Impact Report
2021-2022

Help Us Solve
The Cruel Mystery

LUPUS™

FOUNDATION OF AMERICA
GREATER OHIO CHAPTER

CHRIS BURTON, *diagnosed age 24*

We can build each other up and encourage each other.

"It was incredibly empowering to share my journey with lupus during Men's Health Month to raise awareness of how lupus impacts men, and the importance of support. I hope I inspired other men to join a support group, so we can build each other up and encourage each other."

— CHRIS BURTON, LFA ambassador, diagnosed with lupus in 2012

People with lupus drive the mission of the Lupus Foundation of America and are at the center of everything we do. Their experiences, journey, and hope shape our work. We actively seek their insights as we develop resources, programs, tools, and objectives. Throughout this 2021-2022 Impact Report, you will see lupus warriors at the center - sharing their experiences, voices, impact, and involvement as **one community**.

Help Us Solve
The Cruel Mystery

LUPUS®
FOUNDATION OF AMERICA

The Lupus Foundation of America has an ambitious goal: Improve the quality of life for all people affected by lupus and ultimately bring an end to this cruel mystery. That's not an easy task, but it's one that we don't shy away from either. We also know that working together with people with lupus, caregivers, researchers, health care professionals, government leaders, corporations, public health organizations, and other partners invested in the cause is critical to reaching our goal.

In this annual report, we reflect on our efforts to achieve our mission while working alongside truly amazing supporters that make up the lupus community. We've highlighted activities from the past year that raise voices of those impacted by lupus to improve access to care and reduce medication expenses, empower people with lupus to take steps to manage their care and help advance research, and unite the global community to raise awareness of lupus and engage in activities to help bring an end to this devastating disease. Among our accomplishments this year *together with our national organization, we present the following as it reflects our partnership on a national level and the local level.*

- We launched a first-of-its-kind online self-management program for people with lupus.
- We developed new programs to increase participation in lupus clinical trials among racial and ethnic minority groups.
- We continued to fund research and support researchers at every stage of their career while funding groundbreaking mesenchymal stromal cell research.
- We identified new ways of delivering services to expand our reach - both in-person and virtual.
- We worked with local and global community leaders to implement programs to address health disparities - including helping community health workers better understand the signs and symptoms of lupus, and piloting a new patient navigator program in under-resourced communities.
- We held our first-ever Advocacy Leadership Symposium, bringing together chapters and "grasstops" leaders from key states and congressional districts focused on funding critical lupus programs.
- We put breaking lupus research news in the hands of lupus researchers, health care providers and the broader lupus community through our preeminent scientific journal, *Lupus Science & Medicine* and our daily lupus research news service, Inside Lupus Research.

We invite you to learn more about our impact in this year's annual report and read perspectives from people with lupus and how we are working to meet their needs and amplify their voices.

We are committed to staying connected to those impacted by lupus to ensure our work addresses their needs and unites the lupus community so that we bring an end to this disease.

Suzanne Tierney
President and CEO

Maria Rey Woyma
Chair, Board of Directors

MICHELLE COOPER, *diagnosed age 23*

Uniting The Patient Voice

> *"It's always so energizing to advocate for myself and for everyone with lupus, and to see our voices make a real difference. This year our advocacy efforts, including at the 2022 Summit, helped push provisions that will lower drug costs across the finish line, impacting millions of Americans living with chronic diseases like lupus."* — **MICHELLE COOPER, Lupus Advocate**

Since it was established in 2005, Medicare's prescription drug benefit, Part D, has not included a cap on out-of-pocket spending for its more than 48 million beneficiaries, which includes thousands of people with lupus whose treatment regimens on average include eight medications. The Foundation and its lupus advocates from across the nation have long advocated for this cap and for a "smoothing" mechanism that allows beneficiaries to spread out the costs of medications over the entire year, rather than being owed at one time. On August 16, President Joe Biden signed into law the Inflation Reduction Act which included a $2,000 out-of-pocket cap and a smoothing mechanism!

For people with lupus on Part D plans, the cap could save them thousands each year. Thanks to all of our advocates who made this victory possible, including Michelle and the nearly 400 who advocated for these very policies with members of Congress throughout the year and as part of the **2022 Digital Lupus Advocacy Summit** in June!

THIS YEAR WE ALSO...

- Generated nearly **$20 million in federal funding for lupus research and education programs,** as well as an additional $45 billion for the National Institutes of Health, the largest public funder of lupus research in the world.
- Hosted two important advocacy events, including the 2022 Digital Lupus Advocacy Summit, resulting in **nearly 300 meetings with members of Congress** to continue securing their support for more lupus research and education programs.
- **Expanded our State Advocacy Program in 19 states** to help the Foundation advance legislative and regulatory initiatives specifically focused on ensuring access to high quality and affordable care. For example, we championed state issues to prohibit step-therapy, co-pay accumulators and other policies that limit patient choice and access, including achieving a significant victory in Kentucky to limit step therapy.
- Continued to grow our **national grassroots network, which now consists of more than 40,000 dedicated lupus advocates**. These highly-engaged advocates live in every state and Congressional District.

DÁMARYS SEMPRIT, *diagnosed age 22*

Opportunities to Make a Difference in Research

> *"I joined RAY to be an active part of the solution in the fight against lupus. RAY is designed to move lupus research forward with the power of our lupus experience and journey, making it possible for lupus warriors to be directly involved in shaping future treatments and care."* — **DÁMARYS SEMPRIT, joined RAY in 2021**

RAY: Research Accelerated by You, is our online lupus data platform where people with lupus and caregivers share their experiences to help researchers accelerate the development of new treatments, improve disease outcomes and inform regulatory decision-making. It's critical that we continue to push for a wider arsenal of lupus treatments because we know that this disease impacts everyone differently and one medication may not work for all. This year, we saw continued growth of RAY with nearly 500 new enrollees that are helping to shape the development of future cutting-edge research endeavors.

We continued our efforts to understand the patient journey on a more granular level through adding a longitudinal survey to RAY that allows us to collect information on RAY participants every six months to better see health patterns and trends. We also conducted a data analysis of RAY to see the similarities and differences of those enrolled in RAY, gaining important insights into the diagnosis and treatment experiences of people with lupus, and the impact of the disease on their quality of life.

And this year we also...

- Hosted a global drug development forum with more than 20 leading lupus experts and patients as part of the Foundation's Phase III work on the *Addressing Lupus Pillars for Health Advancement* (ALPHA) Project. **Together, we worked towards identifying new ways to improve clinical trial outcome measures that prioritize the patient voice, are applicable in pediatric lupus clinical trials, and better discriminate therapeutic effects**.
- Continued to see promising results from a trailblazing, Lupus Foundation of America funded study of mesenchymal stromal cells as a potential new therapy for lupus. Based on positive Phase I results which showed minimal side effects, **the study has now transitioned to a multicohort Phase II trial where 41 patients were treated in the first cohort and had no serious safety concerns in Cohort 1 without major side effects and 10/40 have been treated in Cohort 2.**
- **Reported on over 80 articles through our research news bureau *Inside Lupus Research***, bringing the most important research news to people impacted by lupus. Articles ranged from drug development and disease management to health disparities and COVID-19 impact.
- **Increased diversity among the LFA's Lupus Research Action Network (LRAN) and trained nearly 50 new members as peer-to-peer lupus research engagement specialists.** LRAN members work within local communities across the country to share information about the importance of lupus research and Lupus Warrior participation in clinical trials. They help to address barriers to enrollment in clinical trials, provide resources to learn about lupus research, and seek to increase clinical trial participation among racial and ethnic minority groups living with lupus.
- **Received an Impact Factor (IF) of 4.687** in June 2022 for our scientific journal, *Lupus Science and Medicine* (LS&M). An Impact Factor is the average number of times an article published in a journal has been cited by other authors and is one of the most important measures of success for a journal. This new IF for LS&M is the highest current ranking impact factor for any lupus-specific journal and is closely ranked among the most prominent journals in rheumatology. As of this year, LS&M has averaged 140,000 online visits per year and 5000+ mentions on social media and news outlets.


NYOBIE GORDON-RICKS, *diagnosed age 32*

> *"SELF is a wonderful tool for lupus patients. It has helped me stay informed about ways to manage my lupus, keep track of my symptoms and outline what I want to talk to my doctor about during my appointments."*
>
> **— NYOBIE GORDON-RICKS, Lupus warrior & one of 154 SELF pilot testers**

Self-management resources and tools have yielded positive results for hundreds of thousands of people with chronic conditions. Yet there is a significant unmet need for evidence-based, effective and widely available self-management programs for people with lupus. That's why we created - with guidance from people with lupus, their doctors, behavior change scientists, and other experts - Strategies to Embrace Living with Lupus Fearlessly (SELF). SELF is an online self-management program designed to help people with lupus build and enhance skills in four pillars of lupus self-management: managing symptoms, managing stress, managing medications and working with their healthcare team.

During the pilot evaluation phase of the program, **57 percent of users improved one or more self-management skills** to mastery. SELF evaluation participants also reported improvements in fatigue and communication with their health care team. SELF was officially launched in January 2022 and to date, **1546 people have taken steps to manage their disease with the help of SELF**.

We continually work to expand direct services that support people with lupus.

ALSO THIS YEAR WE...

- Saw significant results to address barriers to screening, treatment, and supportive care for individuals living with lupus thanks to the work of four Lupus Foundation of America chapters - Georgia, Philadelphia Tri-State, Greater Ohio and Indiana who **established community-focused patient navigator programs in under-resourced communities.**
- Developed **50 new and updated Spanish-language resources** on the National Resource Center for Lupus as part of our efforts to provide culturally and linguistically appropriate health educational materials to our Spanish-speaking constituents.
- Hosted free virtual education events with helpful resources and insights from medical experts through our virtual Lupus & You program. **This year there were more that 28,000 views of our programs that ranged from lupus and the skin to gut health.**
- Expanded our national network of 125 community-based support groups to include a **new support group designed specifically for youth living with lupus.** Through this new offering young Lupus Warriors are connecting with others their own age, sharing relatable experiences and relevant resources, and realizing they are not alone in their fight against lupus.

MARIA ALEJANDRA HERNANDEZ, *diagnosed age 21*

> *"Our journeys with lupus are incredibly powerful - they can help others struggling to feel less alone, it can provide the information someone needs to talk to their doctor if they suspect lupus and it can create change in lupus research. Having the opportunity to share my story on national news is an honor and helps me feel strong. Raising awareness of lupus is incredibly important and we never know who it will touch."*
>
> **— MARIA ALEJANDRA HERNANDEZ, LFA Northeast Region Ambassador**

Each year in May, the lupus community joins as one across the globe to educate the world about lupus during **Lupus Awareness Month**. Whether it's by chatting with a neighbor about the impact of the disease, sharing lupus facts on social media, presenting about the signs and symptoms of lupus to a community group, or participating in media interviews on a national level - every opportunity to raise awareness of lupus during May is powerful. This year, Northeast Region Ambassador and lupus warrior Maria Alejandra Hernandez shared a glimpse into her journey with lupus on NBC's *TODAY Show* and Telemundo's *Hoy Día*.

This past year, we...

- United to **Make Lupus Visible during Lupus Awareness Month**, highlighting different topics of the often-invisible ways lupus impacts everyday life, sharing resources and facts tied to each topic – including symptoms and diagnosis, impact on the body and quality of life.
- **Raised awareness across the world of the impact lupus can have on any organ in the body through a global survey** conducted by the World Lupus Federation. The survey of more than 6,700 people with lupus from over 100 countries found that 87% reported lupus impacted one or more major organs or organ systems.
- Engaged with more than **140 ambassadors across the country**, who worked in their local communities to raise awareness of lupus through speaking opportunities at community events and sharing information about the disease on social media.
- **Trained rheumatology nurses and other health care providers** on the importance of diversity in lupus clinical trials and armed them with resources to help increase awareness of and participation in trials among racial and ethnic minorities groups. This training was part of the Foundation's new program called Improving Minority Participation and Awareness in Clinical Trials (IMPACT+), which is being supported by an Office of Minority Health grant and aims to increase racial and ethnic minority participation in U.S. lupus clinical trials.
- Partnered, together with the LFA chapter network, with the National Association of Chronic Disease Directors and the National Association of Community Health Workers to **increase knowledge of lupus and lupus-self management resources to nearly 2,500 community health workers**.

Uniting to End Lupus

PATTI EGGLESTON, *diagnosed age 25*

> *"Following my lupus diagnosis, my rheumatologist thought it was a good idea to get involved with the Lupus Foundation of America (LFA), and in 2014 I attended my first Walk to End Lupus Now® event in Seattle. The support I've received since has left me speechless. This year we raised over $6,000!"*
>
> **— PATTI EGGLESTON, Lupus warrior and participant in Walk to End Lupus Now®**

Our Chapter in Ohio performed the boots on the ground work, some highlights include:

- Trained 20 patient navigators and facilitators from across the state.
- Executed hundreds of Chapter " wellness calls" to those isolated during the pandemic.
- Assisted in removing barriers to care through transportation to doctors appointments, medical financial assistance, and mental health assistance.
- Provided education to Community Health Workers about lupus.
- Provided online monthly education programs for patients.
- Worked along side University Hospitals and MetroHealth Hospital to do virtual educational summits in the spring and the fall to those impacted by lupus

And this year we also...

Created a new and innovative digital footprint

1. A new enhanced website was created with the focus on Ohio www.lupusgreaterohio.org.
2. Presented a podcast series that has real conversations with those we serve and experts on lupus.
3. A blog was added to our projects. Allowing readers many options to gain insightful information about living with lupus.
4. Our Living With Lupus Magazine went digital so all could view online.
5. Monthly newsletters were sent to over 16,000 Ohioans each month, each filled with resources, educational opportunities, research, and support.
6. Awareness projects across the state that included digital billboards to draw attention for every to" Know Lupus".

Ways to Give & Get Involved

MAKE A GIFT

Send your donation payable to the Lupus Foundation of America, **Greater Ohio Chapter, 12930 Chippewa Road, Brecksville, Ohio 44141, you can double your donation at www.doubleyourdonation.com.**

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 **www.lupusgreaterohio.org.**

Remember us for your year-end giving gifts.

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. **Help us raise support in Ohio for our line item in the state budget.**

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**, Greater Ohio Chapter.**

HONOR A LOVED ONE

A donation to the Lupus Foundation of America**, Greater Ohio Chapter** 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.

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.

To become a partner, contact Suzanne Tierney, CEO at Suzanne@lupusgreaterohio.org or (888) NO-LUPUS or via www.lupusgreaterohio.org

follow online

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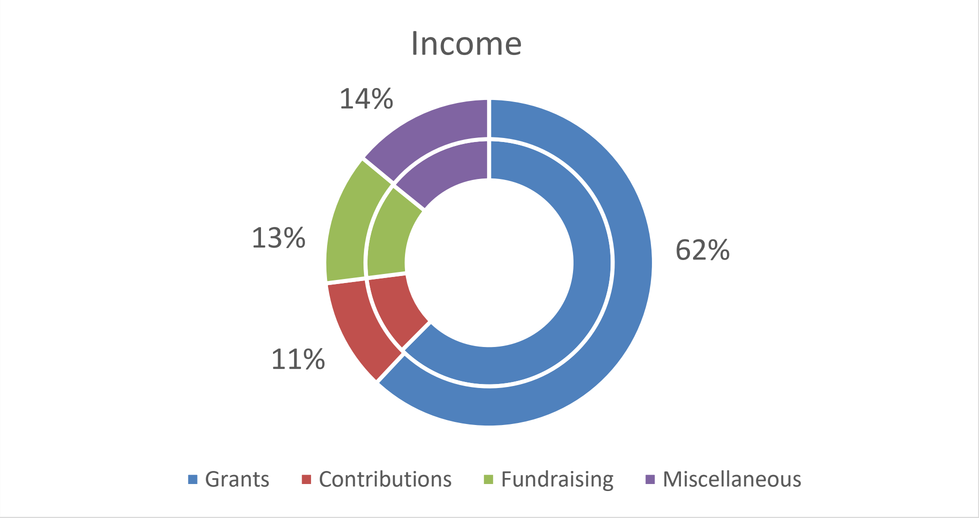
LUPUS FOUNDATION OF AMERICA GREATER OHIO CHAPTER

STATEMENT OF ACTIVITIES

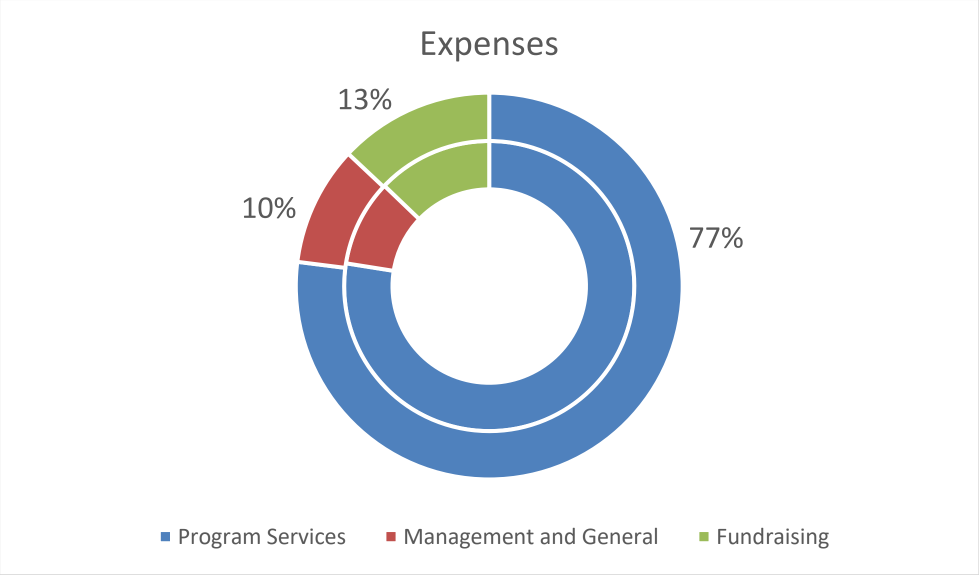
For the Year Ended September 30, 2022



INCOME

Grants	398696	62%
Contributions	67298	11%
Fundraising	81846	13%
Miscellaneous	90460	14%

REVENUE AND SUPPORT	**638,300**



EXPENSES

Program Services	468,076	77%
Management and General	58,233	10%
Fundraising	77,587	13%

TOTAL EXPENSES	**603,896**
CHANGE IN NET ASSETS	34,414
NET ASSETS, BEGINNING OF YEAR	143,373
NET ASSETS, END OF YEAR	177,787

Leadership

Lupus Foundation of America, Greater Ohio Chapter Inc.

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Albert Einstein College of Medicine

F. Jorge Sanchez-Guerrero, M.D., M.S.
University Health Network, Toronto

Ignacio Sanz, M.D. Emory University

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Duke University School of Medicine; Duke Clinical Research Institute

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University of North Carolina at Chapel Hill

Sara Tedeschi, M.D., M.P.H.
Brigham and Women's Hospital; Harvard Medical School

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Medical University of South Carolina

George C. Tsokos, M.D.
Beth Israel Deaconess Medical Center

Victoria P. Werth, M.S., M.D.
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Heartland Chapter
St. Louis, MO

Indiana Chapter
Indianapolis, IN

Lone Star Chapter
Addison, TX

New Jersey Chapter
Livingston, NJ

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North Carolina Chapter
Charlotte, NC

Pacific Northwest Regional Office
Seattle, WA

Philadelphia Tri-State Chapter
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Texas Gulf Coast Chapter
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Wisconsin Chapter
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