A future with NO LUPUS

TOGETHER, WE WILL GET THERE

Help Us Solve The Cruel Mystery

LUPUS™
FOUNDATION OF AMERICA
GREATER OHIO CHAPTER

LUPUS FOUNDATION OF AMERICA,
GREATER OHIO CHAPTER, Inc.
2015 – 2016 Annual Report
DEAR FRIEND OF THE LUPUS FOUNDATION OF AMERICA, GREATER OHIO CHAPTER:

The Lupus Foundation of America, Greater Ohio Chapter (LFA, GOC) continues to be on the leading edge of the fight to end lupus. Our mission remains clear: to improve the quality of life for all people affected by this cruel and mysterious disease through programs of research, education, and advocacy. Lupus is a complex and devastating illness. It requires comprehensive medical care and intense support from multiple resources for patients. We remain steadfast in our commitment to people with lupus and finding a cause and cure for this disease.

We are making progress! The LFA, GOC works closely with our national office in Washington D.C. on initiatives to accelerate lupus clinical trials and bring us closer to finding a cause and cure for lupus. Our strategic plan continues to focus on disease-specific and patient-centric goals, including reduce the time to diagnosis and ensure people with lupus have an arsenal of safe and effective treatments.

We are a strong voice for people with lupus! We reach out daily to our patients through multiple avenues and are singular in our focus to spread lupus awareness. This past year we had the privilege of working with RAMA Consulting, Inc. to conduct the Ohio Department of Health Lupus Needs Assessment, a project to document the personal and public burden of lupus and inform implementation strategies to better serve this community in the next biennium. We look forward to implementing the results of this assessment in 2017!

People with lupus are at the heart of everything we do! This past year the LFA, GOC offered more than 300 support groups with over 1000 participants throughout the state of Ohio. We continue to introduce educational and support programming that is designed to meet the needs of our constituents. All of these efforts help patients get answers to their questions and manage the complexities of living with lupus. Most importantly, it helps them know they are not alone.

We want to thank you for your continued support in helping the LFA, GOC accomplish our vision of a world without lupus.

Sincerely,

Suzanne Tierney,
President & CEO

Lupus Foundation of America, Greater Ohio Chapter, Inc.
LUPUS IS AN URGENT NATIONAL PUBLIC HEALTH ISSUE

Lupus is hidden from view, has a range of symptoms, no known cause and no known cure. In short, it is a cruel mystery. And while lupus can strike anyone at any time, 90 percent of people who develop lupus are young women in the prime of life. The effects of lupus and the medications used to treat the disease are devastating: disability, interruption of careers and infertility.

Smart, effective research is the key to solving the cruel mystery and ending its brutal impact. We challenge what isn't working, while supporting and funding lupus research that is most hopeful — all designed to get treatments in the hands of people with lupus faster and improve their quality of life.

We are determined to bring an end to lupus, while providing answers, support and hope to all affected. Whether an individual has just been diagnosed or has been living with the disease for 10 years, we are your partner every step of the way.

Every day we work toward a future with no lupus. Together, we will get there.
## FINANCIAL HIGHLIGHTS

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

Statement of Activities For the Year Ended September 30, 2016

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
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<tr>
<td><strong>REVENUE AND SUPPORT</strong></td>
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<td><strong>EXPENSES</strong></td>
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<td>Program Services</td>
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<td><strong>CHANGE IN NET ASSETS</strong></td>
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<td><strong>NET ASSETS, END OF YEAR</strong></td>
<td>$61,313</td>
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</table>

**80%** PROGRAM SERVICES

**7%** MANAGEMENT & GENERAL

**13%** FUNDRAISING

A complete copy of the audited financial statements is available online or upon request from the Lupus Foundation of America, Greater Ohio Chapter, Inc by calling 1 (888) NO-LUPUS.

**This reflects the program expenses for the LFA, GOC**
RESEARCH:
2015-2016 RESEARCH INITIATIVES

This year, our national network focused its attention on and resources on a variety of lupus research topics. One very exciting project; “Healthy Mind Healthy You: A Dose Finding Study of Mindfulness”, was initiated by Patients, Advocates, and Rheumatology Teams Network for Research and Service (PARTNERS), which aims to improve healthcare and advance medical knowledge in the field of pediatric rheumatology. PARTNERS, which the LFA is a member of, will take part in a $4 million research project to determine the optimal type and frequency of mindfulness-based treatment for managing stress.

The importance of mindfulness has been recognized as one of the top research priorities by the Institute of Medicine, especially for those with chronic diseases. Lupus patients will often say that flares are accompanied or induced by high levels of stress.

Other exciting research news to report include two research grant recipients that were awarded by the LFA’s Peer-Reviewed Medical Research Grants Program. The LFA supports and awards lupus research areas where gaps in scientific knowledge about lupus exist or that have not received adequate funding. During 2015-2016, the LFA supported two Ohio research projects! More details are provided on the following page.

Information regarding all current funding and research projects can be found by going to www.Lupus.org/research.

“We believe that this research project has the potential to improve patient outcomes and we are proud to be a partner in this initiative,” said Sandra C. Raymond, Lupus Foundation of America President and CEO regarding the PARTNERS “Healthy Mind Healthy You” study.
"Effector Functions and Cellular Targets of Pathogenic Plasmacytoid Dendritic Cells in Lupus" 2015 LIFELINE Grant Program

This grant is made possible, in part, by funds provided by the Lupus Foundation of America, Greater Ohio Chapter and is presented in memory of Kassie McMullin Biglow. Dr. Jorgensen’s project will investigate how the mechanisms of immune cells called plasmacytoid dendritic cells, found to be elevated in people with lupus, may lead to the development of lupus.

2015 Adult Stem Cells

This grant is made possible in part by funds provided by the Lupus Foundation of America, Greater Ohio Chapter. Dr. Singer’s project aims to develop biomarkers that can sensitively detect the therapeutic effect of adult stem cells on people with childhood and adult onset lupus. She will use these biomarkers to develop a test that can be used in clinical trials of mesenchymal stem cells for lupus.
SHINING A LIGHT ON LUPUS: CREATING COMMUNITY AWARENESS

Each year, the Lupus Foundation of America, Greater Ohio Chapter spends many hours creating awareness through our Walk to End Lupus Now™ (WTELN) events. We hold WTELN events in Cincinnati, Columbus and Cleveland every year. Not only are the WTELN events our biggest fundraiser, but they are also a way for people with lupus and their families to connect with other patients and join together with one unified purpose to end lupus. This past year our walks helped us to raise over $175,000 towards accomplishing our mission of improving the quality of life for all people affected by lupus through programs of research, education, and advocacy.

We also create awareness each May by celebrating Lupus Awareness Month. Lupus Awareness Month is an annual observance to call attention to lupus. May 10th we celebrated World Lupus Day and on May 20th we encouraged friends and supporters across the state of Ohio to Put on Purple™ (POP). News stations, offices, schools and employees across the state wore purple to bring awareness and encourage others to ask questions about lupus.

Other events in May included a Wrestle for the Cure event and “Light it Up Purple” where neighborhoods and businesses put purple light bulbs outside their houses and places of employment to encourage lupus awareness. Finally, the Terminal Tower in Cleveland was lit up purple for lupus awareness and the Cincinnati Reds hosted a lupus awareness night. May, 2016 was an exciting month filled with lupus outreach and awareness.

WAYS TO JOIN THE FIGHT

Make a Gift
Send your donation payable to the: Lupus Foundation of America, Greater Ohio Chapter, Inc. 12930 Chippewa Rd., Suite 4 Brecksville, Ohio 44141 or make your gift online at lupusgreaterohio.org

Become a Member
Your membership comes with many benefits and supports us as we fight for a cause and a cure.

Start a Walk Team and Register for the Walk to End Lupus Now™
To join Ohio’s largest lupus walk visit lupusgreaterohio.org

Remember Us in Your Will
Visit lupusgreaterohio.org for more information or contact (440) 717-0183

Be a Corporate Sponsor
Contact Leslie Tierney, VP of Operations at (440) 717-0183 or leslie@lupusgreaterohio.org

Be an Advocate
Make your voice heard and contact us to be a local advocate at (440) 717-0183 or visit lupusgreaterohio.org

Third Party Events
Host a third-party event/fundraiser for the LFA, GOC. Visit lupusgreaterohio.org
EDUCATION: BUILDING STRONG COMMUNITIES

Lupus can be isolating.

Living with its pain and fatigue causes many people to withdraw from their friends and family. People don’t always understand that just because “you don’t look sick” that you really are.

That’s why connecting people with lupus to each other is so important. It lets them know they are not alone and that they can learn from others living with this disease. With chapters and regional offices across the country, the LFA, GOC is on the "frontline" towards building a community of people living with lupus and connecting them to each other as well as lupus experts.

“This year we live in a world where education is at the tips of our fingers. Research is being done to help the community better understand lupus, and to find better diagnostic tools and proper medications. With this progression we are now hopeful that one day we can unlock the mystery to find a cure…”

— Leslie Tierney, VP of Operations and Patient Navigator at the Lupus Foundation of America, Greater Ohio Chapter

This year, the LFA, GOC hosted a busy year filled with programming designed to meet the needs of people with lupus across the state of Ohio. We held over 300 support groups with over 1000 participants. We held four educational summits in Cleveland, Akron, Columbus and Cincinnati. We also hosted monthly New Patient Education classes which provide newly diagnosed lupus patients and their families with information about lupus, and how to live well with the diagnosis.

We also worked daily to answer patient phone calls, mail literature and reach out to physician offices in order to ensure people with lupus have the most up-to-date information relevant to their journey with lupus. We also attended health fairs and distributed important lupus educational literature to the community.

It continues to be our goal to ensure that people with lupus know they are not alone and have the tools necessary to manage their disease. Lupus is tough enough already. By providing invaluable support and resources to people on the local level we ensure that no one with lupus has to go through the journey alone.

OUR NATIONAL NETWORK

The Lupus Foundation of America National Network is composed of affiliated chapters, community partners, regional offices and national support groups in communities throughout the United States. As a united force, we lead a nationwide movement to solve the cruel mystery of lupus and improve the quality of life for all people who suffer from its brutal impact.

California Office
Connecticut Chapter
Farmington, CT
DC/MD/VA Chapter
Washington, DC
Florida Chapter
Boynton Beach, FL
Georgia Chapter
Smyrna, GA
Greater Ohio Chapter
Brecksville, OH
Heartland Chapter
St. Louis, MO
Indiana Chapter
Indianapolis, IN
Iowa Chapter
Des Moines, IA
Kansas Community Partner
Wichita, KS
Lone Star Chapter
Dallas, TX
Mid-South Chapter
Nashville, TN
National Office
Washington, D.C.
New Jersey Chapter
Springfield, NJ
New York
Regional Office
North Carolina Chapter
Charlotte, NC
Pacific Northwest Chapter
Renton, WA
Philadelphia
Tri-State Chapter
Jenkintown, PA
South Carolina Community Partner
Columbia, SC
Texas Gulf Coast Chapter
Houston, TX
Utah Chapter
Salt Lake City, UT
Wisconsin Chapter
Milwaukee, WI
ADVOCACY:
A NATIONAL BLUEPRINT FOR ACTION

The Lupus Foundation of America, Greater Ohio Chapter worked tirelessly in 2015-2016 to advocate for our cause throughout the state of Ohio and bring awareness to lupus. We held many events including POP Day on May 20th.

This past year, the LFA, GOC had the privilege of working with RAMA Consulting, Inc. to conduct the Ohio Department of Health Lupus Needs Assessment, a project to document the personal and public burden of lupus and inform implementation strategies to better serve this community in the next biennium. The project gave lupus patients and rheumatologists a “voice” by participating in focus groups across Ohio. The assessment revealed many areas that need improvement in order to give lupus patients the care and attention they need.

The Ohio Department of Health Lupus Needs Assessment will serve as a framework for the future education of front line physicians and allied health professionals who are often the first to see lupus patients. The Assessment also gives lupus patients a voice. Lupus patients have been “heard” and now lobbyists and activists across the state of Ohio know where best to direct their efforts in order to create a better future for lupus patients.

The results of the Ohio Department of Health Lupus Needs Assessment have been released and a plan to roll them out is already in place for 2017.

“The voices across Ohio came together through seven focus groups. The validity of the patients’ concerns was finally heard. Together, we are here to help everyone with lupus be informed, engaged, and hopeful. We work to improve the quality of life for all people affected by lupus.”

— Suzanne Tierney, President and CEO of The Lupus Foundation of America, Greater Ohio Chapter.
LFA, GOC BOARD OF DIRECTORS & MANAGEMENT

Chair of the Board

Chair

President/CEO

Treasurer

Director

Director

Director

Director

Director

Director

Director

Director

Toll Free: 1(888) NO-LUPUS | Main: (440) 717-0183 | lupusgreaterohio.org
Help Us Solve The Cruel Mystery

LUPUS

FOUNDATION OF AMERICA GREATER OHIO CHAPTER

12930 Chippewa Rd., Suite 4
Breckville, Ohio 44141

Toll Free: 1(888) NO-LUPUS
Main: (440) 717-0183
Fax: (440) 717-0186

www.lupusgreaterohio.org