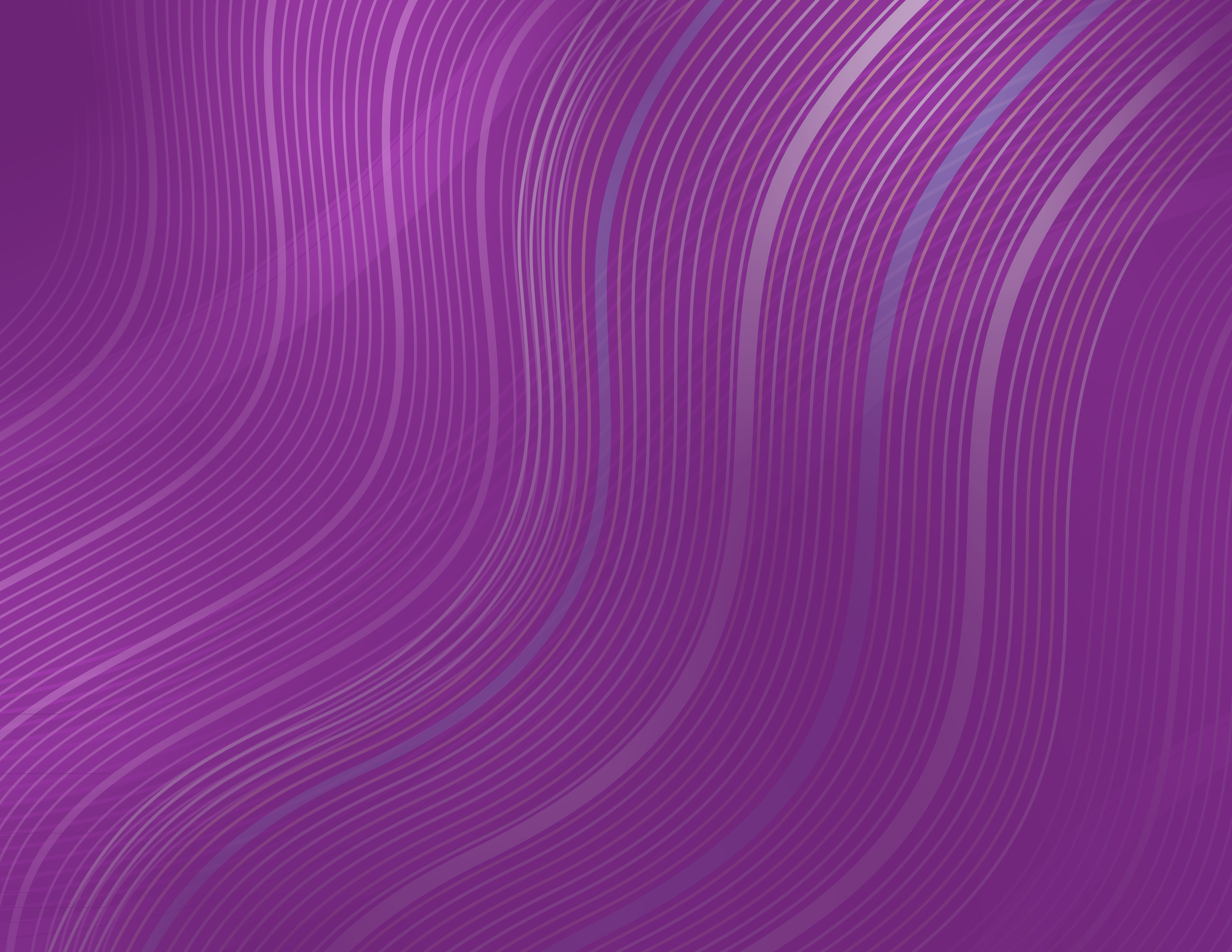
Help Us Solve
The Cruel Mystery
LUPUS®
FOUNDATION OF AMERICA

BUILDING ON OUR MOMENTUM

2020 – 2021 IMPACT REPORT



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The progress we have seen in the past year in lupus research is unprecedented, and could not have been imagined even 10 years ago. After countless roadblocks and failures, the FDA approved two lupus medications in 2021 — Lupkynis in January and Saphnelo in August. We want to take a moment to acknowledge and celebrate this historic milestone with all of our industry partners, lupus advocates, researchers, health care providers and countless others who worked tirelessly to help make this happen. And while we know there is still much work to be done, we just took one significant step closer to achieving our mission.

Progress in lupus research will only continue to accelerate, and we have an opportunity to build on this exciting momentum. That's why removing obstacles to research and increasing clinical trial participation remains a key priority for all of us at the Lupus Foundation of America (LFA). Last year, we launched the Lupus Research Action Network (LRAN), a new peer-to-peer initiative dedicated to increasing knowledge of lupus research and participation in clinical trials among people with lupus. With a growing number of lupus treatments in the drug development pipeline, it is critical that any new treatments are both affordable and accessible. That's why we established and convened the Market Access Working Group, comprised of leading lupus experts across the healthcare ecosystem, including patients and caregivers. The group is focused on addressing access to care issues, such as insurance coverage, health disparities and health technology assessment.

We also could not have imagined the way that the COVID-19 pandemic would have pushed us to adapt our programs and services to meet the needs of people with lupus. People told us what they needed and we listened. We continued to provide the latest information on lupus and COVID-19, including guidance on the COVID-19 vaccines and addressing concerns around returning to school or work safely. We also expanded our online and virtual programs, allowing us to reach more people. We launched our updated education program, *Lupus &You: Answers. Advocacy. Action.*, added support groups for men and youth and increased the number of resources available in Spanish.

We created new opportunities for you to get involved helping to bring an end to lupus and saw more engagement than ever before both here at home and around the world. We expanded our trained volunteer network through our Lupus Ambassador program, and our Pacific Northwest and Northeast offices added new states to their service areas to bring more programs into local communities. And the World Lupus Federation continued to expand its influence and position itself as a leader in the global lupus community by adding new members and completing the first survey of its kind on the global impact of COVID-19. Looking ahead to the coming year, we are excited to share with you our first comprehensive report on health disparities in lupus and the launch of our first online self-management program.

None of this would be possible without you. We are grateful for all who have come forward to support us, partner with us, and most importantly, believe in the power of the lupus community. Thank you.

Steven W. Gibson

Steven Gibson
President & CEO

Susan Manzi MD, MPH

Susan M. Manzi, MD, MPH
Board Chair

RAISING OUR VOICES

TO MEET THE NEEDS OF PEOPLE WITH LUPUS

Every day we fight to ensure that elected leaders at all levels of government are responsive to the voices and needs of people with lupus. As new lupus medications were approved by the FDA, we knew it was important that we take action to ensure that any new lupus treatment is accessible and affordable.

Establishing a Working Group to Address Access to Care

Over this past year, we established and convened the Market Access Working Group, comprised of leading lupus experts across the healthcare ecosystem, including clinicians, researchers, biopharmaceutical companies, and most importantly, patients and caregivers. The group is focused on addressing access to care issues, such as insurance coverage, health disparities, and health technology assessment. This group guided the LFA's work in engaging with the Institute for Clinical and Economic Review (ICER), which assessed the clinical and economic value of two lupus nephritis treatments. The Working Group helped identify health and patient outcome data, and other key factors, such as disability and race that are important to the lupus community and which played an important role in ICER's assessment. ICER's final report found value in both treatments, an important victory that can help ensure people with lupus have access to these critical new options to treat lupus nephritis.

Protecting People with Lupus During the COVID-19 Vaccine Rollout

To ensure protections for the lupus community and other immunocompromised during the COVID-19 vaccine distribution rollout, we joined forces with the Immune Deficiency Foundation (IDF), The AIDS Institute, the American Autoimmune Related Diseases Association (AARDA), and Susan G. Komen to establish the Protecting the Immunocompromised Collaborative. The Collaborative brought the immunocompromised communities' concerns and voices to the attention of the Committee on Equitable Allocation of Vaccine for the Novel Coronavirus, which advised the CDC and policymakers on the Hill.

Ensuring Medications are Accessible and Affordable

The LFA continues to convene more than 60 national organizations in the MAPRx Coalition to support people living with lupus and the more than 44 million Americans who receive prescription drug coverage through Medicare Part D. The Coalition hosted multiple virtual briefings to educate members of Congress and their staff about the Part D benefit as well as opportunities to protect and strengthen the program. Over the past year, the MAPRx Coalition and 27 of its member organizations submitted multiple letters to House and Senate leadership in response to the ongoing congressional efforts to address drug pricing and affordability. The letters urged congressional leadership to establish an out-of- pocket (OOP) cap for Medicare Part D to limit the amount Medicare beneficiaries have to pay for covered prescription drugs along with other key policy recommendations to improve Medicare Part D.

THIS PAST YEAR, WE ALSO:

Registered more than **3,900 advocates** for the Digital Lupus Advocacy Summit, held from March 2-4, 2021, resulting in more than 300 virtual congressional meetings and 3,100 emails sent by lupus advocates to their members of Congress.

Secured $21.5 million in funding for lupus-specific research and education programs, **the most funding Congress has ever approved for lupus-specific program in a single year**, including $9.5 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention (CDC), bringing the total funding to nearly $82 million.

Launched the Lupus Research Action Network (LRAN), a new peer-to-peer initiative dedicated to increasing knowledge and participation in lupus research. We have held two training sessions with nearly 50 lupus advocates on the state of lupus research, lupus drug development, and clinical trials, as well as how to educate others in their community about the value of participating in lupus research.

> *I felt it was important to participate in the Market Working Group and the ICER review because I knew this review could have an impact on these new treatments being accessible for people living with lupus. I know what it feels like to have almost no options for my lupus nephritis and I wanted to ensure that the patient perspective was clearly understood and remained at the center of this conversation.*
>
> **— TONI GRIMES, LUPUS WARRIOR AND LFA AMBASSADOR**

STRENGTHENING OUR IMPACT

ON LUPUS RESEARCH IN ORDER TO TRANSFORM LIVES

This was a year like no other in lupus research. We are proud that studies we have funded contributed to every scientific breakthrough for the last 40 years, and we remain at the forefront of lupus research. To build on this momentum, we continued to fund innovative lupus research, pave a path forward for lupus research and educate people about clinical trials.

Paving the Path for New Treatments

The FDA approval of Saphanelo and Lupkynis this past year are the result of the LFA's ongoing efforts to remove the barriers in lupus research and invest in the next scientific breakthrough. We have funded more than $22 million in general lupus research and $2.5 million in lupus nephritis research. This investment contributed to laying the groundwork for preliminary research leading to major treatment breakthroughs.

Improving Outcomes for Pregnant Women with Lupus

There has been tremendous progress in making pregnancy for people with lupus safer, but there is still an increased risk of complications for many women and no current treatments. Because of the critical need to develop a treatment to improve pregnancy outcomes, the Lupus Foundation of America is funding the IMPACT Study (IMprove Pregnancy in APS with Certolizumab Therapy) through a three year grant.

The IMPACT Study is groundbreaking. It is the first clinical trial of a biologic therapy to help prevent pregnancy complications in women at higher risk for them, increasing their chances of delivering healthy babies. During the first year of the study, pregnancies have been completed in 27 patients with the results showing improved outcomes. The success of the trial has generated increased interest across the United States and international community.

Creating Solutions and Removing Barriers in Lupus Research

The LFA has continued its work on *ALPHA: Addressing Lupus Pillars for Health Advancement*, a comprehensive, multi-phase, global consensus initiative aimed not only at identifying and prioritizing the top challenges in lupus research, but also creating actionable solutions. Previously, ALPHA identified and published the global consensus on barriers to lupus drug development. The project has entered a new phase and established teams organized around the three pillars of need identified as part of its research: access to care, drug development and clinical care. The teams have each begun to establish working groups and identify key issues to address including steroid sparing, health disparities and better understanding the heterogeneity of lupus.

> *We could not have imagined even five years ago the progress we are seeing in new treatments. For more than 40 years, the LFA has been a leader in lupus research, slowly one by one removing barriers that obstructed drug testing, only to encounter another layer of problems. Now it looks like we are starting to get get somewhere.*
>
> **— JOAN MERRILL, M.D., PROFESSOR OF MEDICINE, ARTHRITIS & CLINICAL IMMUNOLOGY PROGRAM, UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER.**

THIS PAST YEAR, WE ALSO:

Received the first Impact Factor for our scientific journal, *Lupus Science and Medicine* (LS&M). An Impact Factor is one of the leading measures and incentives for an author to submit their manuscript to a particular journal. LS&M received the highest ranking for any lupus-specific journal and is closely ranked among the most prominent journals in rheumatology. In the short three months since the journal received its Impact Factor, the journal has had more monthly submissions of manuscripts than ever before and this number is expected to continue to grow.

Recruited more than 1,000 people with lupus and caregivers to participate in Research Accelerated by You (RAY). RAY is an online data platform where people with lupus and caregivers share information about their lupus experience to help researchers accelerate the development of new treatments.

Awarded four new Gary S. Gilkeson Career Development Awards (CDA). These awards are $70,000 per year, for up to two years. They support the next generation of scientists and lupus researchers and also provide each grantee with an established clinical scientist as a mentor, ensuring that grantees have the support and guidance needed during their research.

CREATING A BETTER TODAY

BY PROVIDING ANSWERS, RESOURCES AND HOPE

We continued to evolve and respond to the changing needs of people with lupus during COVID -19, expanding our resources in Spanish, and adding new programs to address the unique needs of men and youth with lupus.

Expanding Our Online and Virtual Programs

We revamped our live education program to a virtual format and renamed it *Lupus & You: Answers. Advocacy. Action*. Attendees heard from lupus experts on key topic areas of interest, learned about helpful resources and tools, as well as ways to engage in advocacy and awareness efforts to help bring an end to lupus. Since the program launched in the spring of 2021, we held three quarterly national events addressing the impact of lupus on the kidneys, the skin and the heart, which had a total of more than 4,000 registered participants. In addition, more than 40 regional events were held across the country.

We also saw continued growth of our monthly podcast, *The Expert Series*, which has had nearly 14,000 plays since it launched in 2020. Our most popular episode in the past year was *Top Questions about Skin and Hair*, which has more than a thousand plays. Additional podcast episodes addressed topics such as: lupus and physical activity, improving health visits, and managing lupus nephritis. The majority of our listeners come from the United States, but we also have international listeners in Australia, the United Kingdom, Canada, Mexico and more.

Increasing Outreach and Resources for the Hispanic/ Latino Community

We developed and translated more than 150 resources into Spanish over the last year. We also expanded our outreach into the Hispanic/Latino community by developing a partnership with the National Alliance for Hispanic Health, which helps review cultural competency of our Spanish-language materials. Our Health Education Specialists conducted outreach to the Hispanic/ Latino community and participated in events where LFA's bilingual resources were shared.

Providing Support to Key Populations Impacted By Lupus

We now have more than 29 national support groups and 50 trained support group facilitators, and recently have expanded to offer support groups for key populations impacted by lupus: including men with lupus, a youth support group for individuals ages 7-25, and a Hispanic/ Latino support group which offers help in English and Spanish.

THIS PAST YEAR, WE ALSO:

Answered nearly 3,000 inquiries submitted to our Health Education Specialists in English and Spanish on diagnosing, living and coping with lupus.

Continued to provide timely up-to-date information and resources on lupus and COVID-19 vaccines, which have been viewed more than 625,000 times. Our COVID-19 general information page was viewed more than 500,000 times in 2021.

Enrolled more than 2,000 people in *Take Charge*, our 12-week email series aimed at providing newly diagnosed people with lupus with the knowledge and skills they need to manage their symptoms.

> *I have had lupus for four years, and I have found the LFA's support groups invaluable, both as a participant and now a facilitator. Support groups provide the community of support that is needed to manage the everyday challenges of lupus. It also provides access to first-hand personal experiences and coping strategies, along with most up-to-date information on research and available resources.*
>
> **— IMASHA ADISA, LUPUS WARRIOR AND LFA SUPPORT GROUP LEADER**

EXPANDING OUR REACH

AT HOME AND AROUND THE GLOBE

Lupus is a disease that knows no boundaries, and touches millions of families around the world, with an often untold and devastating impact. We continued to strengthen our efforts at home to raise awareness and understanding of the impact of lupus through efforts such as our Lupus Awareness Month campaign, while expanding the reach and influence of the World Lupus Federation, and bringing the global lupus community together.

Strengthening the Global Lupus Community

The World Lupus Federation (WLF) is a coalition of more than 250 lupus patient groups in 75 countries united to improve the quality of life for all people affected by lupus. Founded and led by the LFA, the WLF took significant steps this year to expand its reach and position itself as an instrumental leader in the global lupus community. Several strategic planning sessions were held virtually to further develop our relationships and build new ones, and identify better ways for collaboration. One of the most significant WLF highlights this year was the development and deployment of a Needs Assessment Survey of Federation member organizations to better understand their organization's capacity and needs. This assessment pinpointed the challenges these global lupus patient organizations face and how the WLF, led by the LFA, can better support the needs of these critical organizations, from providing them with education materials in various languages to guiding them on the most effective ways to reach more people with lupus with the resources and programs they need. Our work didn't stop there. We also led and piloted a first-of-its-kind global lupus clinical trial education project involving WLF members in France and Australia, aimed at increasing participation in lupus clinical trials.

#MakeLupusVisible on World Lupus Day

On May 10th, the WLF and LFA led the charge of the annual observance of World Lupus Day (WLD) by implementing a successful global social media campaign with the hashtag, #MakeLupusVisible. Our united purpose was to show the many faces of lupus, while increasing understanding of lupus and support for those impacted by the disease around the world. Dozens of awareness shareables and tools were created, translated in nine different languages, and shared with WLF members to create a cohesive global awareness impact on this special day. We generated national media coverage, and saw people from over 100 countries flooding Twitter, Instagram and Facebook with selfies, lupus facts and our awareness shareables.

Global Survey Findings on COVID-19 Pandemic Impact on People with Lupus

The WLF conducted a global survey to understand the broad impact of the COVID-19 pandemic on people with lupus and explore their views on the vaccines. The survey results that were released in April revealed and highlighted the COVID-19 experiences of over 6,100 people with lupus from more than 85 countries. Among the many significant findings was the revelation that 50% of respondents had reported decreased access to at least one aspect of lupus healthcare.

THIS PAST YEAR, WE ALSO:

Launched a partnership during Lupus Awareness Month with PatientPoint to distribute lupus education and support resources to nearly 7,000 physicians and rheumatologists across the United States.

Grew to a combined total of over 409,000 followers across six social channels: Facebook, Twitter, Instagram, LinkedIn, YouTube and TikTok.

Generated nearly 300,000 impressions on social media during Lupus Awareness Month and raised critical funds to support lupus research and education.

> *The World Lupus Federation has worked hard over the years to increase the visibility of lupus, and advance lupus research and education programs globally. It's an honor to be a part of a coalition that is dedicated to all people impacted by lupus and aims to provide greater services and support for them.*
>
> **— TERESA CATTONI, ASOCIACIÓN LUPUS ARGENTINA, WLF MEMBER**

CREATING OPPORTUNITIES

TO MAKE A DIFFERENCE IN THE FIGHT AGAINST LUPUS

Over the past year, we saw total charitable giving in the United States grow significantly, and supporters of the Lupus Foundation of America stepped up, too! Donations received through all of our fundraising programs support the full mission of the Lupus Foundation of America: research, advocacy, education, and care and support services. Take a look and see just how amazing our donors and participants are and what they accomplished this past year to help people with lupus!

LUPUS FOUNDATION OF AMERICA
WALK TO END LUPUS NOW®

Walk to End Lupus Now®

More than 1,500 walkers from all 50 states joined us for our Virtual *Walk to End Lupus Now* event on 10.16.21.

GAME ON! TO END LUPUS
by Lupus Foundation of America

Game On! to End Lupus

More than 102 gamers joined us for our 3 day livestream event from May 7-9 where streamers from around the world raise funds for lupus research and education.

THE VIRTUAL 6 CHALLENGE
for Lupus Foundation of America

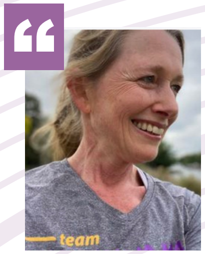
Virtual 6 Challenge

More than 400 challengers joined us for the Virtual 6 Challenge from August 23-28 where participants challenged themselves to complete 6 miles over 6 days.

Donations Made Online

For the first time, more than $1 million was raised online in 2020-2021 from our email fundraising campaigns and from friends and family donating in tribute of someone.

> *Team JMJ has been involved in the Walk to End Lupus Now for the past 10 years walking in San Francisco, California. We formed our team of family and friends in memory of our sister Jervonya M. Jones to create hope, change and progress in the fight against lupus. We fundraise year after year for a cause we are passionate about in hopes to spread awareness and make a difference.*
>
> **— PHYLICIA JONES, TEAM CAPTAIN OF TEAM JMJ**



> *My lupus has been pretty rough on me this past year. I decided I need to do something for myself and other Lupus Warriors and joined the Virtual 6 Challenge. I completed six miles—for the first time, in a very long time. I did it! A huge thank you to the Lupus Foundation of America for creating this event and providing a community of support and motivation so we can cheer each other on. I'm looking forward to running another six and raising money again next year.*
>
> **— SHANNON BANKS, LUPUS WARRIOR**

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/MakeYourMark**.

Livestream for Lupus

Help us raise awareness and funds and battle lupus with a charity stream. Visit **Lupus.org/fundraise/livestream-to-end-lupus**.

Raise Your Voice to Fight Lupus

We are the leader in stimulating federal support for lupus, generating more than $680 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, Director of Corporate Relations, at 202-557-0819 or via email at **Wienand@lupus.org**.

Celebrate 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 Leigh Ann Cardenas at 202-349-1153 or via email at **Cardenas@lupus.org**.

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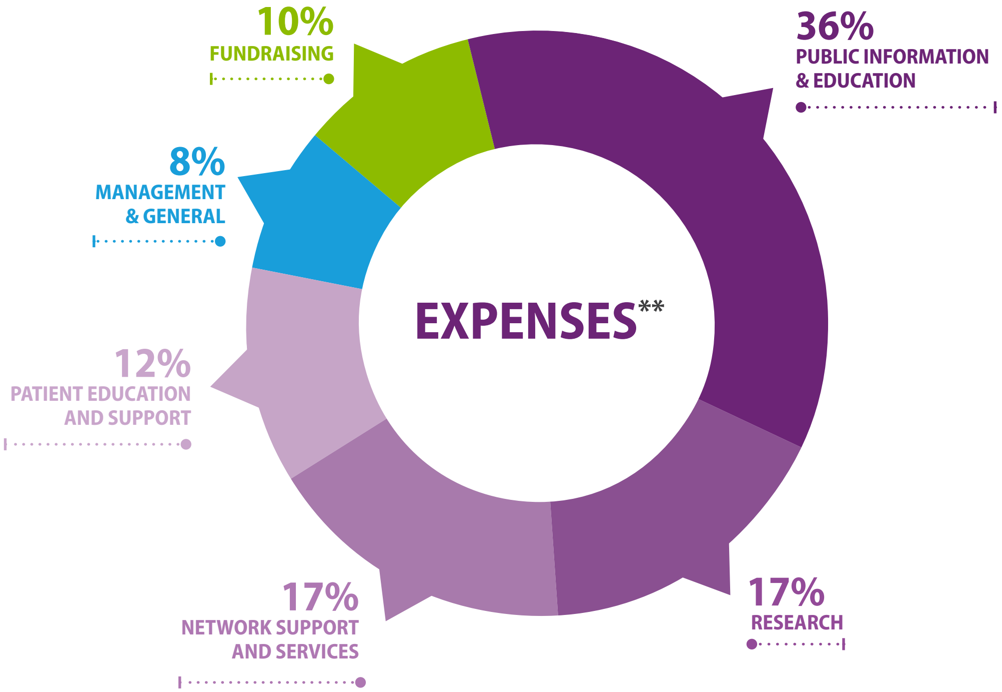
FINANCIAL HIGHLIGHTS



LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2020

REVENUE AND SUPPORT	**12,067,350**
EXPENSES	
Program Services	
Public Information and Education	5,100,940
Professional Relations and Education	8,211
Network Support and Services	2,876,830
Patient Education and Support	705,225
Research	2,777,767
Management and General	1,191,540
Fundraising	1,175,084
TOTAL EXPENSES	**13,835,597**
CHANGE IN NET ASSETS	**(1,768,247)**
NET ASSETS, BEGINNING OF YEAR	**5,393,919**
NET ASSETS, END OF YEAR	**3,625,672**

LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2020

REVENUE AND SUPPORT	**14,877,780**
EXPENSES	
Program Services	
Public Information and Education	5,952,748
Professional Relations and Education	8,211
Network Support and Services	2,855,035
Patient Education and Support	2,004,388
Research	2,810,661
Management and General	1,425,899
Fundraising	1,630,969
TOTAL EXPENSES	**16,687,911**
CHANGE IN NET ASSETS	**(1,810,131)**
NET ASSETS, BEGINNING OF YEAR	**10,534,4039**
NET ASSETS, END OF YEAR	**8,724,272**

**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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The mission of the Lupus Foundation of America is to improve the quality of life for all people affected by lupus through programs of research, education, support and advocacy.

Help Us Solve
The Cruel Mystery
LUPUS®
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