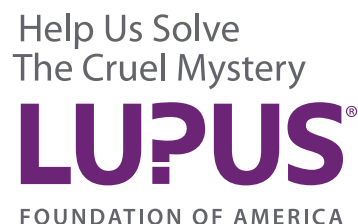


Help Us Solve
The Cruel Mystery
LUPUS[®]
FOUNDATION OF AMERICA

PROGRESS *through* **RESILIENCE**

2022– 2023 **IMPACT REPORT**



The Lupus Foundation of America wouldn't be able to achieve its mission to improve the quality of life for all people affected by lupus without **you**. Without **your support**, we wouldn't be able to fund research that leads to breakthroughs in better managing lupus and new treatment pathways. Without **your input**, we wouldn't be able to create the care and support service programs needed by people with lupus and their loved ones. Without **your voice**, we wouldn't be able to garner the support from Federal agencies and state and local governments to support research funding or policies to improve access to care. **Your resilience has created the incredible progress we continue to see** as we work towards better quality of life, more treatments, improved care, and ultimately a cure.

In this Annual Report we look back on the past year and all that we have been able to accomplish because of **you - the lupus community**, made up of lupus warriors, caregivers, family members, friends, researchers, health care professionals, partners, and so much more. Accomplishments this year because of you include:

- **Funding research that addresses some of the greatest challenges for people living with lupus**, including research focused on lupus nephritis, pregnancy, childhood lupus, new treatment pathways and debilitating symptoms like cognitive impacts.
- Welcoming over 200 lupus advocates to Capitol Hill for the first in-person National Lupus Advocacy Summit since the pandemic, resulting in positive action on policies to improve **access to care for people with lupus**.
- New scientific papers and progress on **improving health disparities** in lupus treatment and care under the LFA's Lupus AIM (Addressing Health Inequities in Minorities) program.
- Adding more voices and experiences to the Research Accelerated by You (RAY) registry to help **accelerate lupus research**.
- Launching SELF - Strategies to Embrace Living with Lupus Fearlessly - the LFA's self-management program as a mobile app, **helping more people improve how they manage their care** at their fingertips.
- **Continued expansion of Spanish language resources to further support Spanish speakers on their lupus journey**, including the launch of Tome Control a new educational email series.
- Relaunching the *Be Fierce. Take Control.*™ awareness program, **helping to reduce time to diagnosis** among Black/African American and Hispanic/Latina individuals

And so much more, detailed within this report – thanks to **you**. We invite you to learn more about what **you helped make possible** this year, and continue to be a part of what is next. Your resilience and strength continues to inspire and motivate us as we push progress forward in lupus support, care and treatment.

Mary T. Crimmings
Interim CEO, Lupus Foundation of America

Joseph Arnold
Chair, National Board of Directors

ADVOCACY



\$22 MILLION

in federal funding approved by Congress for lupus-specific research and education programs, the most ever in a single year.

\$47.5 BILLION

approved by Congress for NIH, **\$143 million** is estimated to be committed to lupus.

NEARLY
200 LUPUS ADVOCATES

attended 179 meetings on Capitol Hill during the LFA National Lupus Advocacy Summit.



THANKS TO ADVOCACY EFFORTS...

- **35 members of Congress** signed as cosponsors on legislation improving access to care that we advocated for during the National Lupus Advocacy Summit.
- **3 states and 1 Federal District** have passed legislation supporting better access to care.
- In the past year, the Foundation welcomed over **4,000 new advocates** across the US.



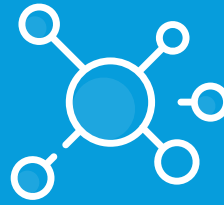
“Being a Lupus Foundation of America advocate is extremely empowering. Instead of feeling defeated by lupus, advocacy gives me a sense of purpose and pride in my resilience. The 2023 National Lupus Advocacy Summit brought me a community of people who understand my challenges, and the incredible opportunity to advocate for policies that will improve the lives for all people with lupus during meetings with members of Congress. The results in increased Federal funding for lupus research and support for policies to improve access to care clearly showed that advocacy works!”

– EMILY SANCHEZ, DIAGNOSED AGE 18



RESEARCH

900 NEW PARTICIPANTS



took action to move lupus research forward by joining Research Accelerated by You (RAY®), LFA's lupus patient registry.

FUNDED
13 RESEARCH GRANTS



supporting studies of potential new treatment pathways, cognitive impairment, lupus and pregnancy, and additional research to address the greatest needs for people with lupus.

27 LUPUS RESEARCH ACTION NETWORK (LRAN) members were trained to improve awareness and knowledge of lupus research and engagement of clinical trials in their communities.



THANKS TO RESEARCH EFFORTS...

- Published a scientific paper from our **Lupus AIM (Addressing Health Inequities in Minorities) program**, on racial health disparities and proposed solutions.
- Launched **four new innovative grants under the Michael Jon Barlin Pediatric Lupus Research Program** addressing the most urgent challenges in childhood lupus.
- LFA Point® issued **5,595 certificates to lupus clinical trialists** on assessment instruments used in clinical trials to accelerate the development of new treatments.



“Early funding and mentorship are critical for researchers in the early stage of their career, and receiving the Gary S. Gilkeson Career Development Award (CDA) from the Lupus Foundation of America was a significant milestone in my research career. It not only provided essential financial support that allowed me to pursue my study on neuropsychiatric manifestations in people with lupus, a devastating symptom for many living with lupus that I’m passionate about helping, but it provided me confidence and mentorship that motivated me to continue my investigations. The award also allowed me to take early steps in my research, enabling me to demonstrate progress and feasibility in my approach that set me up for future funding from the National Institutes of Health (NIH).”

– RUFUI LU, MD, PHD,
2022 LUPUS FOUNDATION OF
AMERICA GARY S. GILKESON CAREER
DEVELOPMENT AWARD GRANTEE



40 LUPUS & YOU EVENTS

were held across the country on topics from mental health to medication management.

2,100 INQUIRIES

from 67 countries answered by Lupus Foundation of America Health Education Specialists, providing non-medical support, resources and guidance.

OVER 9 MILLION VIEWS

of resources and information from the National Resource Center on Lupus, and 56 new resources added.



THANKS TO EDUCATION & SUPPORT SERVICE EFFORTS...

- Over half of respondents to a 2023 survey of participants in LFA's self-care program SELF **improved their medication adherence, doctor-patient communication and experienced less fatigue.**
- **Launched Tome Control**, a new educational email series for Spanish speakers, and **added 35 new Spanish language resources** to the National Resource Center on Lupus, further expanding our culturally and linguistically appropriate health education materials.



“I attended the Lupus Foundation of America’s Lupus & You event to connect with people who understand my daily challenges. It was incredibly empowering to be surrounded by other lupus warriors, and I learned so much from the expert presenters including all the research being done to improve our quality of life!”

— TONYA, DIAGNOSED AGE 44



AWARENESS

OVER

9,000 SHARES

of #WorldLupusDay on May 10.



OVER

170 NATIONAL AMBASSADORS

brought key lupus education and awareness messages to their communities at more than 80 outreach events.

OVER

40,000 VISITORS

to the relaunch of the LFA's *Be Fierce. Take Control™*. awareness campaign's website learned about the signs and symptoms of lupus.



THANKS TO AWARENESS EFFORTS...

- **Thousands united to Make Lupus Visible throughout May for Lupus Awareness Month** by sharing key facts about lupus.
- **Nearly 200 Community Health Workers** were trained on the signs and symptoms of lupus and LFA resources to improve disease education, help reduce time to diagnosis, and connect members of their community with lupus-related resources and support.
- **Raised awareness of lupus to physicians and patients** through education messages in primary care and rheumatologist offices.



“Raising awareness of lupus is so powerful and shows our strength as lupus warriors. Simply sharing facts about signs and symptoms can provide the information someone needs to get diagnosed, or bringing attention to resources and programs can help someone on their lupus journey find the support they need and not feel alone. This year for Lupus Awareness Month it was incredible to see my city of Orlando put lupus awareness up in lights, as landmarks across the city were lit purple and brought attention to our community raising lupus awareness!”

— **TAMISHA, LUPUS FOUNDATION OF AMERICA AMBASSADOR, DIAGNOSED AGE 17**



FUNDRAISING

MORE THAN
**170 ONLINE
STREAMERS**

**raised over \$190,000 during Game On! To End
Lupus**, and marked half a million raised since the
program started in 2020.



OVER
\$3,000,000

**was raised this year by participants in over
40 Walk to End Lupus Now events.**



THANKS TO OUR COMMUNITY...

- **400 Virtual 6 Challengers** logged 6 miles over 6 days to represent the average of 6 years it takes to receive an accurate lupus diagnosis.
- **Over 120 new members** committed to providing reliable sustainable funding year-round by becoming Champions for Hope monthly donors.
- **Received support from the Color Street Foundation**, who raised awareness of lupus during Autoimmune Disease Awareness Month with a limited edition nail strip and \$50,000 donation to the LFA.



“I believe the only way we will find real answers and new treatments is through lupus research, and supporting studies from leading experts in the field through our family foundation with the Lupus Foundation of America (LFA) is such an honor. For me, starting a family was near and dear to my heart, and being diagnosed at 15 meant I had a lot of time to think about how pregnancy and lupus would affect my life. The LFA is a big supporter of many incredible studies, including those focused on lupus and pregnancy. It’s studies like these that the LFA makes sure receive proper funding and give me hope for the next generation of women with lupus who want to start their family. When you donate to the LFA, your donation goes directly to issues that matter to you.”

– COLLEEN FESTA WINFREE,
DIAGNOSED AGE 15



WAYS TO GIVE & GET INVOLVED

MAKE A GIFT

Send your donation payable to the Lupus Foundation of America, 2121 K Street NW, Suite 200, Washington, DC 20037 or make your gift online at Lupus.org/Donate.

BECOME A CHAMPION FOR HOPE

As a Champion for Hope, your monthly gift will provide year-round support for life transforming research, and expert and compassionate support to people living with lupus. Begin your monthly giving at Lupus.org/CFH.

START A WALK TEAM AND REGISTER FOR THE WALK TO END LUPUS NOW®

Walk to End Lupus Now® events provide people affected by lupus and their families with the opportunity to come together for one purpose — ending lupus. Join the world's largest lupus walk at WalktoEndLupusNow.org.

TEAM MAKE YOUR MARK™

Run, walk, bike or swim on your own (or with your favorite group of people) through Team Make Your Mark™ and make your miles matter in the fight to end lupus. Visit Lupus.org/TeamMakeYourMark.

LIVESTREAM FOR LUPUS

Help us raise awareness and funds, and battle lupus with a charity stream. Visit Lupus.org/Livestream.

RAISE YOUR VOICE TO FIGHT LUPUS

We are the leader in stimulating federal support for lupus, generating more than \$684 million for lupus research in the past five years. Become an advocate to raise your voice in support of people with lupus. Visit Lupus.org/Advocacy.

BECOME A CORPORATE PARTNER

Fundraising, matching gifts, direct donation, event sponsorship and in-kind gifts can benefit your organization in more ways than one all while supporting people with lupus and the full mission of the Lupus Foundation of America. To become a partner, contact **Desiree Wienand**, National Director of Corporate Engagement, via email at Wienand@lupus.org.

HONOR A LOVED ONE

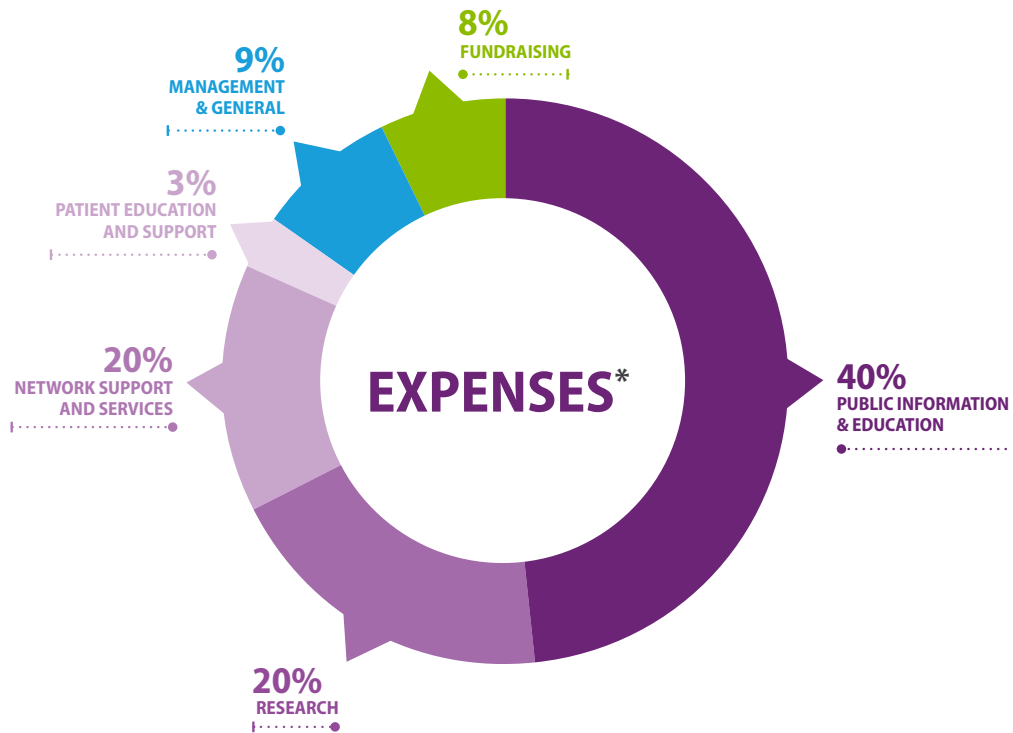
A donation to the Lupus Foundation of America is a thoughtful way to honor someone whose life has been impacted by lupus. Your donation will help to solve the cruel mystery of lupus. Visit Lupus.org/Donate.

PLANNED GIVING

Give now and give later. You can combine your desire to help those touched by lupus through your retirement assets and through your estate planning goals. Visit Lupus.org/PlannedGiving or contact **Teri Yoder**, Vice President of Development and Fundraising, via email at Yoder@lupus.org.

-  [LupusFoundationofAmerica](https://www.facebook.com/LupusFoundationofAmerica)
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FINANCIAL HIGHLIGHTS



LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2022

REVENUE AND SUPPORT	18,190,394
EXPENSES	
Program Services	
Public Information and Education	6,545,776
Professional Relations and Education	18,699
Network Support and Services	3,320,867
Patient Education and Support	471,771
Research	3,292,132
Management and General	1,500,212
Fundraising	1,266,722
TOTAL EXPENSES	16,416,179
CHANGE IN NET ASSETS	1,774,215
NET ASSETS, BEGINNING OF YEAR	3,976,391
NET ASSETS, END OF YEAR	5,750,606

LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2022

REVENUE AND SUPPORT	21,366,484
EXPENSES	
Program Services	
Public Information and Education	7,667,517
Professional Relations and Education	18,699
Network Support and Services	3,288,456
Patient Education and Support	1,593,512
Research	3,292,132
Management and General	1,785,269
Fundraising	1,646,274
TOTAL EXPENSES	19,291,859
CHANGE IN NET ASSETS	2,074,625
NET ASSETS, BEGINNING OF YEAR	6,225,908
NET ASSETS, END OF YEAR	8,300,533

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The Cruel Mystery

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