



Help Us Solve  
The Cruel Mystery  
**LUPUS**<sup>®</sup>  
FOUNDATION OF AMERICA

# **UNWAVERING** **IN OUR MISSION**

**TO IMPROVE THE QUALITY OF LIFE  
FOR PEOPLE WITH LUPUS**

**2019 - 2020 IMPACT REPORT**

**ANGEL, DIAGNOSED AGE 12**



Despite the many challenges and the uncertainty of this past year, we remain unwavering in our mission to improve the quality of life for all people with lupus. Our 2020 annual report takes you right to the latest developments and mission impact we've made over the past year--a year like no other.

Life as we know it changed dramatically this year due to the onset of the coronavirus (COVID-19) pandemic. It caused questions, concerns and anxiety for everyone which were amplified for all those living with lupus who are often more susceptible to infections like COVID-19. The Lupus Foundation of America immediately set up a central hub for [COVID-19 resources](#) in English and Spanish on our National Resource Center on Lupus, which has been viewed more than 380K times. We are committed to providing the most up-to-date health information, and we will continue to respond to the most pressing concerns we hear from lupus warriors and add resources as they become available.

The lupus community was impacted again when we experienced the shortage of the anti-malarial drugs hydroxychloroquine (Plaquenil) and chloroquine (Aralen) as they were investigated for the potential use in treating or preventing COVID-19. We immediately addressed the shortage with federal and state authorities, manufacturers, and health care industry officials, who play a role in helping ensure individuals with lupus have access to the medications they need. And, as we continue our work to bring down barriers that have impeded lupus drug development, this year we are starting to see the results of these efforts, bringing tremendous progress and hope. Two potential new drugs (voclosporin and belimumab) for lupus nephritis have been submitted for review to the Food and Drug Administration (FDA). The potential to have two drugs approved for lupus nephritis in 2021 is groundbreaking! Another drug, anifrolumab, which aims to treat adults with moderate to severe lupus is expected to be submitted to the FDA for approval by the end of this year. In addition, several other drugs are in phase 3 development and the Foundation continues to work in various capacities so people with lupus have an arsenal of safe and effective treatments.

This year we concluded a five-year cooperative agreement with the US Centers for Disease Control and Prevention (CDC) which supported among other things, working with family physicians to improve the time to an accurate lupus diagnosis, raising awareness of lupus among young black and latina women, and the development of the National Resource Center on Lupus, which has been visited more than 18 million times since its launch in 2017, reaching people in every state. I am also excited to share with you the Lupus Foundation of America was awarded a new five-year, multi-million dollar grant from the CDC that will allow us to build upon our work to expand our self-management resources, increase awareness of the signs and symptoms of lupus and address health disparities.

This is the work that needs to be done so that we can end the pain and suffering caused by lupus. You make progress possible. Thank you for being such an important part of our community. With you by our side we will lead the way to a brighter future for all people impacted by lupus.

A handwritten signature in black ink that reads "Stevan W. Gibson".

Stevan W. Gibson  
President and CEO

A handwritten signature in black ink that reads "Susan Manzi MD, MPH".

Susan M. Manzi, MD, MPH  
Board Chair, Medical Director



# ENSURING ACCESS TO LIFE-SAVING MEDICATIONS

#WithoutMyHCQ

*When hydroxychloroquine (HCQ) and chloroquine were identified as possible treatments for COVID-19, the Lupus Foundation of America took swift and immediate action to address the drug shortage and find solutions to ensure these critical medications remained available for people with lupus.*

## Working with Elected Officials and Government Agencies

During the drug shortage we were in constant contact with federal agencies, the White House administration and congressional leaders urging them to take action to address the crisis. This included:

- Partnering with the Arthritis Foundation, American College of Rheumatology and American Academy of Dermatology to urge **the White House Coronavirus Task Force to help preserve access to these medications for people with chronic diseases who rely on them.**
- Working with the **Congressional Lupus Caucus and other congressional leaders to help champion our cause.**
- Ensuring the **US Food and Drug Administration (FDA) recognized the drugs were in shortage** and that they and all government officials and agency leaders understood the impact of the shortage on people with lupus.

## Engaging Stakeholders and Finding Solutions

We also engaged other critical stakeholders in the development and distribution of hydroxychloroquine (HCQ). One of our first steps was to contact more than 12 HCQ manufacturers and wholesalers to help secure supplies and ensure they were aware of the importance of HCQ as a treatment for lupus. To help people with lupus access HCQ during the crisis we:

- **Created a state-by-state tracker of actions taken by state governments and other key stakeholders**, to help guide people with lupus on how to access HCQ in individual states.
- **Identified online pharmacies with supplies of HCQ** for people with lupus who couldn't access their medications locally.

## Making Our Voices Heard

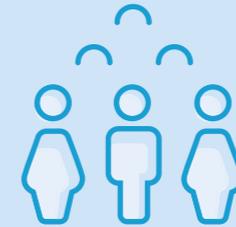
The lupus community also said to us – what can I do, how can I help? **More than 50,000 lupus warriors** immediately raised their voices and sent **138,000+ letters to members of Congress** asking them to ensure access to life-saving medications for people with lupus.

With this crisis, we also recognized we had an opportunity to bring attention to the disease and the impact of COVID-19 on people with lupus. Many lupus warriors stepped

up to share their own experiences of the drug shortage with national and local media and why HCQ was critical for their health and quality of life. By June we had secured **more than 90 national and local media stories highlighting the HCQ shortage** and its impact on people with lupus. Media cover included placements in outlets such as *Good Morning America*, *New York Times*, *The Washington Post*, *ABC News* and the *Wall Street Journal*.

*“When the hydroxychloroquine shortage happened I knew I needed to do something, not only for myself, but all people affected by lupus. The Lupus Foundation of America empowered me, and gave me the information and tools I needed to reach out to my members of Congress to make my voice heard. I am so grateful for everything the Foundation has done to give me this platform, and protect access to the life-saving medications I need.”*

— OLGA LUCIA TORRES, LUPUS WARRIOR AND ADVOCATE



## Together, we are **EMPOWERED**. This past year, we:

- **Generated \$18M+** in lupus-specific funding secured at the Centers for Disease Control and Prevention, Department of Defense, and Office of Minority Health and \$41.7 billion for the National Institutes of Health, the single largest source of government funding for lupus research.
- **Incorporated the lupus patient and community perspective into efforts to accelerate and improve the drug development process** by engaging the FDA through the Agency's Patient-Focused Drug Development initiative and the implementation of the 21st Century Cures Act.
- **Led the MAPRx™ Coalition, a group of 60+ national advocacy organizations**, focused on reducing out-of-pocket costs and improving access to lifesaving medications through Medicare Part D.



A photograph of two women smiling together. The woman on the left has long, wavy blonde hair and is wearing a dark plaid top. The woman on the right has dark hair styled in a bun and is wearing a mustard yellow top. They are both looking towards the right of the frame.

# PROVIDING ANSWERS, RESOURCES AND HOPE

*We know lupus is uniquely challenging enough on its own. And this past year, the onset of the COVID-19 pandemic created even more questions and concerns for people with lupus about the future and how to handle everyday life. We took numerous steps throughout the year to help people affected by lupus navigate the pandemic, while continuously adapting to the current needs and evolving situation.*

## **Creating a One-Stop Resource for Information on COVID-19 and Lupus**

We created a **central gateway** to resources and information about COVID-19 and lupus in English and Spanish that was viewed **more than 380,000 times** through early November. We provided regular email updates to respond to the rapidly evolving situation, as well as Q&A resources to address the top concerns from lupus warriors, ranging from how to keep safe to mental health and well-being. **In total, we now have more than 300 pages of content related to coronavirus and the hydroxychloroquine (HCQ) shortage.** Our network of Health Educators, chapters and regional offices also answered questions, provided resources and ensured on the ground support - and continue to do so.

## Leveraging Social Media to Provide Critical and Timely Updates

We also leveraged social media to share the latest updates on COVID-19 by creating a series of video interviews with medical experts and members of the Lupus Foundation of America team. **More than 160K followers shared our expert interviews further expanding our reach of critical information.** Our coverage of the latest COVID-19 developments continue, including the importance of the flu shot during this time, going back to work or school, and insights on a potential COVID-19 vaccine.



*"THANKS so much for your swift response and I will keep all of this information in mind as we all continue to make our way through the COVID-19 pandemic. Your information is so very helpful, and I appreciate it more than you may realize."*

— RESPONSE TO SURVEY ON THE IMPACT OF COVID-19 PANDEMIC ON PEOPLE WITH LUPUS

Together, we are **INSPIRED**.  
Thanks to your support, we:



- **Relaunched Take Charge**, a 12-week email series geared towards guiding newly-diagnosed people with lupus with knowledge and skills to help manage their lupus symptoms, which has a total of nearly 7,000 subscribers.
- **Hosted over 4,200 plays of our newly launched podcast, Lupus: The Expert Series**, which features leading lupus experts covering a range of important topics from how to prepare for a telehealth visit, to lupus and the kidneys, to trust and participation in research.
- **Launched a partnership with the American Academy of Family Physicians to develop tools and resources** to improve diagnosis and management of lupus. This included co-branded fact sheets, a first-of-its-kind Lupus Care Management Plan that people with lupus can use to prepare for their appointments, and a new continuing medical education course available to help family physicians recognize the signs and symptoms of lupus.
- **Revamped our education and support programs to adapt to this new virtual environment, hosting over 30 online Lupus: Living and Learning events** across the country with timely topics such as managing stress, COVID-19 and lupus, as well as more general topics such as lupus and Raynaud's disease and childhood lupus.

# ADVANCING NEW TREATMENTS FOR LUPUS

*"We are confident our partnership with the Lupus Foundation of America through the Catalyst Grant program will help to further advance lupus research as we support the brightest researchers in North America."*

—TANYA CARLTON, PRESIDENT, LUPUS CANADA

*Lupus is a disease that has no boundaries, it impacts an estimated 5 million people worldwide. But with scientists and partners working together across the globe we can accelerate the search for better treatments and a cure. This past year, we expanded and launched new international partnerships to bring the lupus community closer together in this global fight to end lupus.*

## **Collaborating Across North America to Fund Innovative Research**

Earlier this year the Lupus Foundation of America announced a first-ever partnership with Lupus Canada to fund innovative lupus research through the Lupus Canada Catalyst Award. The award provides funding for one year to Canadian researchers at any stage in their career. The 2020 recipients of the award are Leslie Skeith, MD, Clinical Assistant Professor in the Division of Hematology & Hematological Malignancies, University of Calgary and Megan Barber, MD, PhD, clinical lecturer in the Division of Rheumatology, University of Calgary.

Dr. Skeith and Dr. Barber will study why pregnancy complications occur in women with lupus and antiphospholipid syndrome (APS), an autoimmune disorder and acquired blood clotting condition that is commonly seen in people with lupus. This study will bring a better understanding to why these complications occur so we can predict and prevent these problems in future pregnancies.

## Improving the Management of Lupus Worldwide

The Lupus Foundation of America has a long-standing partnership with the Systemic Lupus International Collaborating Clinics (SLICC), which is an international research organization with 54 members who collectively represent 16 countries and 5 continents. Efforts this year focused on updating the SLICC Damage Index, which is a tool that measures long-term organ damage caused by lupus. This work is timely and highly relevant to physicians and patients globally. Long-term damage is a key clinical outcome used in lupus research and to evaluate the effectiveness of new therapies in clinical trials. Improving SLE damage measurement is therefore a critical next step in the field of lupus research.

## Reaching the first-ever Global Consensus on the Barriers to Lupus Treatment and Care

This was a year of success for the Foundation's Addressing Lupus Pillars for Health Advancement (ALPHA) project. The ALPHA Project was launched in 2018 as a global, multi-phase, consensus-driven initiative seeking to identify and prioritize top urgent and unmet issues in lupus drug development, clinical care, access and value of care. The project reached a significant milestone this year with the publication of the global consensus on the barriers to drug development, receiving nearly 4,000 abstract and publication downloads, media coverage in at least 6 top trade media publications, and finally the launch of a global patient survey reaching over 4,000 individuals and caregivers across 83 countries.



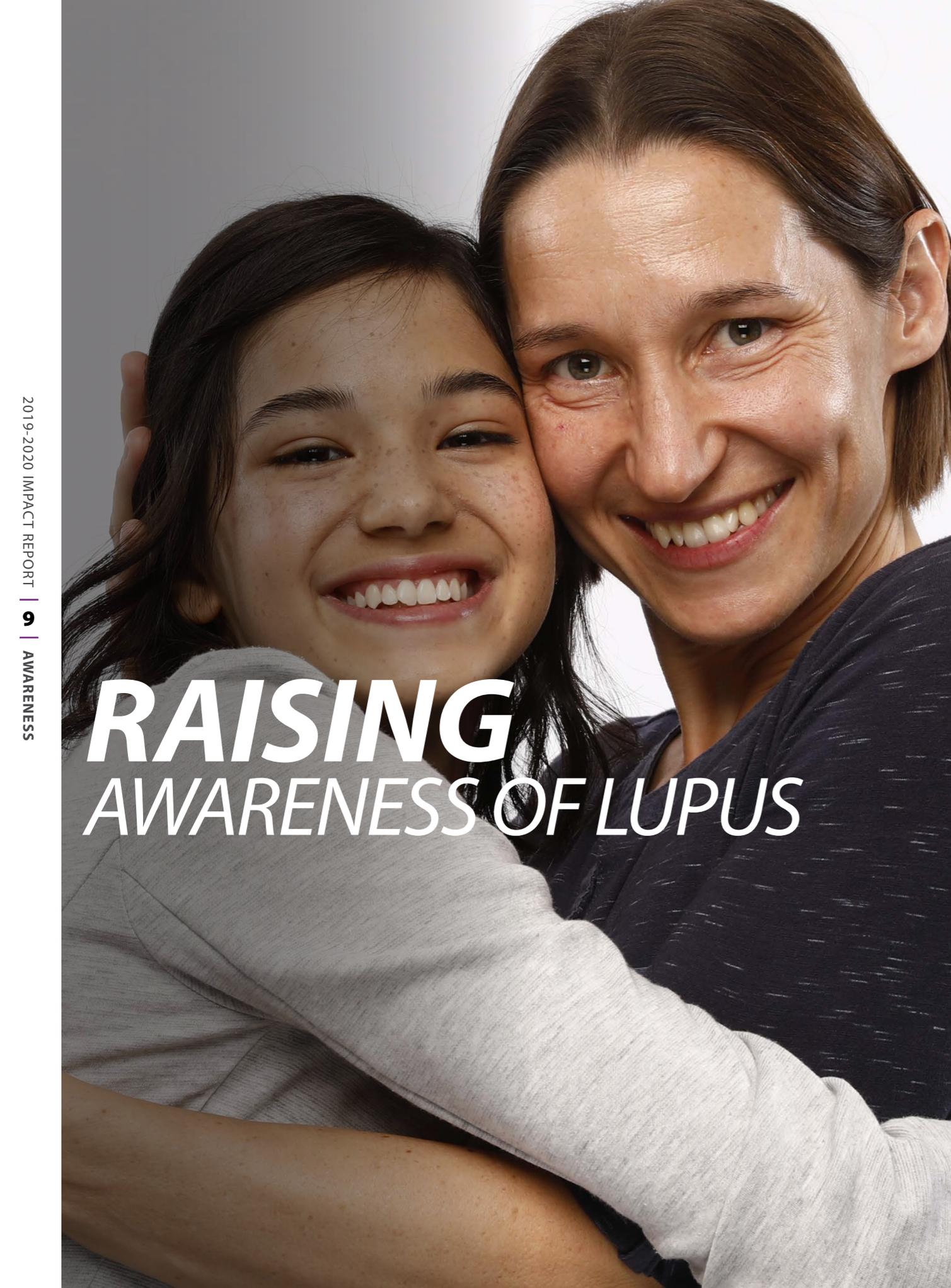
## Together, we are **RESOLVED**: Thanks to your support, we:

- Supported the **COVID-19 Global Rheumatology Alliance's Registry**, which is an important international effort that collects de-identified information from clinicians and people with rheumatic diseases, such as lupus. The information collected in the registry will help evaluate the risk of COVID-19 and improve the way doctors manage rheumatic patients during this time.
- Continued funding for a phase II study to evaluate mesenchymal stem cells as a treatment for lupus. We are now in year three of the study, and the Lupus Foundation of America has committed \$3.8 million over the full five years.
- Launched, **RAY: Research Accelerated by You**, a lupus data platform where people with lupus and caregivers share anonymous information about their lupus experience to help researchers accelerate the development of new treatments and improve disease outcomes.
- Provided more than 6,000 people Inside Lupus Research (ILR) bi-weekly email updates. ILR is our online news bureau that provides timely and accessible research updates from the leading lupus peer-reviewed medical journals, public and private research centers, and medical centers.

Inside LUPUS RESEARCH<sup>SM</sup>  
by Lupus Foundation of America

*"Thank you for being so helpful! Living with SLE since 1984 I feel less alone in all this when receiving your informative and supportive e-mails. A heartfelt thank you to your formidable team."*

—INSIDE LUPUS RESEARCH SURVEY RESPONDENT



# RAISING AWARENESS OF LUPUS

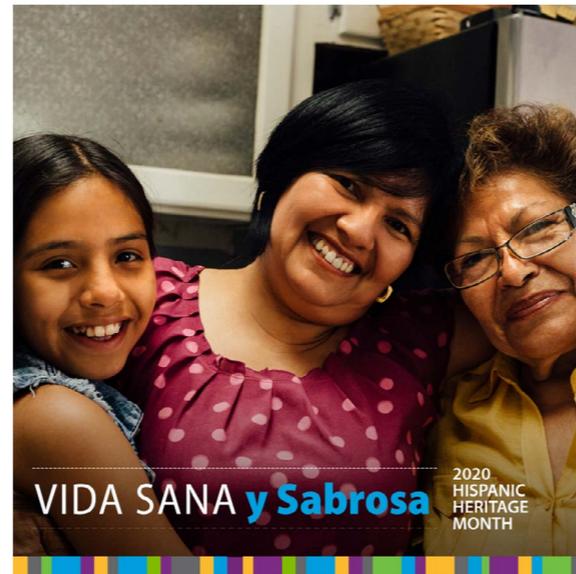
*This past year we created a series of social media campaigns to bring attention to health disparities and highlight resources available to address the unique needs of different audiences impacted by lupus. These campaigns incorporated videos to share lupus warrior voices and those of our experts.*

## **Resources and Answers to Meet Your Needs**

We started the year with our *Lupus Locks* campaign during Black History Month. We produced several videos to present personal, medical and professional perspectives on hair and scalp issues that African Americans with lupus experience. Black women are not only at greater risk for lupus, but hair is a staple in the black community. This was one of our most successful campaigns, reaching more than 400,000 people.

In May, we created videos for Asian Pacific American Heritage Month featuring lupus warriors explaining the importance of family and caregiver support. And, for Men's Health Month we had a *June is for the Gents* campaign, focusing on the needs of men with lupus. Throughout the month, men with lupus posted photographs and shared their own unique lupus journeys on social media. We also had several interviews and videos with medical experts and people with lupus.

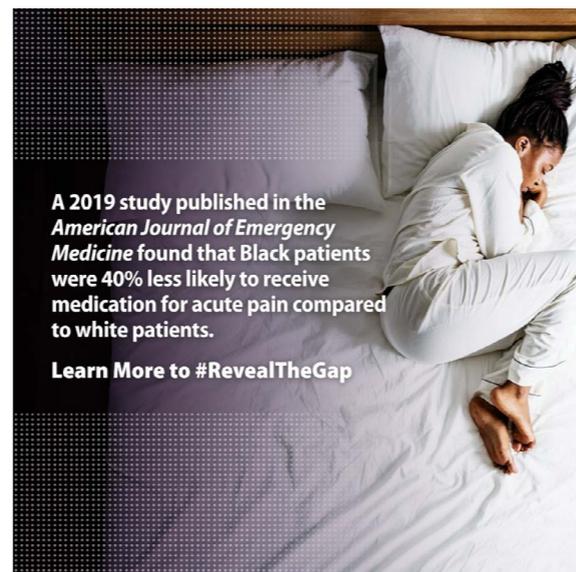
In September, we ran a campaign for Hispanic Heritage Month, which included 11 new videos, and had more than 200,000 impressions across all channels, for both the Spanish and English language audiences. We highlighted the important role of food in the Hispanic culture by featuring healthy recipes from celebrity Chef Ingrid Hoffmann, who also lives with lupus.



### Raising Awareness of Health Disparities

At the end of August we kicked off our #RevealTheGap campaign, an effort designed to highlight the disparities in health care treatment and outcomes for people and communities of color. The campaign featured a live panel with doctors and people with lupus discussing their experiences. **The posts for #RevealTheGap found a large and grateful audience, pulling in almost 200,000 impressions across all social channels.**

**In total all of these campaigns generated more than one million impressions across all channels.**



*"The Lupus Foundation of America recognizes the diverse and unique ways that lupus impacts different communities. The resources they have are invaluable. I also appreciated the opportunity to have the platform to share my story, and the important role caregivers play, during Asian Pacific American Heritage Month."*

— KAREN NG, LUPUS WARRIOR



### Together, we are MOTIVATED. Thanks to your support, we:

- Launched the new educational, [What is Lupus Video](#), that provides an engaging explanation of what lupus is, its impact and the difficulty in diagnosing, treating and living with this complex and unpredictable disease.
- Provided information and resources to the more than 7M annual visitors to [lupus.org](#) and generated 64M impressions across all social media channels.
- Made Lupus Visible this past May with 4.5 million impressions, more than 182K views of our videos and a 9% increase in traffic to our Lupus Awareness Month homepage.
- The LFA continues to serve as the World Lupus Federation (WLF) Secretariat, spearheading efforts to bring global attention and awareness to the needs of people with lupus. This past year the Federation coordinated the annual observance of World Lupus Day (WLD) on May 10. An array of shareable materials and digital assets created by the LFA were used by WLF members to spread lupus awareness messages on WLD, which led to the #WorldLupusDay hashtag totaling a reach of 102,224,833.

# RALLYING SUPPORT TO HELP END LUPUS

*Individuals, corporations and foundations further the Lupus Foundation of America's mission through their dedicated involvement and financial support. From Walk to End Lupus Now®, to charity streaming and virtual fundraisers, and more, we deeply appreciate our many generous donors who demonstrated their powerful, ongoing commitment to ending lupus through participating in our fundraising efforts.*

## **Transitioning Programs to Virtual Experiences and Creating New Opportunities.**

Like many organizations that depend on face-to-face fundraising events to elicit financial support and build relationships, the COVID-19 pandemic challenged us to rethink our plans for the year. Our response culminated in transitioning our programs to virtual experiences and creating new opportunities.

Much to our surprise and delight these virtual events allowed even more donors, lupus warriors, and their families and friends to attend, participate and share reactions in a real-time environment, while remaining safe at home.

## **Livestream to End Lupus**

Game On! to End Lupus united streamers from around the world to play video games and use their platforms to talk about lupus, show support for people with lupus and raise money for the Lupus Foundation of America. In May we held our first three-day event that consisted of 36 streamers all coming together to raise money for the fight against lupus.

WALK  
TO END  
LUPUS  
NOW

WHY I WALK:

FOR



## Virtual 6 Challenge

Many of the races, walks and marathons that people had planned to participate in were canceled this year. That's why we launched the Virtual 6 Challenge – encouraging lupus warriors, their families and friends, to run, walk, bike or even paddleboard for 6 miles in the first 6 days of September. This goal was inspired by the fact it takes an average of six years for someone to receive a correct lupus diagnosis from the first time they notice their symptoms. Over 500 challengers participated in this virtual endurance event, raising critical funds for lupus research, education and support programs.



## Raising Awareness for Lupus, One Mask at a Time

Even the simplest act can have a huge impact.

As part of Lupus Awareness Month, the Foundation conducted a month-long fundraising campaign to not only raise funds to support our important work, but to provide an opportunity for donors to help raise awareness of lupus and follow public health recommendations when they wore our new facemask.

We offered an exclusive branded face mask as an incentive to help people with lupus, and their loved ones, bring awareness to this disease while staying safe. This new opportunity welcomed new donors, brought back past supporters, and emboldened current donors to support our mission even more.

*“For me, participating in Team Make Your Mark’s Virtual 6 Challenge this fall brought me a motivating challenge, but more importantly a community of lupus warriors that continues to be a source of positivity, inspiration and support.”*

— JILL, LUPUS WARRIOR AND TEAM MAKE YOUR MARK VIRTUAL 6 CHALLENGE FINISHER



*“When I was first diagnosed with lupus, I knew I wanted to give back but didn’t know how. Live streaming on Twitch has given me the platform to do my part in finding a cure. I’m so grateful for the opportunity to drive awareness to so many people around the world.”*

— COCOCONFESSION, TWITCH FUNDRAISER AND 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](https://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](https://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](https://WalktoEndLupusNow.org).

## Make Your Mark™

Use your passion to raise funds for lupus through a local event, special occasion, athletic competition or whatever you have in mind to make your mark in the fight against lupus.

[Lupus.org/MakeYourMark](https://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](https://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 \$615 million for lupus research and education in the past five years. Become an advocate to raise your voice in support of people with lupus. Visit [Lupus.org/Advocacy](https://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 critical lupus research that improves the lives of millions. To become a partner, contact Desiree Wienand, Director of Corporate Relations, at 202-557-0819 or via email at [wienand@lupus.org](mailto: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](https://Lupus.org/Donate).

## Planned Giving

With a planned gift to the Lupus Foundation of America, you can combine your desire to help those touched by lupus with your retirement and estate planning goals.

Visit [Lupus.org/PlannedGiving](https://Lupus.org/PlannedGiving) or contact Leigh Ann Cardenas at 202-349-1153 or via email at [cardenas@lupus.org](mailto:cardenas@lupus.org).

## Follow Online

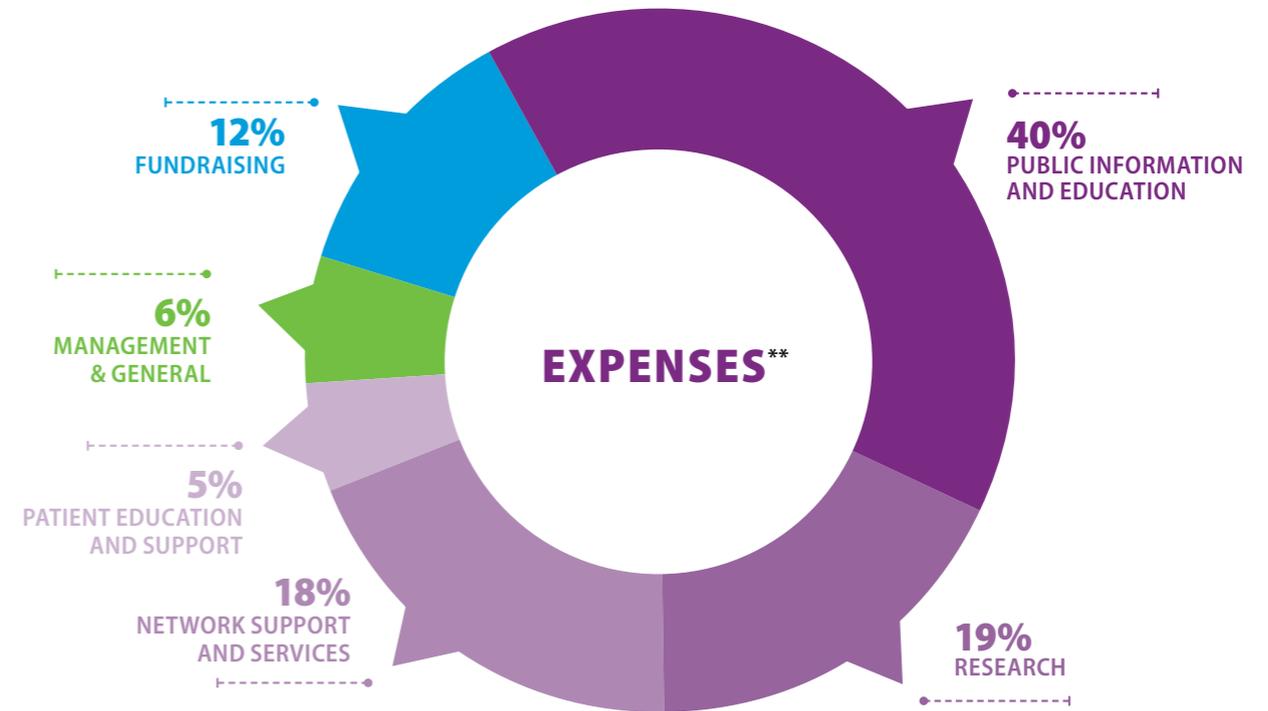
 [LupusFoundationofAmerica](https://LupusFoundationofAmerica)

 [LupusOrg](https://LupusOrg)

 [LupusOrg](https://LupusOrg)

 [LupusFoundation](https://LupusFoundation)

# FINANCIAL HIGHLIGHTS



## LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2019

<b>REVENUE AND SUPPORT</b>	<b>\$17,423,486</b>
<b>EXPENSES</b>	
Program Services:	14,172,971
Public Information and Education	6,960,834
Network Support and Services	3,063,813
Research	3,219,669
Patient Education and Support	856,544
Professional Relations and Education	72,111
Management and General	1,027,330
Fundraising	2,074,387
<b>TOTAL EXPENSES</b>	<b>17,274,688</b>
<b>CHANGE IN NET ASSETS</b>	<b>148,789</b>
<b>NET ASSETS, BEGINNING OF YEAR</b>	<b>5,245,121</b>
<b>NET ASSETS, END OF YEAR</b>	<b>\$5,393,919</b>

## LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2019

<b>REVENUE AND SUPPORT</b>	<b>\$ 21,301,743</b>
<b>EXPENSES</b>	
Program Services:	16,986,481
Public Information and Education	7,911,392
Network Support and Services	2,925,813
Research	3,217,169
Patient Education and Support	2,859,996
Professional Relations and Education	72,111
Management and General	1,395,034
Fundraising	2,702,428
<b>TOTAL EXPENSES</b>	<b>21,083,943</b>
<b>CHANGE IN NET ASSETS</b>	<b>217,800</b>
<b>NET ASSETS, BEGINNING OF YEAR</b>	<b>7,815,364</b>
<b>NET ASSETS, END OF YEAR</b>	<b>\$ 8,033,164</b>

\*\*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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