO

Lupus Awareness Support Group

6320 Dorchester Ave;
Chicago, IL 60637
Generally meets the 1st Saturday of the month
Leader: Nancy

Chicago Trinity United Church of Christ Lupus Support Group

400 W. 95th St. Room 102;
Chicago, IL 60628
Generally meets quarterly the 3rd Saturday of the month
Leader: Robertha

Rush Lupus Support Group

Tower Resource Center,
1650 W. Harrison St., 4th Floor,
Suite 04527, Chicago, IL
Generally meets the 2nd or 3rd Saturday of the month
Leader: LaShon

“Lupus Spoons” – Lupus Support Group

Queen of Angels (Voss Parish Center)
4412 N Western Ave, 2nd floor
Chicago, IL 60625
Typically held the 2nd Saturday of the month
Leader: Mari

Lupus Connection Support Group

Advocate South Suburban Hospital
17800 Kedzie Ave;
Hazel Crest, IL 60429
Generally meets the 3rd Saturday of the month except for July and August
Leader: Gloria

OUTSIDE CHICAGO

Marion Lupus Support Group

Heartland Regional Medical Center,
Conference Room 2;
333 West DeYoung St. (Route 13);
Marion, IL 62959
Generally meets the 3rd Tuesday of the month
Leader: Karen

Glenview Lupus Support Group

Glenview Public Library
1930 Glenview Rd.; Glenview, IL
Generally meets the 3rd Saturday of the month
Leader: Chris

Central Illinois Lupus Support Group

Village of Greenup Municipal Building
in the Board Room
115 W Cumberland St
Generally meets the 2nd Monday of the month from 6-7pm
Leader: Jenny

Edward-Elmhurst Health | Healthy Driven Lupus Support Group

Meetings are typically monthly on Saturday from 11am-12:30pm
Leader: LaShon

VIRTUAL SUPPORT GROUPS

Lupus Spoons 2.0 Support Group

Meets on the 3rd Wednesday of the month from 6pm-7pm
Leader: Mari

Purple Swan Lupus Support Group

Virtual Only Group
Meets on the 3rd or 4th Saturday of the month from 10am-12pm
Leader: Sharonna

SPANISH LANGUAGE SUPPORT GROUPS

Las Cucharas de Lupus/ Lupus Spoons

Solo virtual
Generalmente se reúnen el 4to jueves de cada mes, excepto en noviembre
Hora: 6pm-7pm
Líder del Grupo: Mari

Tributes

We are honored by your donations in honor or memory of those important to you.

Tribute donations are a special way to recognize someone you care about. Donations can be made in celebration of the memory of a loved one or in honor of a person or event.

To find out more or to request donation envelopes contact info@lupusil.org or call us at 312-542-0002.

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Frances Smith-Riney

Anonymous

Karen Steybe

Mr. Gerard P Thomas, Jr.

We apologize for any errors or omissions. Please contact us with any questions at info@lupusil.org or call 312-542-0002.

Volunteers

The Lupus Society of Illinois (LSI) relies on the generosity of our volunteers to achieve our mission! If you have a desire to invest your time and talents in an organization that is having a positive impact on the lupus cause, we have just the place for you!

Contact us at info@lupusil.org or call 312-542-0002.



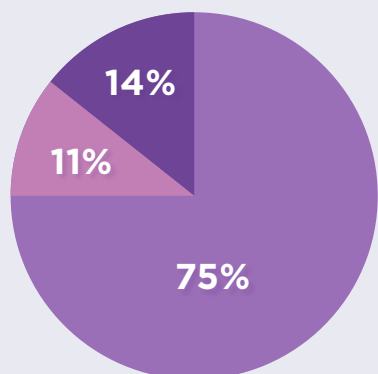
You are at the heart of everything we do.

We understand that lupus can cause confusion and challenges – often unexpectedly. We are here to provide the programs and services you need to live well with this often-devastating disease.

- Patient education programs and materials
- Referrals to physicians, community services, resources, and assistance
- Health educators/navigators available to answer questions and provide medically sound information about lupus
- Newsletters and alerts
- Information and updates from local and international lupus medical experts
- LSI events and support groups
- Living with Lupus grant provides financial assistance for a lupus-related expense to qualifying applicants
- Our programs and services are accessible via phone, online, and in-person

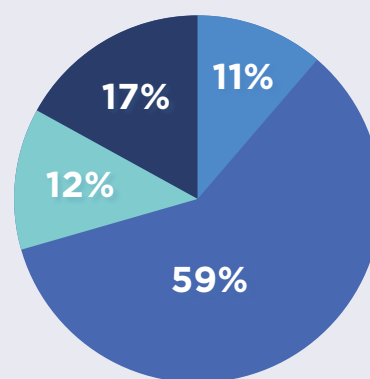
Statement of Financial Position

October 1, 2021 to September 30, 2022



Expenses

Program, Awareness & Research	\$370,386
Management & General	\$53,220
Fundraising	\$69,702
	\$493,308



Revenue

Foundations/Corporations/CFC	\$67,981
Individuals	\$359,913
Grants	\$75,105
Special Event/Other	\$103,674
	\$606,673