

Help Us Solve
The Cruel Mystery

LUPUSTM

FOUNDATION OF AMERICA
HEARTLAND CHAPTER

together
as one
community

2021- 2022 ANNUAL REPORT

Uniting the Patient Voice

- On August 16, 2022 President Joe Biden signed into law the **Inflation Reduction Act which included a \$2,000 out-of-pocket cap and a smoothing mechanism!** For people with lupus on Part D plans, the cap could save them thousands each year. Thanks to all of our advocates who made this victory possible, and the nearly 400 who advocated for these policies with members of Congress.
- Generated nearly **\$20 million in federal funding for lupus research and education programs**, as well as an additional \$45 billion for the National Institutes of Health, the largest public funder of lupus research in the world.
- Local advocates, including **Heartland Chapter Ambassador Michelle Cooper**, participated in the 2022 Digital Lupus Advocacy Summit, where they met with members of Congress asking them to continue their support for lupus research and education programs.



"It's always so energizing to advocate for myself and for everyone with lupus, and to see our voices make a real difference. This year our advocacy efforts, including at the 2022 Summit, helped push provisions that will lower drug costs across the finish line, impacting millions of Americans living with chronic diseases like lupus."

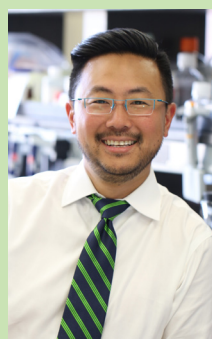
- **Michelle Cooper**, Lupus Advocate

Providing Opportunities to Engage in Research

- RAY: Research Accelerated by You** is our online lupus data platform where people affected by lupus share their experiences to help researchers accelerate the development of new treatments, improve disease outcomes, and inform regulatory decision-making. It's critical that we continue to push for a wider arsenal of lupus treatments because we know that this disease impacts everyone differently and one medication may not work for all.
- Hosted a global drug development forum with more than 20 lupus experts and patients as part of the Foundation's Phase III work on the Addressing Lupus Pillars for Health Advancement (ALPHA) Project. **Together, we worked on identifying new ways to improve clinical trial outcomes that prioritize the patient voice, are applicable in pediatric lupus clinical trials, and better discriminate therapeutic effects.**
- Continued to see promising results from a trailblazing Lupus Foundation of America funded study of mesenchymal stromal cells as a potential new therapy for lupus. Based on positive Phase I results which showed minimal side effects, **the study has now transitioned to a multicohort Phase II trial.**

Helping Patients Feel Empowered

- In January of 2022, we launched **Strategies to Embrace Living with Lupus Fearlessly (SELF)**, an online self-management program designed to help people with lupus build and enhance skills in four pillars of lupus self-management: managing symptoms, managing stress, managing medications, and working with their healthcare team. During the pilot evaluation phase of the program, **57% of users improved one or more self-management skill** to mastery. SELF evaluation participants also reported improvements in fatigue and communication with their health care team.
- Hosted free virtual education events with helpful resources and insights from medical experts through our virtual **Lupus & You and Let's Talk About It programs**. We also record and post our educational programming on our popular YouTube Channel.
- After two long years, we **welcomed girls and young women with lupus back to our Summer Jam Youth Retreat** at Trout Lodge in Potosi, MO for a fun and inspiring weekend.
- Hosted a **Virtual Young Women's Retreat** that included a panel of young lupus warriors in their 30s who shared tips and inspiration for thriving with lupus.
- Partnered with the National Association of Chronic Disease Directors and the National Association of Community Health Workers to develop and host a **training program for Community Health Workers to help them broaden their knowledge about lupus and self management.**
- The Heartland Chapter received a \$50,000 grant to pilot a **Patient Navigator Program in partnership with the Washington University Lupus Clinic**. The program addresses barriers to screening, treatment, and supportive care for individuals living with lupus.



"I cannot understate how critical the Patient Navigator Program will be for our patients here at the Washington University Lupus Clinic. The time constraints placed on our providers have forced us to look externally to provide critical disease information and community resources for our patients. Having the Patient Navigator here in our clinic and **meeting one-on-one with our patients after their visits will improve overall disease management**, which will result in better health outcomes."

- **Alfred Kim, MD, PhD**, Co-Director of the Lupus Clinic at Washington University

Together As One Community





- Each year in May, the lupus community joins as one across the globe to educate the world about lupus during **Lupus Awareness Month**. Whether it's by chatting with a neighbor about the impact of the disease, sharing lupus facts on social media, presenting about the signs and symptoms of lupus to a community group, or participating in media interviews - every opportunity to raise awareness of lupus during May is powerful.
- We launched a new **Lupus Ambassador Program** in 2022 and trained 11 Ambassadors who worked in their communities to raise awareness of lupus through speaking opportunities at community events and sharing information about the disease on social media.
- Our local social media platforms continue to provide a way to **educate people about the signs and symptoms of lupus** and where to go if they suspect a lupus diagnosis. During May Lupus Awareness Month and Put on Purple Day, hundreds of people liked and shared our information and graphics to help raise awareness of lupus.

Ways to Give & Get Involved

We rely on community support to make our programs available to as many people as possible. All gifts are tax-deductible to the extent allowed by law, and are essential to our ability to meet the needs of people living with lupus in our community.

- Donate by mail, phone, or securely online.
- Join our Circle of Heroes with a gift of \$500 or more.
- Donate monthly or quarterly.
- Support us when you shop at AmazonSmile.
- Donate in honor or memory of someone.
- Leave a lasting legacy by including us in your will or living trust.
- Become a corporate sponsor.
- Volunteer your time.
- Walk and fundraise for the Walk to End Lupus Now in St. Louis or Kansas City.

Follow Us Online

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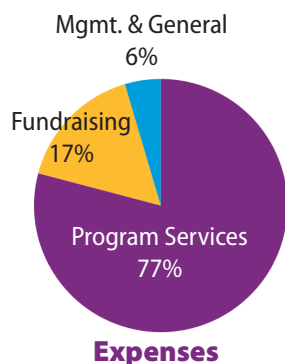
Learn more about more ways to give and get involved at lupus.org/heartland

Uniting To End Lupus

- We were excited to once again unite together as one for the **2022 Walk to End Lupus Now** events in St. Louis at our new location in Creve Coeur Park and in Kansas City at Shawnee Mission Park. Hundreds of walkers attended and raised over \$85,000 to end lupus.
- The Purple Ball was also held in a new location in 2022 - NEO on Locust. We welcomed over 200 guests to the in-person event and hundreds more participated in our online auction. **The Purple Ball was a huge success, raising over \$104,000.**
- We continue to be grateful for the support of our generous event and program sponsors, individual donors, and the United Way of Greater St. Louis.



Financial Highlights



STATEMENT OF ACTIVITIES

September 30, 2022

REVENUE	
Federated Campaigns	\$ 57,972
Fundraising Events	\$162,390
All Other Contributions	\$375,541
Investment Income	\$ 233
Other Revenue	\$ 4,126
Total Revenue	\$600,262
EXPENSES	
Program Services	\$315,098
Management & General	\$ 18,811
Fundraising	\$ 76,843
Total Expenses	\$410,752
REVENUE LESS EXPENSE	\$189,510

STATEMENT OF FINANCIAL POSITION

September 30, 2022

ASSETS	
Cash and Cash Equivalents	\$350,982
Accounts Receivable/Promise to Give	\$ 13,389
Prepaid Expenses	\$ 24,121
Certificates of Deposit	\$147,372
Property and Equipment	\$ 6,855
Other Assets	\$ 1,569
Total Assets	\$544,288
LIABILITIES	
Accounts Payable	\$ 19,262
Accrued Payroll	\$ 10,145
Other Accrued Expenses	\$ 30,800
Total Liabilities	\$ 60,207
NET ASSETS	
Unrestricted	\$406,079
Temporarily Restricted	\$ 78,002
Total Net Assets	\$484,081
TOTAL LIABILITIES & NET ASSETS	\$544,288

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2021-2022

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THANK YOU TO OUR CIRCLE OF HEROES

Major donors from October 2021 - September 2022

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The Heartland Chapter main office is located in St. Louis, Missouri. Our chapter territory includes Missouri, Kansas, and southern and central Illinois.

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