

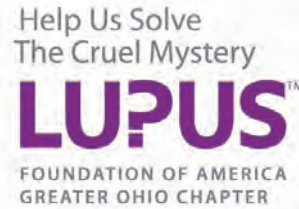


Help Us Solve
The Cruel Mystery
LUPUS[™]
FOUNDATION OF AMERICA
GREATER OHIO CHAPTER

UNWAVERING **IN OUR MISSION**

TO IMPROVE THE QUALITY OF LIFE
FOR PEOPLE WITH LUPUS

2019 – 2020 IMPACT REPORT



Life as we know it has certainly changed over the past year due to the onset of the COVID-19 pandemic. Anxiety has been at an all-time high, especially for lupus patients who are immunocompromised and susceptible to infections and illnesses like COVID-19. Despite the pandemic, we remain committed to our mission to improve the quality of life for all people affected by lupus through programs of research, education, and advocacy.

We have learned a great deal over the past year. The obstacles we faced together will certainly impact us for years to come. Like the rest of the world, our organization had to adapt to a new reality. The COVID-19 pandemic was like nothing the Chapter had ever seen. We were challenged with ensuring the 60,000 Ohioans had access to the resources and support they need, even though all fundraising and operations had ceased.

The Lupus Foundation of America, Greater Ohio Chapter (LFA, GOC), immediately responded by creating impactful digital programming with educational summits, social media campaigns, an enhanced website including up-to-date Covid resources, and much more. Staff and the network of patient navigators and facilitators spent time checking in with the most vulnerable lupus patients. It was challenging, but the Chapter was able to change course while continuing to support Ohio's lupus population.

The lupus community was also impacted by the shortage of the antimalarial drug hydroxychloroquine (Plaquenil) and chloroquine (Aralen) as they were investigated for the potential use in treating COVID-19. The Chapter responded by working with the LFA and the State of Ohio and Governor DeWine's office to ensure that lupus patients had access to their medications.

Additionally, this past year, there were important developments regarding potential treatments for lupus and lupus nephritis that have made tremendous progress. Stay tuned to LFA, GOC social media for important updates regarding these new treatments. The LFA continues to work towards ensuring people with lupus have safe and effective treatments.

As we reflect back on this year of uncertainty and the many challenges we faced, there is one word that comes to mind that reflects the strength of our lupus community. That word is resilience. We have come together in our darkest hours to overcome and persevere in the fight against lupus. Let us all be reminded of our strength, our community, and our continued commitment to fight against lupus. Thank you for being an important part of the lupus community. Together, we will make a brighter future for all people impacted by lupus.

Suzanne Tierney
CEO & President

Maria Woyma
Chair, Board of Directors



ENSURING ACCESS TO LIFE-SAVING MEDICATIONS

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, the LFA was 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

The LFA also engaged other critical stakeholders in the development and distribution of hydroxychloroquine (HCQ). One of the 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 the LFA:

- 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

Making Our Voices Heard

Across Ohio and the country, the community asked how they could help? More than 50,000 lupus warriors 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.

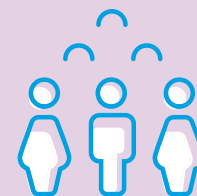
With this crisis, the LFA also recognized an opportunity to bring attention to the disease and the impact of COVID-19 on people with

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, the LFA 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:

- The Lupus Foundation of America, Greater Ohio Chapter became the first Chapter in the country to receive a line item in the state budget. Governor Mike DeWine signed H.B. 166 into law on July 17, 2019 creating the state's operating budget for the 2020-2021 biennium. Line item 440481 designated funding directly to the Lupus Foundation of America, Greater Ohio Chapter for lupus awareness.
- The LFA 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.



PROVIDING ANSWERS, RESOURCES AND HOPE

Lupus is a difficult disease to manage and is uniquely challenging. This past year, the onset of the COVID-19 pandemic, created even more questions and concerns for people with lupus. The LFA, GOC office temporarily closed, and all fundraising and education events were halted, all while patient demand for services increased.

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

The LFA, GOC responded by creating a COVID-19 portal on LupusGreaterOhio.org with real-time information from both state and federal resources so that patients could navigate the pandemic. Content was reviewed daily to ensure the most accurate and up-to-date information was available. In addition, the National Office also responded with both English and Spanish resources which were viewed more than 380,000 times through fall.

The LFA, GOC also provided regular email updates, responded to hundreds of email inquiries, and provided Q&A resources addressing top concerns as quickly as possible. Ohio's patient navigators also fielded questions and placed over 1000 patient wellness check calls to ensure our most vulnerable lupus patients had the support they needed.

Leveraging Social Media to Provide Critical and Timely Updates

The LFA, GOC launched a social media campaign addressing the pandemic. The focus was to ensure lupus warriors across Ohio had the latest, most up-to-date resources on both the state and federal level regarding the rapidly evolving situation. Posts created focused on the hydroxychloroquine shortage, protective measures, Ohio rules and regulations, CDC guidelines, travel warnings, disease-specific information, and much more.

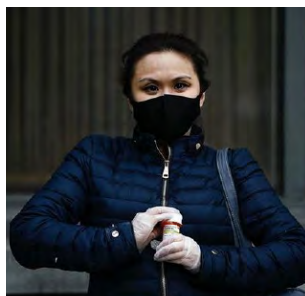


Together, we are **INSPIRED**.



Thanks to your support and funding from the State of Ohio, we:

- Hired and trained twenty patient navigators to provide support services and serve as a resource for the 60,000 lupus warriors estimated to be living with lupus in Ohio.
- Revamped in-person support groups to a digital format to ensure patients had the necessary resources and support during the pandemic without personal risk.
- Modified educational summits to digital, web-based programming which attracted over 500 attendees. Expert topics included: COVID-19, disparities, psychosocial concerns, telehealth, medications, and more.
- Provided Personal Protective Equipment (PPE) kits to summit attendees to help prevent spread of COVID-19.



"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



ADVANCING NEW TREATMENTS FOR LUPUS

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

Collaborating Across North America to Fund Innovative Research

Earlier this year, the LFA 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 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.

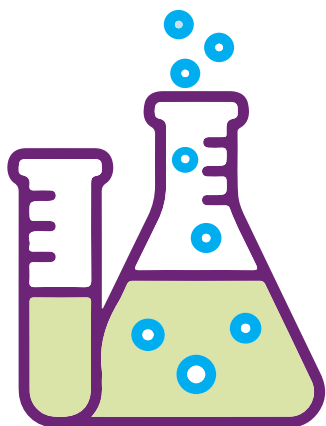
AWARDING PROMISING LOCAL RESEARCH

The Lupus Foundation of America Gary S. Gilkeson 2019 Career Development recipient was awarded to several researchers including Ohio's Emily Littlejohn, DO, MPH, a rheumatologist in the Department of Rheumatic and Immunologic Diseases and the Cleveland Clinic and Clinical Assistant Professor in the Cleveland Clinic Lerner College of Medicine at Case Western Reserve University. She directs the Cleveland Clinic Lupus Cohort (CCLC), a longitudinal bio repository that banks blood and urine of lupus patients and is co-director of the Lupus Clinic.

Dr. Littlejohn's overarching project goal is to acquire the expertise necessary to lead a clinical research program devoted to systemic lupus erythematosus (SLE) that will leverage advances in electronic health records and bioinformatics. Within the framework, the project will investigate the trends of antinuclear antibodies.



The aim of the project is to first apply electronic health record (EHR) phenotyping techniques of noisy labeling to construct a patient population that will be the substrate for longitudinal lupus research. From this cohort, authors plan to characterize longitudinal trends of ANA titers throughout the course of disease, both in patients with lupus and those who have "incomplete lupus" or are at risk for the disease. Authors will then investigate if the use of hydroxychloroquine is associated with changes in ANA positivity or strength over time. In addressing these aims, the authors hope to elucidate the utility of serial ANA testing in lupus patients and provide data to guide decision making related to ANA ordering.



Together, The LFA is Resolved: Thanks to your support the National organization:

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.



RAISING AWARENESS OF LUPUS

This past year, the LFA, GOC focused on ensuring lupus remained at the front of Ohio's public health agenda. Through lobbying efforts, we found that many Ohioans and legislators had heard of lupus but didn't know what it was. The LFA, GOC realized a need to educate and bring greater awareness, because to have **NO** lupus, we must first **KNOW** LupusResources and Answers to Meet Your Needs

Bringing Lupus to the Attention of Ohioans

Funding from the State of Ohio allowed the LFA, GOC to launch a major KNOW Lupus campaign directed at raising awareness of the disease. The campaign focused on educating the public on lupus and providing screening tools to determine if a person could possibly have lupus. The campaign utilized digital technology, SEO marketing and display advertisements that generated 125,000 impressions per month.

The LFA, GOC released "Be Fierce," a PSA campaign targeting those at risk of developing lupus, generating much needed awareness in underserved communities. A "Be-Fierce" minority-specific digital marketing campaign was also launched and targeted 30 minority-specific social media sites with a digital reach of 10,000+.

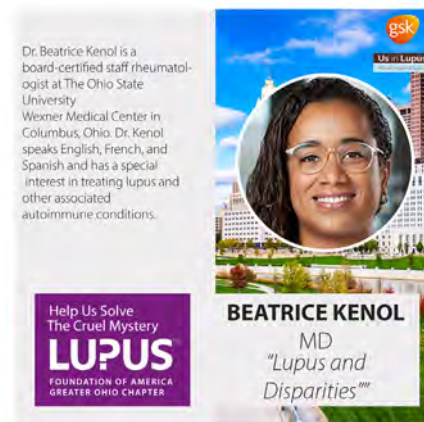
The LFA, GOC also launched a weekly "hot news" social media campaign with topics related to lupus which reached over 40,000 people.

Raising Awareness of Health Disparities

At the end of August, the LFA kicked off #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 LFA, GOC recognizes the importance of addressing health disparities and the disproportionate impact lupus has on people of color. Our efforts are focused on providing programming aimed at increasing access to care, reducing the time to diagnosis, and decreasing the burden that lupus has on communities of color. This past year, in addition to our digital media campaigns, we implemented diversity and disparities training to community leaders across the state and trained numerous minority organizations on the impact of lupus and how to recognize the symptoms.

The virtual education summit on June 13, 2020 with OSU Wexner Medical Center in Columbus also featured Beatrice Kenol, MD who presented on Lupus



and Disparities. Her talk focused on the statistics and causes of disparities, their geographic prevalence, and various resources and solutions.



Together, we are MOTIVATED. Thanks to you and our generous funders, we:

- Created a digital Living with Lupus magazine reaching 15,000 Ohioans with patient success stories, updates on medications and research, helpful tools, tips, resources, and more.
- Hosted three digital education summits and five in-person summits featuring over 15 lupus experts with a combined audience of over 620 attendees.



RALLYING SUPPORT TO HELP END LUPUS

The Lupus Foundation of America, Greater Ohio Chapter relies on the generous support of individuals, corporations, grants, and state funding to further our mission. Our existence isn't possible without you. We deeply appreciate our many donors who have participated in fundraising efforts and demonstrated their ongoing commitment to eradicating lupus. We know that this year has been difficult for so many, but you have helped to keep our momentum going, even during the pandemic. We couldn't be more grateful.

Transitioning Programs to Virtual Experiences and Creating New Opportunities

Like so many other organizations that depend on in-person fundraising events for financial support, the COVID-19 pandemic challenged us to rethink our fundraising plans for the year. Lupus patients have been particularly vulnerable during the pandemic and we soon came to understand that a virtual world was necessary not only for the foundation, but for the patients. Our response included transitioning all educational and support programming to virtual and telephonic platforms. The transition did not come without a few glitches, however, much to our surprise we found an increase in attendance at many of our programs. The virtual world brought out even more patients, friends, family members, and donors from across the state, while remaining safe at home.



Lupus Awareness Month

Lupus Awareness Month is an opportunity for the lupus community to join together to raise funds and awareness of the impact of lupus. Not only does awareness help bring about funding, but it helps reduce time to diagnosis by educating those who otherwise would have ignored symptoms or avoided seeing their doctor.

On May 1, 2020, the LFA, GOC kicked off Lupus Awareness Month with a “lupus facts” social media campaign. On May 14, 2020 Terminal Tower in Cleveland lit up purple to raise awareness and to kick off POP (Put on Purple) Day on May 15. For POP Day, the LFA, GOC initiated a #POPDaYOhio selfie challenge so constituents could show how they were raising lupus awareness. In addition, the LFA, GOC presented six hours of on the hour Facebook Live programming and #POPDaYOhio prize giveaways.

Furthermore, billboards and kiosks were placed across Ohio in key markets to generate awareness, education, and funding for lupus research.



LUPUS AWARENESS MONTH

WAYS TO GIVE & GET INVOLVED



We thank our supporters, volunteers and activists throughout Ohio who join with us year after year in the fight to end lupus. Without you, our work would not be possible. We are partners with a shared mission to improve the quality of life for all those affected by lupus.



Make a Gift

Visit www.LupusGreaterOhio.org or to donate by mail, send a check made payable to the Lupus Foundation of America, Greater Ohio Chapter, Inc. 12930 Chippewa Rd, Suite 4, Brecksville, Ohio 44141.

Start a Team and Register for the Walk to End Lupus Now®

The nation's largest lupus walk raises money for lupus research, increases awareness of lupus and rallies public support. Register today at www.LupusGreaterOhio.org.

Volunteer or Become an Advocate

We are always in need of volunteers and advocates! Make your voice heard by calling our office at 1 (888) NO-LUPUS for more information or fill out an application online at www.LupusGreaterOhio.org.

Become a Member

Your membership with the LFA, GOC, Inc. comes with a long list of benefits aimed to help ease your lupus journey. Your membership also supports us as we fight for a cause and a cure. Find out more at www.LupusGreaterOhio.org.

Planned Giving

To discuss options for leaving a lasting legacy, e-mail us at info@LupusGreaterOhio.org or call 1 (888) NO-LUPUS.

Stay Aware of the Fight to End Lupus. Follow us at:

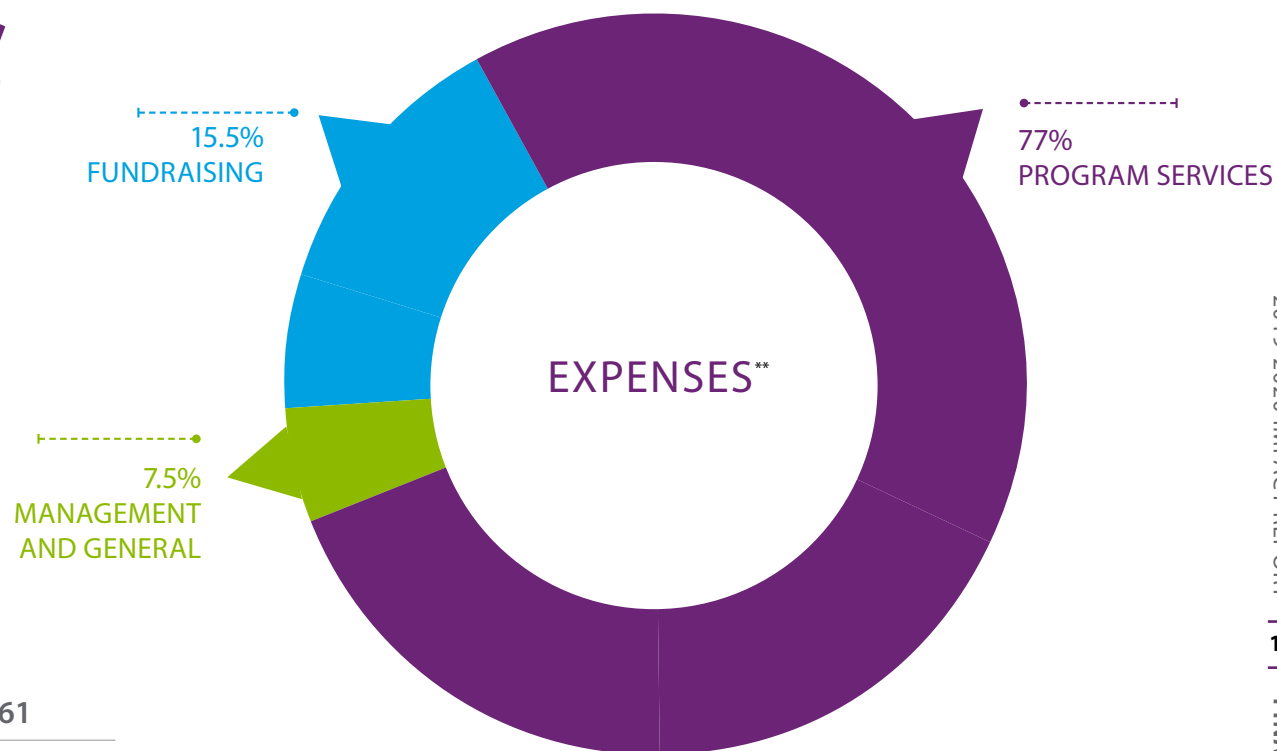
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FINANCIAL HIGHLIGHTS

LUPUS FOUNDATION OF AMERICA, GREATER OHIO CHAPTER

Statement of Activities For the Year Ended September 30, 2020

REVENUE AND SUPPORT	\$397,161
EXPENSES	
Program Services:	\$373,515
Management and General	\$36,284
Fundraising	\$75,450
TOTAL EXPENSES	\$485,249
CHANGE IN NET ASSETS	- \$88,088
NET ASSETS, BEGINNING OF YEAR	\$193,996
NET ASSETS, END OF YEAR	\$105,908



ADVOCACY & AWARENESS



RESEARCH & SCIENTIFIC INITIATIVES



EDUCATION & SUPPORT SERVICES

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North Carolina Chapter
Charlotte, NC

Pacific Northwest Regional Office
Seattle, WA

Philadelphia Tri-State Chapter
Philadelphia, PA

Southern California Regional Office
Los Angeles, CA

Texas Gulf Coast Chapter
Houston, TX

Wisconsin Chapter
Milwaukee, WI

Help Us Solve
The Cruel Mystery

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GREATER OHIO CHAPTER

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12930 CHIPPEWA RD,
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WWW.LUPUSGREATEROHIO.ORG

MISSION:

The Lupus Foundation of America, Greater Ohio Chapter is dedicated to improving the quality of life for all people affected by lupus through programs of research, education, and advocacy.