





#### Letter from the Board Chair and President & CEO

At the heart of the Lupus Foundation of America's mission is one constant: *you*. Your voice, experiences, and strength shape every step we take. This report reflects the progress we're making together — and the lives being changed because of it.

The stories and outcomes shared here show how we're advancing our core strategic priorities: reducing time to diagnosis, ensuring access to safe and effective treatments, expanding support and care, and securing the funding needed to move our mission forward. Importantly, these stories reflect the community strength of the Lupus Foundation of America (LFA).

We're here for people with lupus at every stage of their journey. From answering thousands of individual questions and offering support groups nationwide, to providing tools and education programs to explore online, and we continue to expand access to reliable, accurate, and personalized support.

Our research investments are changing the standard of care in lupus. This year, we funded 12 new studies focused on (1) better understanding lupus symptoms such as fatigue and memory issues, (2) advancing treatment options for immune system and kidney complications, and (3) improving self-management, including medication adherence. We proudly continue our pioneering investment in pediatric lupus research and predicting and preventing lupus, while investing in the future of lupus research by supporting scientists at every career stage.

Lupus awareness is also improving. Since 2019, national awareness has increased significantly — a vital step in building broader understanding of the disease and its impact. The Lupus Foundation of America is driving global awareness of the disease because we know that when more people understand lupus, access to compassionate and timely diagnosis and care becomes easier - and people with lupus can feel more understood.

Our advocacy efforts have never been more urgent — or more effective. Together, we helped secure \$153 million in Fiscal Year 2025 federal funding for lupus research and education, and advanced policies that expand access to care and reduction of treatment costs. We continue to lead national coalitions and global partnerships to elevate the needs of people with lupus.

Our work is powered by a passionate community. At Walk to End Lupus Now® events across the country, thousands came together to raise awareness and critical funds while supporting lupus warriors. Whether walking, advocating, volunteering, sharing your story, or providing financial support — your actions with the Lupus Foundation of America are creating real change.

Thanks to you, this past year has been one of innovation, momentum, and meaningful impact. Together, we're getting closer to a life without lupus.

Joseph Arnold

Chair, National Board of Directors

Louise Vetter

President & CEO, Lupus Foundation of America

3

### REDUCING THE TIME TO

# **Diagnosis**



hen Selena first noticed a butterfly-shaped rash across her face, intense swelling and hair loss, she had no idea these were symptoms of lupus. At just 24 years old, lupus wasn't even on her radar. It took multiple doctor visits, a trip to the ER and finally a kidney biopsy before she received a diagnosis of lupus nephritis.

Like many young women her journey to diagnosis was long, frustrating and filled with uncertainty. Today, she's transforming that experience into purpose. As part of the Lupus Foundation of America's "Be Fierce. Take Control." lupus awareness campaign, Selena uses her voice to raise awareness, encourage self-advocacy and empower others to seek answers sooner.

This is the heart of the campaign: real stories, real women and a clear message —listen to your body, speak up, and take control.

And this multi-year campaign is working.

- With nearly 18 million digital impressions, the campaign is reaching women with life-saving information about early lupus symptoms.
- More than 72,000 visits to the Be Fierce. Take Control. website —including more than 17,000 visits to symptom and diagnosis tools —are helping individuals take the first step toward getting care.
- Outreach through Historically Black Colleges and Universities, the Essence Festival of Culture, and **local community events** ensures that awareness reaches those at greatest risk.
- Influencer partnerships and targeted digital content are amplifying stories that resonate, especially among young women who often feel overlooked in the healthcare system.

By combining culturally relevant outreach, personal storytelling and digital strategies, the Be Fierce. Take Control. campaign is making a measurable impact in the fight for earlier lupus diagnosis.

## Awareness. Education. Access. – The Key to Lupus Diagnosis

The journey to a lupus diagnosis is often long and uncertain. At the Lupus Foundation of America (LFA), we believe that reducing the time to diagnosis begins with awareness, education, and access to trusted individuals, resources and information.

To equip frontline health professionals with accessible information on lupus, we created a Community Health Worker (CHW) Resource Hub. This online hub built in collaboration with CHWs across the country features ondemand learning modules covering lupus signs and symptoms, treatment options, and resources available to support people with lupus.

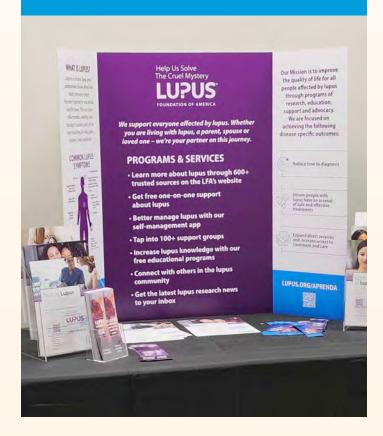
As the national convener of Lupus Awareness Month, the Lupus Foundation of America brings communities together each May to raise public understanding of lupus. This year's Make Lupus Visible campaign reached tens of thousands of people, and also featured the relaunch of the KNOW Lupus Quiz. This interactive tool to educate the public about lupus in a fun and memorable way engaged more than 13,000 people in less than a month, helping them learn more about lupus in a fun and memorable way.

Local events and lupus storytelling efforts further amplified the voices of people living with lupus across the country. Volunteer Lupus Ambassadors participated in more than 110 outreach efforts to bring vital lupus education and awareness to their communities.

And these efforts are making a measurable difference: results from our new national survey that we released in May revealed a 10% increase in lupus awareness compared to a 2019 benchmark.

## In the Community: Expanding Access Through Library Outreach

"Knowledge is power—and it should be available to everyone." To ensure reliable lupus education reaches the public where they live and learn, the Lupus Foundation of America launched library-based awareness displays called Lupus Health Corners in 20 public libraries across five states. These displays offer yearround, walk-up access to lupus information, symptom guides, and local resources. A second phase of libraries will be added in late 2025, expanding this grassroots initiative to new communities and further supporting early awareness at the local level.



STRATEGIC GOALS

# **Arsenal of Safe** and Effective **Treatments**



inety percent of people with lupus are women, often diagnosed during their childbearing years. Latasha, like many women with lupus, faced physical, emotional, and financial challenges trying to conceive. Women with lupus face significantly higher risks of pregnancy complications, including preeclampsia, fetal growth restriction, and preterm birth. During her pregnancy journey, Latasha participated in lupus research, which gave her strength and sense of hope.

Supporting research to improve pregnancy outcomes has been a priority for the Lupus Foundation of America (LFA). Thanks to the support of generous donors, the LFA has funded the IMPACT Study (IMprove Pregnancy in APS with Certolizumab Therapy), evaluating whether adding certolizumab to standard care reduces pregnancy risks for women with or without lupus and antiphospholipid syndrome (APS, a condition involving abnormal blood clotting). This past year, the study wrapped up Phase II research and showed 93% of study participants with healthy pregnancies brought home healthy babies—a marked improvement over the 38% survival rate for previous pregnancies among study participants. These findings offer renewed hope for women with lupus, showing a promising pathway to healthier pregnancies and brighter futures for families.

The LFA also supported other promising research. In February 2025, the MiSLE Phase II study—exploring mesenchymal stromal cells as a potential new lupus therapy — reached a major milestone with completing study enrollment. In addition to providing funding for the study, our efforts helped drive awareness and recruitment efforts.

Investing research dollars in early-career investigators is essential to expanding and sustaining a skilled rheumatology and lupus research workforce. This year, the Lupus Foundation of America awarded funding to seven students pursuing careers in lupus research through the Gina M. Finzi Memorial Student Summer Fellowship and two early-career investigators through the Gary S. Gilkeson **Career Development Award.** 

**STRATEGIC GOALS** 

The Lupus Foundation of America strategically invests in research that focuses on discovering the breakthroughs that can lead to early intervention, better therapies, and even disease prevention. Here is a list of 12 research grantees we awarded funding to this year:

#### Gina M. Finzi Student **Summer Fellowship Program**

GRACE CROSSLAND (Mentor: Sladjana Skopelja-Gardner, PhD)

Dartmouth College, Geisel School of Medicine

Project Title: Defining the role of mucosal-associated invariant T (MAIT) cells in cutaneous lupus erythematosus

VANESSA ESTRADA (Mentor: James J. Pestka, PhD)

Department of Microbiology, Genetics, & Immunology, Michigan State University

Project Title: Omega-3 Fatty Acids: Omega-3 Effects on Interferon Gene Methylation in Lupus Macrophages

**ROHAN GUPTA** (Mentor: Betty Diamond, MD)

The Feinstein Institutes for Medical Research

Project Title: Determining the Role of the Aryl Hydrocarbon Receptor (AHR) in NPSLE

JERIK LEUNG (Mentors: S. Sam Lim, MD, MPH;

Cam Escoffery, PhD, MPH, CHES)

**Emory University** 

Project Title: Using Photovoice to Understand Self-Management Behaviors in Lupus

SARA SMITH (Mentor: Gabriela K. Fragiadakis, PhD)

The Regents of University of California, San Francisco Project Title: Uncovering the Molecular Underpinnings of Lupus Nephritis with Multi-Omic Analysis

**EMMA WELTER** (Mentor: Montserrat Anguera, PhD)

The Trustees of the University of Pennsylvania

Project Title: Investigating the Impact of Lupus-Like Disease on the Inactive X Chromosome in Age-Associated B Cells

JIN XUAN ZHOU (Mentor: Andrea Knight, MD, MSCE)

Hospital for Sick Children, Toronto

Project Title: Diffusion Tensor Imaging Metrics and Neurocognitive Function in cSLE

#### Gary S. Gilkeson Career **Development Award**

JARED GRAHAM, PHD, (Mentor: Karen Gould, PhD, MEd),

**University of Nebraska Medical Center** 

Project Title: Assessing the Role of SHP2 on B Cell Prolifera

JACQUELYN NESTOR, MD, PHD (Mentors: Andrew Luster, M.D.,

Ph.D.; Alexandra-Chloé Villani, PhD; April Jorge, MD)

**Massachusetts General Hospital** 

Project Title: Unraveling CD4+ T cell imbalance in SLE

#### **Pediatric Lupus Research Grant**

NAYIMISHA BALMURI, MD, Assistant Professor of Pediatrics,

Johns Hopkins University School of Medicine Project Title: Does Air Pollution Influence the Baseline Characteristics of Pediatric SLE?

**REBECCA SADUN, MD, PHD,** Associate Professor of Medicine and Pediatrics,

**Duke University School of Medicine** 

Project Title: Validation of a Survey to Assess Barriers to Medication Adherence in cSLE

#### **Lupus Canada Catalyst Award**

MOHAMED OSMAN, MD, PHD, Associate Professor of Rheumatology,

**University of Alberta** 

Project Title: Defining the molecular drivers of fatigue in lupus: a pilot study

#### **Honoring the Pioneers Driving Scientific Progress**

In 2024, we hosted the Evelyn V. Hess Reception and proudly celebrated three distinguished research leaders whose significant contributions continue to shape the future of lupus science and inspire the next generation of innovators. The honorees were Dr. Brad H. Rovin of Ohio State University, recipient of the Evelyn V. Hess Award; Dr. Alí Duarte-García of the Mayo Clinic, recipient of the Mary Betty Stevens Young Investigator Prize; and Dr. Anca Askanase of Columbia University, our Medical-Scientific Advisory Council (MSAC) honoree.









Dr. Alí Duarte-García

Dr. Anca Askanase

#### **Accelerating Patient-Centric** Research and Education

Too often, people with lupus share that existing treatments don't meet their needs. That's why the Lupus Foundation of America established RAY (Research Accelerated by You)® — a patient registry that centers the voices of people with lupus and their caregivers in driving research forward. With more than 4,300 participants, RAY is the most robust lupus patient data repository in the world.

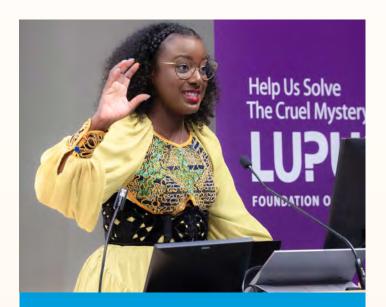
**STRATEGIC GOALS** 

This year, RAY participants shared their preferences for drug development through advisory panels and focus groups, and completed research surveys — all essential steps in developing more effective, patient-focused therapies. By prioritizing patient voices in research, the RAY platform continues to ensure diverse representation in research, reflecting the wide range of experiences across race, ethnicity, disease type and the heterogeneity of lupus. Notably, RAY played a key role in supporting education for nearly 20 clinical trials, focusing on CAR-T therapy, SLE, lupus nephritis, discoid lupus erythematosus, and other non-CAR cell therapies.

The Lupus Foundation of America also engaged federal agencies, including the U.S. Food and Drug Administration on the use of real-world evidence, community engagement action plans and the optimization of patient advisory committees. It also educated lupus community leaders to advance patient-focused drug development, increase participation in lupus research and clinical trials, and elevate the patient voice.

Beyond supporting research, the Lupus Foundation of America remained committed to educating the lupus community about scientific advances. Through a series of expert-led scientific webinars, viewed by thousands, our research team brought timely updates directly to people with lupus and their families. Topics included the new lupus nephritis guidelines from the American College of Rheumatology, as well as two webinars on CAR cell and T-cell engager therapy.

These initiatives — powered by our community of donors, partners and expert collaborators — help ensure that people with lupus are not only represented in research but fully informed and engaged in the future of their care.



#### In the Community:

The Lupus Foundation of America's Lupus & You **Empowerment Conferences provide important** education, research, support and community engagement opportunities for people impacted by lupus all across the country. The events feature expert speakers sharing lupus-specific education information, as well as the latest in lupus clinical trials and ways to participate in research. Several members of our Medical-Scientific Advisory Council spoke at conferences this year, including Dr. Ashira Blazer (pictured above). Dr. Blazer presented information on promising new lupus treatments on the horizon, and the importance of clinical trials and research participation. In the past year, we held more than 25 in-person Lupus & You Empowerment Conferences welcoming 1,200 people living with lupus and their care partners.

















**EXPAND DIRECT SERVICES AND** 

## **Increase Access** to Treatment and Care

**STRATEGIC GOALS** 



aena was diagnosed with lupus in 2013 and in 2017 with lupus nephritis (lupus-related kidney disease) — after alarming symptoms like swelling and difficulty breathing sent her searching for answers. Living on the remote island of Tinian, part of the Northern Mariana Islands and a US territory, she had limited access to specialists and no clear understanding of what kidney involvement meant. "I felt completely alone," she recalls. "No one around me had heard of lupus nephritis, and I didn't know where to turn."

It was through personal stories shared by the Lupus Foundation of America (LFA) that Raena found hope and understanding. "Those stories helped me realize I wasn't alone — and that I could survive this."

After experiencing kidney failure in 2021 and receiving a lifesaving transplant from her husband, Raena now volunteers as a Lupus Foundation of America lupus nephritis support group leader, offering others the community and guidance she once needed.

Recognizing the growing need, the LFA expanded its efforts this year to inform and support those living with lupus nephritis. We enhanced our Lupus Nephritis Information Hub with new medically reviewed articles, podcasts, and a webinar on the new lupus nephritis treatment guidelines published by the American College of Rheumatology. Our Check In With Your Kidneys campaign in March sparked a 581% increase in link clicks to kidney health resources revealing the strong demand for trusted information.

To build global awareness, as secretariat of the World Lupus Federation, we amplified findings from a new global survey, which revealed that 43% of respondents reported having little or no knowledge about lupus nephritis, yet 85% reported experiencing one or more symptoms associated with lupus nephritis — underscoring the critical need for earlier education and monitoring.

Lupus nephritis is one of the most serious complications of lupus — and, together, through shared stories, support and resources we're helping more lupus warriors protect their kidneys — and their futures.

#### **Empowering People, Advancing Access**

From local support groups to national coalitions, the Lupus Foundation of America (LFA) reaches thousands of people with education, tools and advocacy to improve life with lupus. More than 7,000 people participated in Lupus & You National Webinars, gaining trusted guidance on topics like pain, fatigue, flares and relationships, plus 1,500 joined in-person, Lupus & You Empowerment Conferences nationwide. Our support group network remained a cornerstone of connection and encouragement, with 70 groups, 142 trained facilitators, and 1,500 participants this year. We also established new support groups focused on kidney care, military families, central nervous system lupus and more. Our self-management program, SELF: Strategies to Embrace Living with Lupus Fearlessly, continued to grow, with more than 11,500 people registered and new print guides developed to reach individuals with limited internet access.

More than 2,300 people from 63 countries turned to our Health Education Specialists for support—receiving personalized help with diagnosis, finding physicians, and navigating daily challenges of living with lupus. Together, these resources reflect the LFA's unwavering commitment to ensuring that every person with lupus — and their family and loved ones — have access to the information, tools and support they need.

#### **Protecting Access to Research and Care**

This year, the LFA was a strong and persistent voice in Washington — leading national efforts to protect and advance policies critical to people with lupus. With funding and access at risk, our advocacy was more urgent—and more relentless—than ever.

We led efforts to preserve research and public health funding, safeguard Medicaid and Medicare, and protect access to care, prescription drugs and telehealth. Our team engaged all levels of government to ensure the lupus community's voice was heard.

As convener of the MAPRx coalition of 60+ national organizations, we defended access to medications for people

with chronic conditions. We also provided leadership and joined other coalitions, advocating for lupus priorities at the National Institutes of Health, Centers for Disease Control and Prevention, the Department of Defense, the Office of Minority Health, the Centers for Medicare and Medicaid Services and the Food and Drug Administration.



#### In the Community:

The Lupus Foundation of America's National Lupus Advocacy Summit brought more than 300 lupus advocates from across the country to Capitol Hill to share their stories and urge Congress to expand research funding and protect access to care. Shortly after, the Senate Appropriations Committee approved legislation to fund critical lupus programs in 2026. Building on this momentum, the LFA led a Congressional recess grassroots campaign in August, mobilizing advocates to meet with lawmakers locally to advocate for lupus priorities as the legislation process continues.



aking a difference in the fight to end lupus means something special to each person who joins us. For many, it's the Walk to End Lupus Now® — an event filled with energy, connection, and hope. Walkers and fundraisers come together to honor themselves, loved ones, or those who cannot walk, celebrating progress while pushing for more research, better care, and a cure.

Christine Zammett is one of those walkers. Since 2016, she has joined the Washington, DC Walk with her family and friends, bringing her glowing personality, supportive spirit, and determination to every step. Beyond the Walk, Christine has raised her voice in powerful ways. This past May, she shared her story on Capitol Hill at the National Lupus Advocacy Summit, urging Congress to expand research funding and protect access to care. She also inspired others in her community by speaking at a local Lupus & You Empowerment Conference. Christine shows how one person's passion can ripple outward—fueling awareness, advocacy, and hope.

The mission of the Lupus Foundation of America is only possible because of people like Christine—and thousands more who give their time, energy, and resources. Whether it's through fundraising with a team at the Walk to End Lupus Now®, or logging six miles in six days through the Virtual 6 Challenge, and even livestreaming a favorite video game or hobby, there are an incredible amount of inspiring and creative ways that people make a difference. And, each participant - and donor that supports them - is making an impact, through donations, raising awareness and inspiring hope.

And, beyond events, countless others are making donations, many that unlock a matching gift, or giving in other ways like including the Lupus Foundation of America in a will for a lasting legacy. Each contribution, no matter the size, makes a difference. Together, we are driving progress toward a future free of lupus.

## In the Community: Being a Part of the Movement



The 4th Annual Sip and Support fundraiser is hosted by Lupus Foundation of America national Board Member, Western Division Leadership Council member, former US Women's National Soccer team player, and Olympian, Shannon Boxx. With wine tasting, an annual cornhole tournament and dinner, each guest makes an impact during this fundraiser.



Game On! To End Lupus, a virtual fundraiser with individuals across the nation uniting for a month-long streaming event each May, has brought hundreds from the passionate online gaming community together for the past five years. This year, the Game On! family celebrated an amazing milestone - they raised \$1 million dollars raised for the Lupus Foundation of America since the program started! (Pictured: Game On! participants at annual TwitchCon conference)



Corporate support at events and programs, including Walk to End Lupus Now® events, bring another level of support from the community - from company-wide walk teams and sponsorships to in-kind donations and lunch and learn awareness events. (Pictured: Cullinan Therapeutics team members at their sponsor tent at the Boston Walk to End Lupus Now.)



Hundreds across the country join together virtually to take on six miles in six days for the Virtual 6 Challenge, representing the average of six years it takes to receive a lupus diagnosis. This year, over 350 completed the challenge raising nearly \$70,000. (Pictured: Lupus warrior and Lupus Foundation of America support group leader Karen Ng taking her Virtual 6 Challenge steps in Hawaii.)









## Ways to Give and Get Involved

There are many ways to make a difference in the fight to end lupus, from making a donation and becoming a monthly donor to incorporating the Lupus Foundation of America into your planned giving or becoming a fundraiser through an event. Here are just some ways you can make an impact:

#### 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.

#### **Workplace Giving**

Many workplaces have programs where they will double or even triple your donation. Find out if your company has a matching gift program, and other ways to give through your workplace. **Lupus.org/workplace-giving**.

#### **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**.

#### 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 or join Game On! to End Lupus in May. Visit Lupus.org/Livestream to get started and stream for a cause.

#### **Raise Your Voice**

Join the fight by raising your voice for lupus advocacy. Over the past five years, we've helped secure more than \$785 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/Pay-Tribute**.

#### **Planned Giving**

Create a lasting legacy by helping those affected by I upus through planned giving. You can support lupus research and care with your estate planning goals. **Visit Lupus.org/PlannedGiving** or contact Jamison Skala, Senior Vice President of Development and Fundraising, at 202.809.7426 or via email at **Skala@lupus.org** 

#### **Donate a Vehicle**

You can donate your car, truck, boat or RV to the Lupus Foundation of America and receive a tax deduction while supporting the mission to end lupus. Find out more at Lupus.org/donate-a-vehicle

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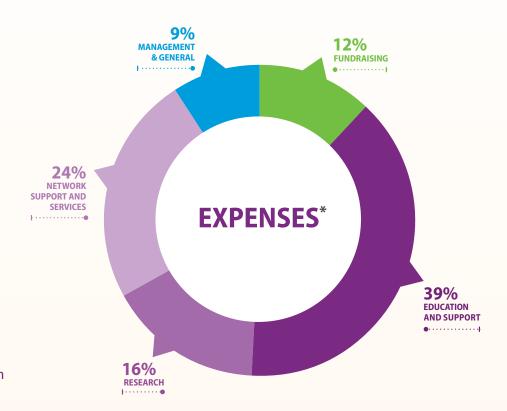
Jinoos Yazdany, M.D., M.P.H.

University of California, San Francisco

# Financial Highlights

#### 79¢ of every \$1 fuels our mission.

Your gift goes where it matters most—into research, education, advocacy, and life-changing support for people with lupus and their families. This strong commitment to accountability and transparency has earned the highest recognition from respected charity evaluators, including *Charity Navigator*, the Better Business Bureau, and the National Health Council. Your donation isn't just a gift—it's a sound investment in creating a future without lupus.



#### **LUPUS FOUNDATION OF AMERICA**

Statement of Activities For the Year Ended September 30, 2024

REVENUE AND SUPPORT	16,642,068
EXPENSES	
Program Services	
Education and Support	7,090,945
Network Support and Services	4,296,251
Research	2,835,184
Management and General	1,698,148
Fundraising	2,281,396
TOTAL EXPENSES	18,201,924
CHANGE IN NET ASSETS	(1,559,856)
NET ASSETS, BEGINNING OF YEAR	7,990,988
NET ASSETS, END OF YEAR	6,431,132

## LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2024

REVENUE AND SUPPORT	16,853,348
EXPENSES	
Program Services	
Education and Support	8,272,491
Network Support and Services	4,296,251
Research	2,835,184
Management and General	1,866,707
Fundraising	2,535,726
TOTAL EXPENSES	19,806,359
CHANGE IN NET ASSETS	(2,953,011)
NET ASSETS, BEGINNING OF YEAR	10,032,418
NET ASSETS, END OF YEAR	7,079,407

<sup>\*</sup>A 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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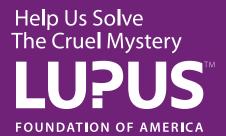
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