



2023-2024 **IMPACT REPORT**

CONNECTIONS

Our Path Together to End Lupus

Help Us Solve
The Cruel Mystery

LUPUS[®]

FOUNDATION OF AMERICA

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

Living with lupus is a journey no one should walk alone. At the Lupus Foundation of America, we are dedicated to walking alongside you – providing support, education, and hope as we work tirelessly to **bring an end to this disease**. We are here for you – connected together – to offer you access to lupus education programs, access to a helping hand as a trusted partner, access to make your voice and experiences heard, and access to better care and treatments.

None of this would be possible without you. This Impact Report showcases the tremendous impact you've made – your courage, your presence, your voice, and your power inspire everything we do. Here's a glimpse of what we've accomplished together this year:

- **Funded groundbreaking research poised to change lives**, including studies looking at the impact of the gut on lupus nephritis, improving pregnancy outcomes, and future frontiers of better predicting and ultimately preventing lupus for future generations.
- **Advocated for policy changes on Capitol Hill** securing support from federal, state, and local governments to improve access to care for people living with lupus.
- **Connected people across the country** through in-person Lupus & You Empowerment conferences, and in-person and virtual support groups.
- **Built communities through shared passions**, from hundreds of streamers participating with *Game On! To End Lupus™* to completing six miles together through the *Virtual 6 Challenge* or taking steps at 45 local *Walk to End Lupus Now®* events – the world's largest lupus walk program.
- **Expanded access to critical tools and resources**, from our self-care app SELF, helping people with lupus better manage their symptoms, medications, and more, to one-on-one guidance from our Health Education Specialists.
- **Enhanced and grew access for community health care workers to learn about lupus** with educational resources and courses, helping to reduce the time to diagnosis.

As we reflect on the incredible progress of the last year, we're already hard at work on building the future. We're excited to step into the new year, connected together, alongside you.

You continue to inspire each step forward. You drive our progress today and will lead us to a life free of lupus.



Louise Vetter
President and CEO, Lupus Foundation of America



Joseph Arnold
Chair, National Board of Directors

ADVOCACY



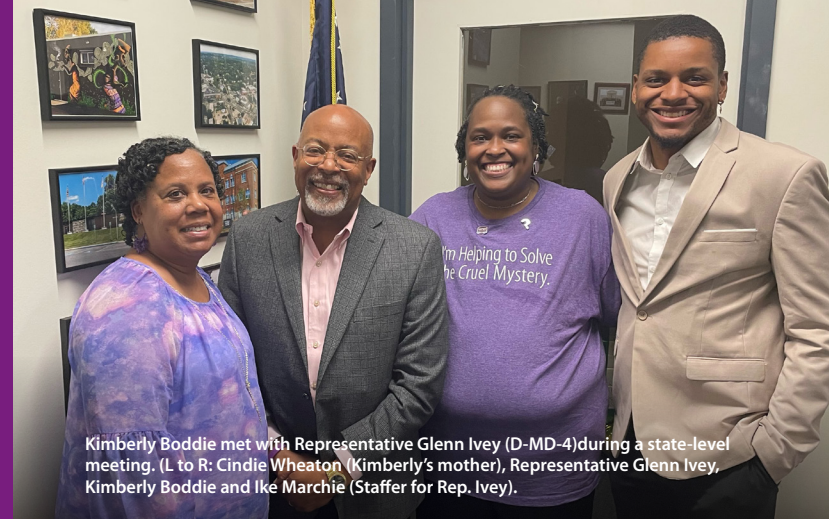
MORE THAN 300 PASSIONATE ADVOCATES

from 30 states came together in Washington, DC for the Lupus Foundation of America's 2024 National Lupus Advocacy Summit. They met with lawmakers in **145 face-to-face meetings on Capitol Hill**, advocating for better access to care and securing vital lupus-related research and education program funding.



\$138 MILLION

in NIH-funded research committed to lupus, which will support research that can lead to new treatments and improved care for people living with lupus.



Kimberly Boddie met with Representative Glenn Ivey (D-MD-4) during a state-level meeting. (L to R: Cindie Wheaton (Kimberly's mother), Representative Glenn Ivey, Kimberly Boddie and Ike Marchie (Staffer for Rep. Ivey).

THANKS TO ADVOCACY EFFORTS...

- **Advocates across the country continued to champion important lupus policies that improve access to lupus medications.** Through state-level meetings with federal elected officials, pushing for national reforms like the Safe Step Act and HELP Copays Act, which **aim to remove delays and financial hurdles, ensuring patients can get the prescriptions they need when they need them.**
- **The Lupus Foundation of America led a coalition of over 60 groups to pass legislation improving patient access through Medicare Part D.** Starting in 2025, people with lupus enrolled in Medicare Part D will have their prescription drug costs capped and can opt into the new Medicare Prescription Payment Plan, allowing them to spread costs over monthly installments.



“So much is out of your control when you live with lupus, but being a lupus advocate empowers me because I know I can make a difference. The Lupus Foundation of America’s National Lupus Advocacy Summit is my favorite event because I feel seen and understood. It’s a vital experience where lupus warriors and caregivers can connect with others affected by lupus, learn about the newest trends in treatments, and advocate for policies to improve our lives. And, the most powerful impact is making my voice heard and educating my representatives about lupus. We get to show them the real-life impact of the policies we advocate for, and put a face and a story to proposed legislation.”



– **OLGA LUCIA TORRES,**
Diagnosed age 26



RESEARCH

LAUNCHED THE **PREDICT AND PREVENT LUPUS RESEARCH GRANT**



providing significant funding for innovative research aimed at identifying people at high risk for lupus and ultimately preventing the onset of serious and life-threatening consequences associated with the disease.

20 MEMBERS



of the Lupus Research Action Network received specialized training to help them confidently engage fellow lupus warriors in conversations about lupus research and engaging in clinical trials. Every participant walked away feeling more empowered to bring these critical conversations to their communities.

OVER **1,200 PEOPLE**

joined our lupus patient and caregiver registry – Research Accelerated by You (RAY®) – now with nearly 4,000 people taking the step to advance research and help bring us closer to better treatments and cures.

Through RAY, we supported the advancement of clinical trials in lupus, lupus nephritis, discoid lupus and cell therapy including protocol development, study education, and survey development and execution.



RESEARCH UPDATE...



2023 Lupus Foundation of America Pediatric Lupus Grant awardee Joyce Chang, MD, MSCE, is studying the brain’s decision-making and cognitive functions in children. Her research found that children with lupus tend to have slower reaction times and more difficulty with certain cognitive tasks compared to healthy children. She also observed greater brain activity in certain areas, suggesting that children with lupus need to work harder to complete tasks - particularly those involving slow processing and impulse control.

This grant provided a pivotal investment in Dr. Chang’s research that is moving our understanding of cognitive function in children with lupus forward. Findings from her study have since been published in two journals and her team was able to go on to receive further funding from the National Institutes of Health. Currently they are recruiting more participants to strengthen their data, including healthy siblings of other patients, and hope to also understand more about how lupus severity and medications impact brain function.



“Receiving the 2024 Gary S. Gilkeson Career Development Award from the Lupus Foundation of America has been a pivotal moment in my career. This support has allowed me to advance our group’s research on lupus nephritis and how gut dysbiosis can influence disease progression - a critical area with potential to reshape treatment strategies. The mentorship provided through this award by Drs. Silverman and Ruggles further reinforced my dedication to advancing the field of autoimmune disease research - there’s no greater reward than helping patients transition from multi-organ involvement to a state where they can maintain disease stability, improving their quality of life. These experiences inspire me as I strive to develop new therapies that can lead to better outcomes for people living with lupus.”

**- ABHIMANYU AMARNANI, MD, PHD,
2024 Gary S. Gilkeson Career
Development Award Grantee**



EDUCATION

LAUNCHED NEW SUPPORT GROUPS

including a Lupus 101 group for those newly diagnosed and the Lupus Warrior Well for spiritual encouragement. These groups, along with 15 new regional support groups, are building stronger connections and providing essential support to people with lupus and their families across the country.

OVER
2,000
INQUIRIES



from 56 countries were answered by our Health Education Specialists, providing non-medical support, resources, and guidance. No matter where in the world lupus warriors are located, they can count on receiving the support they need.

2,619 NEW USERS

joined SELF, LFA's self-care program, since the mobile app launch in September 2023. SELF now supports 5,350 people living with lupus, providing access to valuable tools for managing their symptoms, medication, stress and tips for working with their healthcare team.



Participants asking questions at the Lupus & You Empowerment Conference held in Baltimore, MD.

CONNECTING COMMUNITIES THROUGH LUPUS EDUCATION...

Lupus & You education events reached nearly 10,000 people across the country during in-person and online meetings, delivering the latest lupus information and research from expert speakers at 37 events. In 2024, we introduced in-person Lupus & You Empowerment

Conferences, bringing people together for expert-led sessions to help navigate a life with lupus and make meaningful connections with other attendees that last far beyond the day's event. The events featured topics including the latest advancements in lupus research, treatments and clinical trials, lupus nephritis and medication management, health and wellness, and patient and physician panels. These events do more than educate - they build community and empower attendees.



“Lupus & You Empowerment Conferences do just what the name says – they empower you. When you are given a diagnosis of lupus, you can feel alone, confused, and misunderstood – but these events provide a safe space to come together, engage with one another, learn and find connection. They make sure that whether you are new to this journey or have been on this road quite a while, there’s a place for you to find support, and learn about that latest on lupus research, medical advancements and topics you can relate to. The Lupus Foundation of America and the Lupus & You Empowerment Conference allowed me to find community in lupus.”

– **MANDY REMMELL, LUPUS FOUNDATION OF AMERICA AMBASSADOR,**
Diagnosed age 33



Help Us Solve The Cruel Mystery

LUPUS[®]

FOUNDATION OF AMERICA

Our mission is to improve the quality of life for all people affected by lupus through programs of research, education, support and advocacy.

In order to achieve our vision, we have set these critical strategic outcomes:



Reduce the time to disease diagnosis



Ensure people with lupus have an arsenal of safe and effective treatments



Expand direct services and increase access to treatments and care

AWARENESS

OVER 170 AMBASSADORS

engaged in 100+ outreach efforts bringing vital lupus education and awareness directly to their communities.

IN MAY, THOUSANDS UNITED

to Make Lupus Visible during Lupus Awareness Month, highlighting the physical, emotional and economic impact of lupus.

As part of our role leading the **World Lupus Federation**, we conducted a survey revealing **91% of respondents were taking or have taken oral steroids to treat their lupus**. This finding shed light on the long-term effects of steroids and the need for more lupus-specific treatments.

OVER 41,000 ACCESSED EDUCATIONAL RESOURCES

on what lupus is, symptoms and diagnosis through the **Be Fierce. Take Control.**® awareness campaign. The campaign aims to raise awareness of lupus and reduce time to diagnosis for young Black/ African American and Latina/Hispanic American women, who have a higher chance of developing lupus in their lifetime.

OVER 70 LUPUS WARRIORS

and family members shared their story through the “Voices of Lupus” platform on our website, raising awareness of the unique journey each person with lupus experiences.



Kadra Ali, PULSE Project Manager, sharing information and answering questions at the Virginia Community Healthcare Association (VCHA) Conference.

RAISING AWARENESS IN THE HEALTHCARE COMMUNITY...

We launched the Community Health Worker (CHW) Resource Hub, offering on-demand learning modules that increase CHW's knowledge about lupus, including signs and symptoms, diagnosis, treatments, management, resources and support available to those living with lupus. The education and awareness driven by the hub for frontline healthcare workers will help to reduce the time to diagnosis and help improve the quality of life of those living with lupus. To date, more than 3,000 CHWs have been trained through both the hub and in-person efforts by local chapters and regional offices.





“I became a Lupus Foundation of America Ambassador to be part of the bigger picture – raising awareness about lupus so more people understand this disease. Education and awareness can lead to early diagnosis and treatment. I want to help others understand this largely invisible disease and bring education, resources and hope directly to people living with lupus. As a lupus warrior myself, being a Lupus Foundation of America Ambassador is very empowering, and I know I’m making a difference - for myself and others that have lupus.”

– **PAMELA KLINGER-MILAZZO,**
*Lupus Foundation of America
 Ambassador, Diagnosed Age 32*



FUNDRAISING

MORE THAN 400,000 MILES WALKED



and \$3,000,000 raised at 45 *Walk to End Lupus Now*® events across the country that brought over 10,000 walkers together to unite for a shared cause, taking each step toward a future without lupus.

447 LUPUS WARRIORS,

family members, friends and partners participated in the Virtual 6 Challenge and logged 6 miles over 6 days through activities like walking, running, biking, hiking, rowing and swimming. Their efforts raised over \$64,000 and symbolize the average of 6 years it takes to receive a lupus diagnosis.

OVER 170 NEW CHAMPIONS FOR HOPE,



committed to supporting our mission by providing steady and sustainable funding year-round by becoming monthly donors.



Connie's Crew at the New York City Walk to End Lupus Now at Seaport District NYC Pier 17

TAKING STEPS TOGETHER

Connie's Crew raised \$36,879 for the Walk to End Lupus Now in New York City. The team walked in memory of their friend/coworker who passed away this year, with team members flying in from across the country to walk for Connie and an end to lupus.



Game On! To End Lupus participants and fans at 2024 TwitchCon in San Diego, CA

STREAMING TO END LUPUS...

In 2020 the Lupus Foundation of America, in partnership with a dedicated group of streamers, launched Game On! To End Lupus – a livestreaming campaign held each May. This year marked 5 years of livestreaming on Twitch and YouTube with 188 streamers. Thanks to their dedication, more than \$195,000 was raised in May 2024, bringing our lifetime charity stream fundraising to over \$850,000!



“I organized a fundraiser at a local restaurant in honor of my mother who we lost to lupus in 1998. While I’ve since been diagnosed with lupus myself, it was important to me to honor her and her fight, especially the hurdles she faced around misdiagnosis. I wanted to raise awareness of lupus, particularly among the African American community where I grew up, and make a difference by raising funds to help bring an end to this disease. I know I have the ability to make an impact, something I take very seriously, and my fundraiser was an important part of that.”

**- TAMARA MARSICO,
DIAGNOSED AGE 23**



WAYS TO GIVE & GET INVOLVED

MAKE A GIFT

Make a difference by sending 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

Become a Champion for Hope and your monthly gift will provide year-round support for life-changing research 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®

Bring your family, friends, and community together by starting a team for *Walk to End Lupus Now*®. Join the world's largest lupus walk and take meaningful steps toward ending lupus. Register 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*™. Every mile brings us closer to ending lupus. Get started at Lupus.org/TeamMakeYourMark.

LIVESTREAM FOR LUPUS

Use your platform to raise awareness and funds with a charity stream. Visit Lupus.org/livestream to get started and stream for a cause.

RAISE YOUR VOICE TO FIGHT LUPUS

Join the fight by raising your voice for lupus advocacy. Over the past five years, we've helped secure more than \$768 million for lupus research. Become an advocate today at Lupus.org/Advocacy.

BECOME A CORPORATE PARTNER







Support the fight against lupus while benefiting your organization through fundraising, matching gifts, direct donation, event sponsorship and in-kind gifts. To explore corporate partnership opportunities, contact **Desiree Wienand, National Director of Corporate Engagement**, at 202.349.1173 or via email at Wienand@lupus.org.

HONOR A LOVED ONE

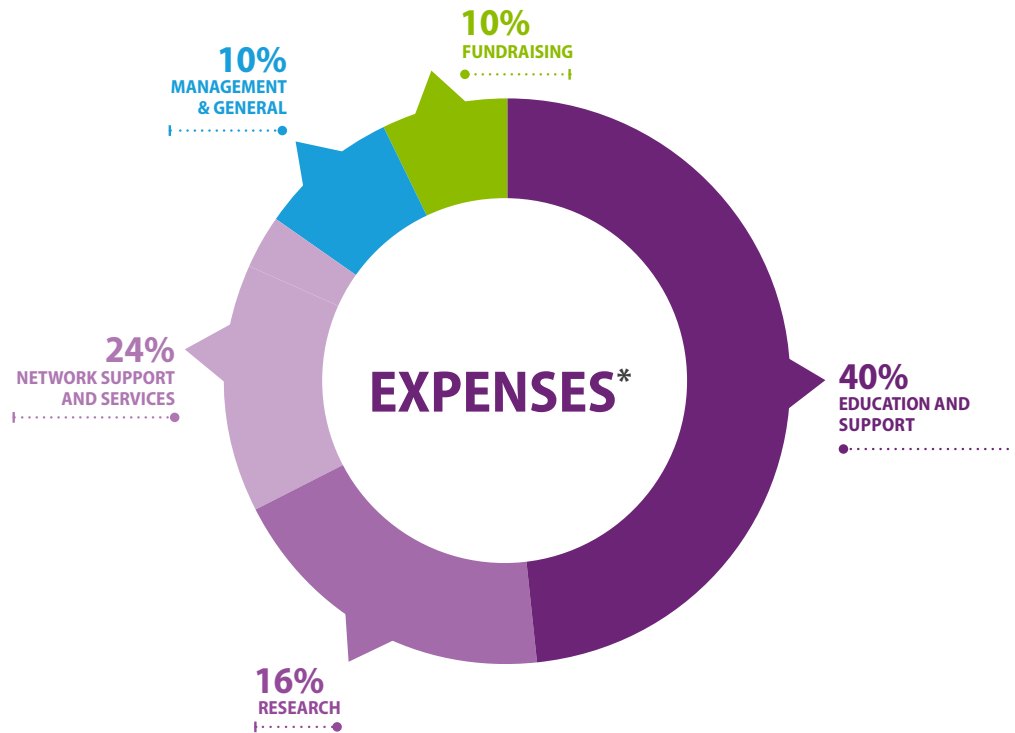
Honor a loved one affected by lupus with a meaningful donation. Your donation will help to solve the cruel mystery of lupus. Visit Lupus.org/Donate.

PLANNED GIVING

Create a lasting legacy by helping those affected by lupus through planned giving. You can support lupus research and care with your estate planning goals. Visit Lupus.org/PlannedGiving or contact Teri Yoder, Vice President of Development and Fundraising, via email at Yoder@lupus.org.

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-  [Lupus Foundation of America, Inc.](https://www.linkedin.com/company/Lupus-Foundation-of-America-Inc)

FINANCIAL HIGHLIGHTS



LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2023

REVENUE AND SUPPORT	17,973,121
EXPENSES	
Program Services	
Education and Support	6,345,185
Network Support and Services	3,740,847
Research	2,540,043
Management and General	1,491,110
Fundraising	1,615,554
TOTAL EXPENSES	15,732,739
CHANGE IN NET ASSETS	2,240,382
NET ASSETS, BEGINNING OF YEAR	5,750,606
NET ASSETS, END OF YEAR	7,990,988

LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2023

REVENUE AND SUPPORT	20,800,946
EXPENSES	
Program Services	
Education and Support	10,609,612
Network Support and Services	1,262,952
Research	2,540,043
Management and General	1,827,749
Fundraising	2,075,398
TOTAL EXPENSES	18,315,754
CHANGE IN NET ASSETS	2,485,192
NET ASSETS, BEGINNING OF YEAR	7,729,751
NET ASSETS, END OF YEAR	10,214,943

*A complete copy of the audited financial statements is available online or upon request from the Lupus Foundation of America National Office by calling 202-349-1155, or writing to Lupus Foundation of America, 2121 K Street NW, Suite 200, Washington, DC 20037

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Visit [Lupus.org/Chapters](https://www.lupus.org/chapters) for more information.

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\$100,000+

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Help Us Solve
The Cruel Mystery

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