

Help Us Solve  
The Cruel Mystery

**LUPUS**<sup>TM</sup>

FOUNDATION OF AMERICA  
GREATER OHIO CHAPTER



# One Community TO END LUPUS

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2018 – 2019 IMPACT REPORT

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In 2018 the Lupus Foundation of America, Greater Ohio Chapter (LFA, GOC) finished our partnership with RAMA Consulting and the Ohio Department of Health which focused on implementing portions of the 2016 Lupus Needs Assessment recommendations. We completed a tremendous amount of work that lasted several years including; forming over 50 partnerships with state and healthcare agencies; educating over 460 healthcare professionals across Ohio on lupus; holding statewide lupus summits which attracted over 400 participants; and distributing a lupus toolkit to over 5000 healthcare providers in Ohio.

Yes, we accomplished a great deal, but we are not done! In fact, 2019 was a monumental year for the LFA, GOC. We embarked on an uncharted course that produced a fruitful outcome. During November of 2018, we began the process of lobbying for funds in the Ohio State Budget to come directly to the Lupus Foundation of America, Greater Ohio Chapter. We took a bus loaded with over 50 advocates and spent a long, tiresome, yet highly educational day at the Ohio statehouse where we met with both state senators and representatives. What did we learn? A great deal. First and foremost, we learned that our work is not done. Most of the legislators had heard of lupus, but didn't really know what it was. So, we decided to go back and educate them. After many months and many trips to the Ohio Statehouse meeting with legislators, our efforts paid off. On July 18, 2019, HB 166 was passed creating the state of Ohio operating budget for 2020 and 2021 which included a lupus earmark for \$193,120 for each year of the budget. Our constituents will see many exciting programs during 2020 and 2021 and we look forward to bringing them to you.

The Lupus Foundation of America is also hard at work advocating for lupus patients on a national level with an aggressive research-focused agenda. More information is included in this impact report.

In addition to our many advocacy efforts, the LFA, GOC staff was busy raising awareness, fundraising, and educating our friends across the state. We held three successful Walk to End Lupus Now® events in Cleveland, Cincinnati, and Columbus. We held eight educational summits, multiple third-party fundraisers, the Liberty Mutual Golf outing, participated in many Lupus Awareness Month events including POP Day and World Lupus Day, and much, much more. In addition, we provided monthly support groups and new patient education meetings across the state.

Simply put, there is never a dull moment at the LFA, GOC. We are busy making sure we are reaching out to our most important constituents, lupus patients and their caregivers. As always, you are at the heart of all we do and we are so grateful to have met and worked with so many of you. We are also incredibly thankful for our funders and their continued support of the lupus mission. Remember, we won't stop until there is a world without lupus. This is our commitment to you.



Suzanne Tierney CEO & President  
Board of Directors



Maria Woyma Chair,  
Board Chair, Medical Director



# One Community TO END LUPUS

## \$2.4M

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**SECURED FROM THE CENTERS  
FOR DISEASE CONTROL  
AND PREVENTION** for studies to  
determine lifetime impact of lupus on  
children and teens.

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**FIRST-OF-ITS KIND**  
study sets research agenda  
for childhood lupus.

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It will take the hard work of many people and organizations to end lupus. That's why the Lupus Foundation of America is so proud of all the work that we are accomplishing alongside our partners. This year we took many bold steps towards a cure.

### ENDING CHILDHOOD LUPUS

This year, there were many bold steps taken towards finding a cause and a cure for lupus, especially for children and teens. Lupus tends to be more severe and aggressive in children than adults. There is still so much unknown about how lupus affects children, especially long-term.

While there is much more to learn, this year the Lupus Foundation of America (LFA) saw major advancements that will expand the research effort on childhood lupus and improve the treatment and care of children with lupus. This year, we partnered with CARRA (Childhood Arthritis and Rheumatology Research Alliance) to publish the results of a year-long effort focused on identifying and prioritizing the top research needs in childhood lupus. The study, "Research Priorities in Childhood-Onset Lupus: Results of a Multidisciplinary Prioritization Exercise" identified the most urgent areas needing 5 research in childhood lupus as nephritis (inflammation of the kidneys), clinical trials, biomarkers,



neuropsychiatric disease and skin. Additionally, the U.S. Centers for Disease Control and Prevention (CDC) awarded a three-year \$2.4 million grant to CARRA to support a patient registry that will allow us to understand the lifetime impact of lupus on children and teens who are living with the disease. The funds to support this CDC grant to CARRA are a direct result of our work with Congress to dedicate more resources to childhood lupus research and the tireless efforts of lupus warriors who participate in year-round advocacy initiatives.

## **FDA APPROVES USE OF BENLYSTA® FOR CHILDREN AND TEENS WITH LUPUS**

In the spring of 2019, the U.S. Food and Drug Administration (FDA) approved BENLYSTA for use in children and teens with the disease. This approval represents a major advancement for treating childhood lupus. BENLYSTA is the only therapy developed specifically for lupus, and was first approved by the FDA in 2011 for use in adults. Prior to this approval, children and adolescents only had access to older medications that were developed for other diseases and had never been tested in children with lupus.



“There are important differences between adults and children, and significant knowledge gaps limit our understanding of the best treatments and long term outcomes in children with lupus. That’s why it was important for the pediatric lupus community to come together and publish for the first time what areas of research can have the greatest impact for children with lupus.”

— AIMEE HERSH, Chair of  
the CARRA Systemic Lupus  
Erythematosus Committee



“The ALPHA Project establishes global consensus among people with lupus and professionals and is an essential first step towards creating a clear and focused path forward for more timely and accurate diagnosis, greater access to care and improved treatment options for people living with lupus.”

— KENNETH A. GETZ, MBA, Center for the Study of Drug Development at Tufts University School of Medicine

## INCREASING PARTICIPATION IN CLINICAL TRIALS

Lack of participation in clinical trials remains a key barrier to the development of new treatments. Through the Foundation’s Center for Clinical Trial Education, we provide resources for people with lupus who are interested in learning more about clinical trials. As part of our efforts, the Foundation partnered with several pharmaceutical companies, including Eli Lilly, Gilead and Imperial/Mallinckrodt on clinical trial education and awareness initiatives to educate people about current trials happening across the country. Currently, more than 40 companies are investigating potential therapies for lupus, and participation in clinical trials is crucial to furthering lupus research. The LFA also saw promising news when AstraZeneca announced positive trial results in the summer of 2019 for the Phase III TULIP 2 trial for anifrolumab, a potential new medicine for treatment of moderate-to-severe lupus in adults.

## IDENTIFYING THE BARRIERS TO LUPUS CARE AND TREATMENT

This year, the Foundation brought together experts from 20 countries to provide the first-ever global consensus on key issues that will address barriers to improving lupus diagnosis, care and treatment development. The Addressing Lupus Pillars for Health Advancement (ALPHA) Project released its report this summer. The ALPHA Project is a collaboration with Tufts University School of Medicine Center for the Study of Drug Development and a Global Advisory Committee (GAC). This study provides an actionable framework to advance the lupus field. Experts agreed upon the five top barriers to improving outcomes in lupus including: lack of diagnostic biomarkers, flawed clinical trial design, lack of access to clinicians familiar with lupus, lack of treatment adherence and barriers to effective management of lupus due to socioeconomic status. In the coming years, thanks to supporters like you, the ALPHA Project will focus on identifying actionable solutions to each of these barriers.





# One Community TO MAKE OUR VOICES HEARD

We must remain vigilant in our efforts to make lupus a national health care priority. Thanks to our constituents, we have a track record of success in opening new sources of federal funding and partnering with federal agencies and members of Congress to work on developing a comprehensive approach to lupus care and treatment.

## **SUCCESS IN LOBBYING FOR STATE FUNDING**

We fight on a state level to make sure lupus stays in front of Ohio legislators and remains a priority. In November of 2018, a bus loaded with fifty advocates from across the state met with legislators to lobby for step-therapy reform and funding for lupus. After many months and many trips to the Ohio Statehouse meeting with legislators, our efforts paid off. On July 18, 2019, HB 166 was passed creating the state of Ohio operating budget for 2020 and 2021 which included a lupus earmark for \$193,120 for each year of the budget. Our constituents will see many exciting changes during 2020 and 2021 and we look forward to bringing them to you.





## **FIGHTING FOR STEP-THERAPY REFORM IN OHIO**

The Lupus Foundation of America, Greater Ohio Chapter joined forces with a coalition of over 50 patient and physician groups to advocate for step-therapy reform. On January 4, 2019, Governor John Kasich signed Senate Bill 265 into law. Ohio now joins 18 other states that have enacted laws that regulate the use of step therapy. Step therapy is a process where health insurers deny coverage of physician prescribed medication, requiring patients try other more affordable medications first. The patient must fail those medications before they can receive the prescribed medication. This process prevents timely access to prescribed medications. This was a major victory for Ohio lupus patients!

## **ENSURING ACCESS TO AFFORDABLE MEDICATIONS**

We fight on a national level to ensure people with lupus have access to affordable medications. That's why 15 years ago the LFA convened MAPRx, a coalition of more than 60 national family, patient advocacy and health professional organizations committed to strengthening and protecting Medicare Part D. Medicare Part D is the

prescription drug benefit of Medicare signed into law by President George W. Bush in 2003 to help millions of Americans who rely on Medicare to get the medications they need at an affordable cost. In September 2018, President Bush spoke at a special summit the LFA hosted with our MAPRx coalition partners to celebrate the 15th anniversary of the enactment of Medicare Part D.

## **NEW FUNDING FOR LUPUS RESEARCH AND EDUCATION**

Thanks to thousands of grassroots advocates across the country, the LFA continued to increase and generate new funding for lupus research and education. This past year the LFA secured:

- **\$7.5 million** for the National Lupus Patient Registry Program at the Centers for Disease Control and Prevention
- **\$1 million increase** from 2018 funding;
- **\$5 million** for the Lupus Research Program at the Department of Defense;
- **\$39.1 billion** for the National Institutes of Health, which is expected to provide nearly \$128 million for lupus research;
- **\$2 million** for the Office of Minority Health's National Health Education Lupus Program.





# One Community TO RAISE AWARENESS

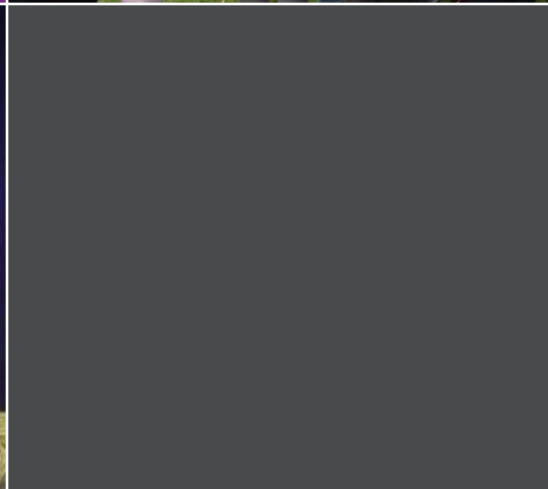
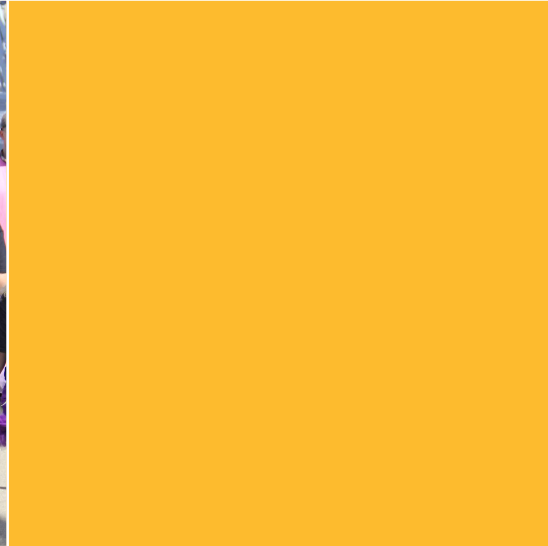
Increasing public awareness of lupus is vital, not only to getting people diagnosed and treated sooner, but for ensuring the disease gets the attention and resources it needs. We need to continue to engage support from all corners — foundations, corporations, media, celebrities, community organizations and individuals who are impacted every day by this devastating disease.

## INCREASING AWARENESS AMONG COMMUNITIES AT-RISK FOR LUPUS

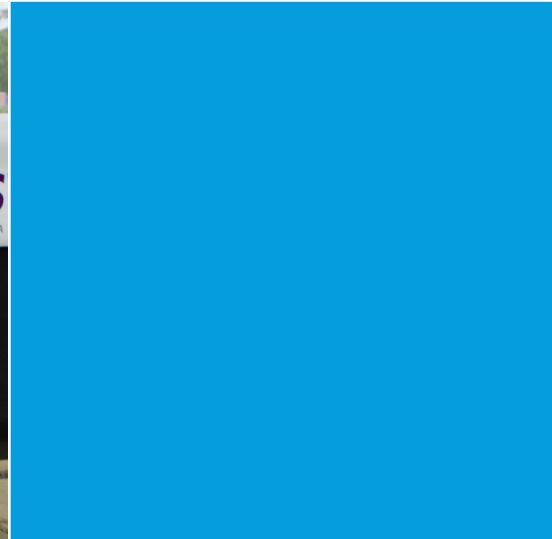
Hispanics and African Americans are at a two-to-three times greater risk for lupus, making awareness and outreach into those communities crucial. This year, the LFA forged a new partnership with Minor League Baseball (MiLB). The program, ¡Adiós Lupus!™ is an engagement initiative designed to reach out to the Hispanic community who frequent minor league ballgames. The LFA was the first official charity partner of MiLB's Copa de la Diversión, a program designed to embrace the culture and values of the participating teams' Hispanic/Latino communities. On a national level, 66 teams from 28 states, including Ohio, participated and reached more than 377,000 fans.

On May 16, 2019 the LFA, GOC spent the kickoff to POP Day with MiLB team the Lake County Captains at Classic Park in Eastlake, Ohio. Support group facilitator, Pam Mendicino threw the first pitch. The Captain's mascot Skipper dressed as a lupus hero. Our staff had the opportunity to connect with many people to bring lupus awareness.











54M

**IMPRESSIONS** through  
the Be Fierce. Take Control®  
awareness campaign, across the nation.

50

**THE NUMBER OF  
ATTENDEES** at the first Ohio  
minority health lupus summit.

In addition, the LFA continued the ongoing, "Be Fierce. Take Control.®" campaign to raise awareness of the signs and symptoms of lupus among young Latino and African American women. The Centers for Disease Control and Prevention supported program also seeks to empower individuals with the resources to take the next step if they suspect they may have lupus. On a national level, the campaign reached an estimated audience of 54 million through social media, digital advertising and public service announcements in English and Spanish.

In Ohio, the LFA, GOC held a "Be Fierce. Take Control.®" lupus summit at Stephanie Tubbs Jones Health Center in East Cleveland. Dr. Van Warren of University Hospitals was the featured speaker. In addition, Michael Liner Esq and Andrew November, Esq of Liner Legal spoke on, "Lupus and Social Security Disability". Finally, the LFA, GOC spoke regarding "Health Disparities and Lupus". The event was successful in reaching minority communities, creating awareness, and educating lupus patients on how to better navigate their illness.

be  
fierce  
TAKE CONTROL





# One Community TO SUPPORT & EDUCATE

The LFA, GOC is your partner on your journey with lupus. We are here to listen and to make sure that everyone touched by lupus gets the resources, services and support they need. Our work has earned public trust and our advice is credible and authoritative.

## REGISTERED NURSE AND HEALTH EDUCATOR OFFERS SUPPORT AND GUIDANCE

The LFA, GOC is one of the few Chapters in the United States that has an in-house Registered Nurse (RN) to help educate and answer questions about lupus. Leslie Tierney, RN responds to thousands of phone calls, provides in-person New Patient Education classes, leads digital education programs, speaks at lupus summits, and attends additional clinical lupus training programs to ensure that patients across Ohio have access to the most recent, up-to-date information on lupus available. As both a nurse and health educator, Ms. Tierney strives to answer every inquiry with empathy and expertise. In addition, she collects necessary demographic information which provides agencies such as the Ohio Department of Health and the Ohio Commission on Minority Health with necessary data to aid in the care of lupus patients.

# 1.5K

**THE NUMBER OF PEOPLE**  
that reached out to the LFA, GOC  
office for more information.

# 587

**THE NUMBER OF ATTENDEES**  
at support groups and New Patient  
Education.



"The LFA, GOC is a reliable resource for the 60,000 lupus patients and their caregivers across Ohio. We ensure that the most up-to-date information on lupus is available. Our office stands ready to assist when called. We understand that people with lupus need support beyond what they receive from their healthcare providers. We strive to work alongside the medical community to help empower patients. We assist providers by delivering access to education and supportive tools that patients can depend on."

— LESLIE TIERNEY, VICE PRESIDENT OF OPERATIONS, LFA, GOC

# 25K

### THE NUMBER OF PEOPLE REACHED

through LFA, GOC social media.

## MODEL OF EXCELLENCE

The LFA, GOC serves as a model of excellence and leader among chapters in responding to patients and providing resources. This past year, we spent countless hours fielding calls and distributing inquiry packages to patients and caregivers across Ohio. We distributed over 500 inquiries and responded to over 1000 calls during the year. We provided approximately 200 in-person and telephonic support groups and attended many health fairs across Ohio in addition to the Ask the Experts series. We also reached over 25,000 people on Facebook, Instagram and Twitter. We announced multiple action alerts, distributed a monthly newsletter to over 9,500 people and worked tirelessly with state legislators to keep the fight against lupus alive.

## A NEW PROGRAM TO REACH HEALTH PROFESSIONALS

On a national level, LFA partnered with Medscape Education to develop and promote a Certified Medical Education (CME) program for health care providers and a patient education program called "Clinical Advances in Systemic Lupus Erythematosus." The goal of the program is to improve symptom and disease

management and empower patients to communicate and be an effective member of their health care team. The program launched in the summer of 2019, reaching more than 53,355 physicians and healthcare professionals, and 34,906 participated in the program. After completing the program, 86 percent of health care professionals said they plan to modify treatment and screening practices, and 87 percent said they would recommend the activity to others. After completing the program, 86 percent of health care professionals said they plan to modify treatment and screening practices, and 87 percent said they would recommend the activity to others.

## LAUNCH OF NEW PATIENT-FOCUSED WEBSITE

At the end of 2018, we joined with the LFA to roll-out a new and improved website. LupusGreaterOhio.org is now faster and optimized for mobile device viewing and social media sharing. The website is full of medically sound content and enhancements which include more responsive design and enhanced navigation to better connect visitors with information.





# One Community TO FIGHT LUPUS



## BUILDING A COMMUNITY OF LUPUS WARRIORS

In Ohio, the LFA, GOC continues to build a community of lupus patients, caregivers, family members, friends, community members and healthcare professionals. This year, we hosted many gatherings including three major walks across the state in Cleveland, Columbus, and Cincinnati. The Walk to End Lupus Now® events are our biggest fundraisers and a fan-favorite amongst lupus patients. As in previous years, the walks were days of great joy and unity. Patients felt a sense of community and realized that they were not alone in their fight.

In addition, the staff and our volunteers were busy raising awareness, fundraising, and educating our friends across the state. We held eight educational summits, multiple third-party fundraisers, the Liberty Mutual Golf outing, participated in many Lupus Awareness Month events including POP Day and World Lupus Day, and much, much more. In addition, we provided monthly support groups and new patient education meetings across the state.

Our story is not over until there is a world without lupus. Until then, we must do our best to come together and create a community of lupus warriors. We do that together, as one, and invite you to come along. Remember, there is no “I” in lupus, just “us”.



“The Walk to End Lupus Now® means coming together with my family and friends to show that none of us are in this fight alone. I’m proud to stand beside my fellow lupus warriors as we raise awareness and fundraise for this cause that is so important to so many of us.”

— AMANDA KEPIC,  
LUPUS WALK PARTICIPANT



## THANK YOU TO OUR MAJOR DONORS

*The Lupus Foundation of America, Greater Ohio Chapter wants to extend our sincerest gratitude to the following individuals and organizations whose generous contributions make our mission possible.*

Assurant, Inc.  
DRS Enterprises, Inc  
GlaxoSmithKline  
Harmony Homes Realty  
Liberty Mutual Insurance  
Progressive Insurance  
The Golland Estate  
The Insurance Industry Charitable Foundation  
The Juanita Byrnes Estate  
The MetroHealth System  
The Ohio Commission on Minority Health  
The Ohio Department of Health  
The Sam J Frankino Foundation  
Top Dawg Delivery and Logistics  
University Hospitals Cleveland Medical Center  
Us in Lupus

## JOIN THE COMMUNITY

### Make a Gift

Visit [www.LupusGreaterOhio.org](http://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](http://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](http://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](http://www.LupusGreaterOhio.org).

### Remember us in your Will and Estate Planning

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

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



[facebook.com/lupusgreaterOH](https://facebook.com/lupusgreaterOH)



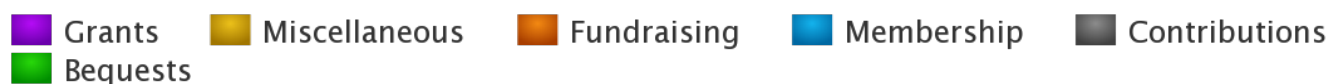
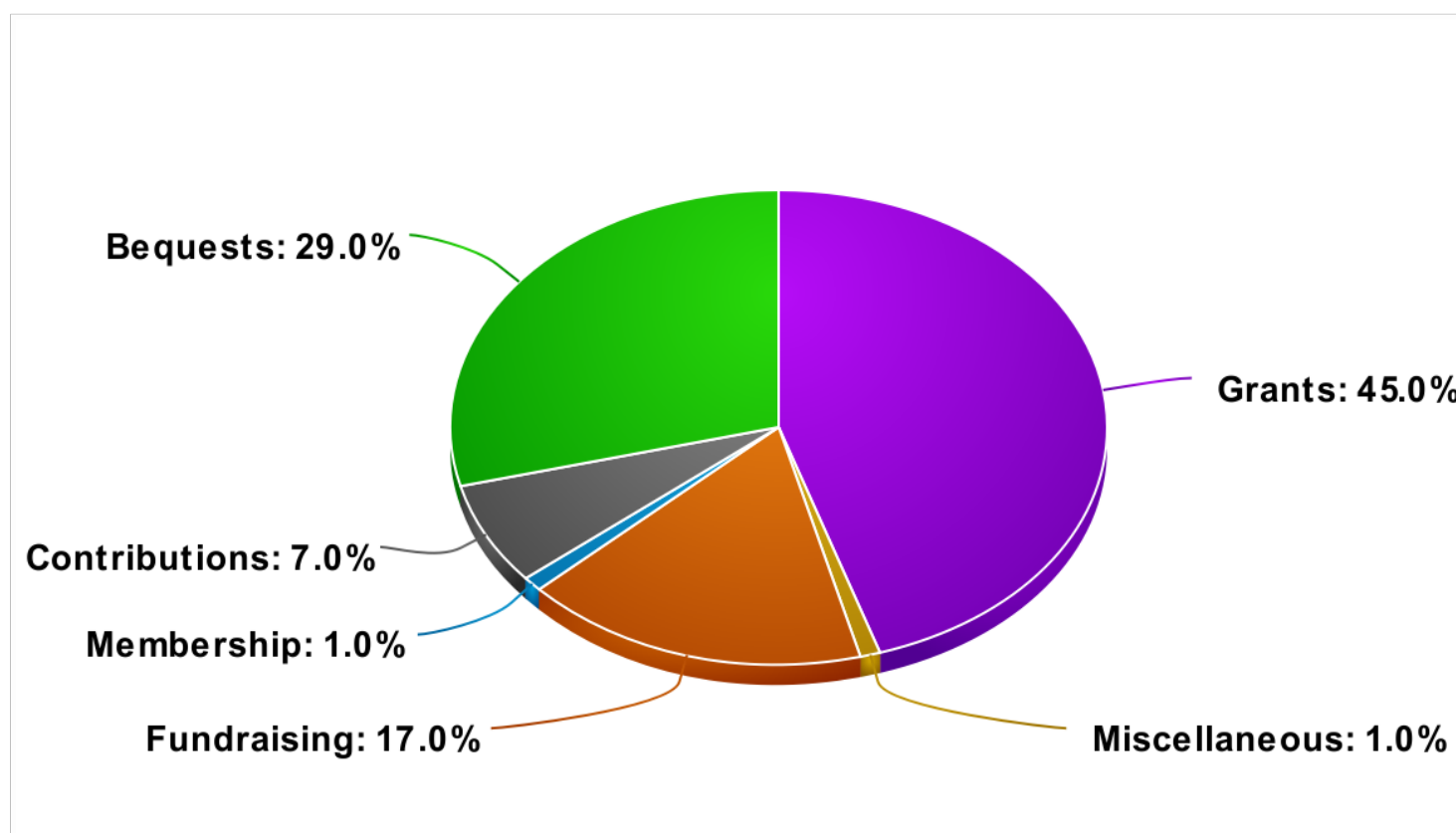
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[twitter.com/lupusgreaterOH](https://twitter.com/lupusgreaterOH)



## Financial HIGHLIGHTS



### LFA, GOC FINANCIAL HIGHLIGHTS: INCOME

Statement of Activities For the Year Ended September 30, 2019

#### INCOME

Grants	276,463
Contributions	42,139
Bequests	177,691
Fundraising	111,424
Membership	3,250
Miscellaneous	2,705
<b>TOTAL INCOME</b>	<b>613,672</b>

### LFA, GOC FINANCIAL HIGHLIGHTS: EXPENSES

Statement of Activities For the Year Ended September 30, 2019

#### EXPENSES

Program Services	340,012
Management and General	32,756
Fundraising	59,307
<b>TOTAL EXPENSES</b>	<b>432,075</b>

A complete copy of the audited financial statements is available online or upon request by calling 1 (888) NO-LUPUS or writing to Lupus Foundation of America, Greater Ohio Chapter 12930 Chippewa Rd. Suite 4, Brecksville, Ohio 44141.

# LFA, GOC BOARD OF DIRECTORS & MANAGEMENT

- Maria Rey Woyma**, Chair of the Board
- Mark Wester**, Treasurer
- Diana Fleming, MSN, RN**, Secretary
- George Sagaris**, Director
- Jeannine Valenti**, Director
- Stanley Ballou, MD**, Medical Advisor/Director
- Lisa Bordner**, Director
- Rachel Scava**, Legal Advisor/Director
- Mark Shelton**, Director
- Gregory Tavrell**, Director

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## LFA, GOC MANAGEMENT STAFF

- Suzanne Tierney, President & CEO**  
President/CEO
- Leslie Tierney, RN**  
VP of Operations/Patient Navigator
- Kathy Holmes**  
Finance Manager

# MEDICAL-SCIENTIFIC ADVISORY COUNCIL

- |   |  |
|---|--|
| <b>STANLEY BALLOU, MD</b><br>MetroHealth Medical Center | <b>TRINE JORGENSEN, PhD</b><br>Cleveland Clinic      |
| <b>ABBY ABELSON, MD, FACR</b><br>Cleveland Clinic       | <b>NORA SINGER, MD</b><br>MetroHealth Medical Center |
| <b>HOWARD EPSTEIN, MD</b><br>Cleveland Clinic           | <b>HOWARD SMITH, MD</b><br>Cleveland Clinic          |
| <b>RULA HAJJ-ALI, MD</b><br>Cleveland Clinic            | <b>VAN WARREN, MD</b><br>University Hospitals        |

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## NATIONAL NETWORK

- |   |  |
|---|--|
| <b>National Headquarters</b><br>Washington, DC  | <b>New Jersey Chapter,</b><br>Livingston, NJ                   |
| <b>Florida Chapter,</b><br>Boynton Beach, FL    | <b>Northeast Regional Office,</b><br>New York, NY              |
| <b>Georgia Chapter,</b><br>Atlanta, GA          | <b>North Carolina Chapter,</b><br>Charlotte, NC                |
| <b>Greater Ohio Chapter,</b><br>Brecksville, OH | <b>Pacific Northwest Regional Office,</b><br>Seattle, WA       |
| <b>Heartland Chapter,</b><br>St. Louis, MO      | <b>Philadelphia Tri-State Chapter,</b><br>Philadelphia, PA     |
| <b>Indiana Chapter,</b><br>Indianapolis, IN     | <b>Southern California Regional Office,</b><br>Los Angeles, CA |
| <b>Iowa Chapter,</b><br>Des Moines, IA          | <b>Texas Gulf Coast Chapter,</b><br>Houston, TX                |
| <b>Lone Star Chapter,</b><br>Dallas, TX         | <b>Wisconsin Chapter,</b><br>Milwaukee, WI                     |
| <b>Mid-South Chapter,</b><br>Nashville, TN      |  |



***We honor those from our lupus community  
that have passed.***

*Gary Bellino*

*Jane Benovich*

*Laverne Boeing*

*Charles Cook*

*Shermane Dishman*

*Lashaydra Edmonson*

*Kristine Faust*

*Jim Foliano*

*Laura Graham*

*Rocco Gualtieri*

*Karen Horvath*

*Carol Legan*

*Charlene Molitoris*

*Cheryl Ostrowski*

***May they rest in eternal peace.***

*Brad Petticrew*

*Brenda Phillips*

*Albino Pinesi*

*Nancy Roth*

*Thelma Smith*

*Michelle Spallino*

*Robert Stone*

*Sherry Valenti*

*Durant Valenti*

*Theresa Vandver*

*Jennie Virant*

*June Wright*

*Michael Yeager*

*Johanna Zambory*

Help Us Solve  
The Cruel Mystery  
**LUPUS**<sup>TM</sup>

FOUNDATION OF AMERICA  
GREATER OHIO CHAPTER

**LUPUS FOUNDATION OF AMERICA, GREATER OHIO CHAPTER**

12930 CHIPPEWA ROAD, BRECKSVILLE, OHIO 44141

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MAIN: (440) 717-0183

**LUPUSGREATEROHIO.ORG**