A future with NO LUPUS

TOGETHER,
WE WILL
GET THERE

LUPUS FOUNDATION OF AMERICA
2014 – 2015 Annual Report
DEAR FRIEND OF THE LUPUS FOUNDATION OF AMERICA,

For a world with no lupus, we must know lupus.

That’s why we are taking a smarter approach to lupus by focusing on understanding the underlying causes and funding research areas that will have the greatest impact for people living with lupus. We are dedicated to improving the way in which new drugs are developed and tested in order to get them into the hands of physicians and patients faster. In the pages that follow, you’ll read about one of our Foundation-funded researchers, Dr. Kathleen Sullivan, who is leading the way to better understanding lupus-related kidney disease in children and adolescents.

We are more committed than ever to making lupus a public health priority. We are working with government and industry leaders to make sure lupus receives the attention and funding needed to improve people’s lives. We also launched the KNOW LUPUS public awareness campaign that has already reached millions of Americans who now are learning about this devastating disease. Awareness is a year-round effort. We’re just getting started, and you will continue to hear more about the campaign and how you can raise awareness in your communities.

We do all of this while giving those living with lupus the support and resources they need to live better lives. Our website, Lupus Now® magazine, health educator network, support groups, and education programs are available to provide caring and educated support and the most up-to-date information on living well with lupus.

As we look forward to 2016 the challenges are daunting—federal funding for lupus research continues to be at risk and clinical trials need to be changed to reflect the complex realities of lupus so that safer and more effective treatments can get to those who need them most.

But we are confident that with your support, we will continue moving closer to our shared goal—a future with no lupus.

Thank you again for constantly inspiring us to do more for those touched by lupus. You truly make all of our good work possible.

Sandra C. Raymond
President and CEO

Conrad Gehrmann
Board Chair
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.
### LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2014

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<tr>
<th>REVENUE AND SUPPORT</th>
<th>$ 12,832,264</th>
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<th>EXPENSES</th>
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<td>Program Services</td>
<td>9,536,031</td>
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**This reflects the program expenses for the Lupus Foundation of America national office.**

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, 2000 L Street NW, Suite 410, Washington, DC 20036.

### LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

Statement of Activities For the Year Ended September 30, 2014

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<td>NET ASSETS, END OF YEAR</td>
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RESEARCH: PROGRESS FOR THE NEXT GENERATION

Speed is key. We challenge research that isn’t working and fund projects that will have the greatest impact. Our goal is to get treatments into the hands of people with lupus faster and improve their quality of life. Every bit of data, every research study, brings us one step closer to solving the cruel mystery of lupus.

Our research commitment includes directing attention and resources toward research studies on lupus in children and teens that will help build a future in which no child has to experience lupus. Because we recognize that lupus has heart-breaking implications for a child’s development and longevity, we are the first and only lupus advocacy organization in the United States with a dedicated childhood lupus research agenda.

This year, our pediatric research efforts were focused on lupus-related kidney disease in children and adolescents. Up to 80 percent of children and adolescents with lupus will develop lupus nephritis which, if not adequately controlled, can lead to kidney failure, the need for chronic dialysis or kidney transplantation, and even death.

Kathleen Sullivan, M.D., Ph.D., Professor of Pediatrics, Division Chief, Allergy and Immunology, The Children’s Hospital of Philadelphia, received a multi-year grant to develop a test to accurately diagnose and measure kidney disease activity in children with lupus. This would allow for more personalized care and less invasive treatment options.

Through your support, Foundation funded researchers like Dr. Sullivan will improve the quality of life for future generations and all people affected by the disease.

“The Foundation is addressing a critical need for the development of a diagnostic tool that could dramatically improve the quality of life for tens of thousands of children living with lupus nephritis.”

— Dr. Gary Gilkeson, Chair of the Lupus Foundation of America Medical-Scientific Advisory Council
LIFELINE Grant Program™

**BETTY P. TSAO, PH.D.**  
Professor of Medicine, The Regents of the University of California, Los Angeles, CA  
*This grant is presented in memory of Kassie McMullin Biglow.*  
Functional Genomics of SLE-associated GTF2IRD1/GTF2I

**JILL P. BUYON, M.D.**  
Director, Division of Rheumatology  
New York University School of Medicine  
New York, NY  
*This grant is the 2014 Lucy Vodden Research Grant Award, established in memory of Lucy Vodden by the Lupus Foundation of America and Julian Lennon.*  
Preventive Approach to Congenital Heart Block with Hydroxychloroquine: PATCH

**DIANE L. KAMEN, M.D.**  
Associate Professor of Medicine,  
Director of Clinical Research Medical University of South Carolina, Charleston, SC  
*This grant is presented in honor of The Cooper Family Foundation.*  
Impact of the Gut Metagenome on Autoimmunity

**MARK J. MAMULA, PH.D.**  
Professor of Medicine  
Yale University, New Haven, CT  
*This grant is made possible in part by funds provided by Lupus Foundation of America Connecticut Chapter.*  
Post-translational Modifications in Tolerance and Autoimmunity

**Michael Jon Barlin Pediatric Research Program**

**KATHLEEN SULLIVAN, M.D., PH.D.**  
Professor of Pediatrics, Division Chief, Allergy and Immunology, The Children’s Hospital of Philadelphia, Philadelphia, PA  
*This $500,000 multi-year grant is made possible through the generous support of the Wallace H. Coulter Foundation, in memory of Michael Jon Barlin. This grant is also made possible in part by funds provided by The Louis Berkowitz Family Foundation and the Lupus Foundation of America Philadelphia Tri-State Chapter through the generous support of the Scott James Exler Fund for Pediatric Lupus of The Philadelphia Foundation.*  
Urinary HER2 as a Biomarker for Lupus Nephritis

**Gina M. Finzi Memorial Student Summer Fellowship Program**

**MILENA GIANFRANCESCO**  
University of California, Berkeley, CA  
MENTOR: Lindsey Criswell, M.D., M.P.H.  
Causal Inference Approach to Study Disease Activity in Lupus

**JENNIFER MALL**  
Allegheny-Singer Research Institute, Pittsburgh, PA  
MENTOR: Joseph Ahearn, M.D.  
CVD Risk Factors and Events in the Pittsburgh Lupus Cohort Over 20 Years

**LAURA PLANTINGA**  
Emory University, Atlanta, GA  
MENTOR: S. Sam Lim, M.D., M.P.H.  
End-stage Renal Disease Incidence Among Newly Diagnosed SLE Patients

**PRITI PRASAD**  
University of California, Los Angeles, CA  
MENTOR: Ram Raj Singh, M.D.  
Analysis of Innate B cells in a Model of Chemically-induced Pulmonary Lupus

**DANIEL SHU**  
Temple University, Philadelphia, PA  
MENTOR: Philip L. Cohen, M.D.  
Expression of MAVS-inhibitory Protein NLRX1 in Systemic Lupus Erythematosus

**SHI SU**  
Boston University, Boston, MA  
MENTOR: Tamar Aprahamian, Ph.D.  
The Role of Retinaldehyde and Adipogenesis in Systemic Lupus Erythematosus

**Career Development Award**

**LAURA LEWANDOWSKI, M.D.**  
Duke University Medical Center, Durham, NC  
MENTOR: Laura E. Schanberg, M.D.  
PULSE: Pediatric Update on Lupus in South Africa: Epidemiology & Management

**LFA Collective Data Analysis Initiative (CDAI)**

**MIMI KIM, SC.D.**  
Professor and Head, Division of Biostatistics Department of Epidemiology and Population Health Albert Einstein College of Medicine of Yeshiva University and Montefiore Medical Center, Bronx, NY  
An Integrated Analysis of Data from Placebo Groups Participation in Multi-Center Clinical Trials for Lupus

**Lupus Insight Prize**

**BRUCE RICHARDSON, M.D., PH.D.**  
Professor of Internal Medicine, Division of Rheumatology Chief, Section of Rheumatology Ann Arbor Veteran Affairs Hospital  
Ann Arbor, MI  
Gene/Environment Interactions in Lupus
BATTLING LUPUS: CREATE A FUTURE WITH NO LUPUS

It’s not the first fight Shelbi Collin had against lupus, but it was by far the most fun.

On a warm late summer day, the Battle took place. There was family. There was barbecue. There were water balloons. Everyone got soaked.

And it was for a great cause—to raise awareness and support critical research for the Lupus Foundation of America through the inaugural Epic Water Balloon Battle Against Lupus™.

Her family’s efforts made Shelbi the top water balloon fundraiser in the country.

The Battle was a sweet moment for Shelbi. She has been living with lupus almost her whole life. She just didn’t know it. The aches and pains she experienced as a child were not just from playing sports. When she went away to college and devoted herself to her studies, they just didn’t go away. In fact, her health grew worse—she was constantly tired and simply didn’t have the energy of her peers. Doctors simply dismissed her worsening symptoms as “in her head.”

When she was 24, she was finally diagnosed. Everything she had experienced since she was a child now made sense.

Thanks to her treatment plan, Shelbi’s lupus is under control. Yet she knows that for so many others, lupus remains a painful struggle. To create a future with no lupus, she knows that there’s so much more to be done to raise awareness and support for critical research.

The Epic Water Balloon Battle Against Lupus is just one way that you can support the Lupus Foundation of America. Whether you host your own fundraiser, become a captain of a Walk to End Lupus Now™ team or make a donation, your financial support brings us one step closer to a future with no lupus.

“What could be better than raising money and awareness for lupus while soaking your family with water balloons?”
— Shelbi Collin of Plattsburg, NY

WAYS TO GIVE

Make a Gift
Send your donation payable to the: Lupus Foundation of America 2000 L St., NW, Suite 410 Washington DC, 20036 or make your gift online at lupus.org/donate

Become a Champion for Hope
Make a monthly donation online at lupus.org/donate

Start a Walk Team and Register for the Walk to End Lupus Now®
Join the nation’s largest walk, visit WalkToEndLupusNow.org

Make Your Mark™
Host an event and fundraise for the Lupus Foundation of America. Visit lupus.org/makeyourmark

Be a Corporate Sponsor
Contact Kathryn Douglas, Director of Corporate Relations at 202.525.9178 or douglas@lupus.org

Remember Us in Your Will
Visit lupus.org/plannedgiving for more information or contact 202.349.1153

Be an Advocate
Make your voice heard and visit our Legislative Action Center at lupus.org/advocacy
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.

“When people with lupus share experiences, we all learn from each other and are stronger as a community.”
— Annette Myarick, President and CEO, Lupus Foundation of America Philadelphia Tri-State Chapter

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 Foundation is on the frontlines, building a community of people living with lupus and connecting them to each other as well as lupus experts.

The Lupus Foundation of America, Philadelphia Tri-state Chapter provides information and advice to thousands of people every year living with lupus in Pennsylvania, Delaware and southern New Jersey.

Each person is connected to someone living with lupus. Each of their 11 support groups is led by someone with lupus. All support group leaders are trained by someone living with lupus. Their peer-to-peer model ensures that people with lupus are there to support each other.

Annual symposiums held in each state bring together hundreds of people living with lupus so that they can learn from each other how to live better. Programs are offered not just on health topics, but coping, social and psychological issues, and lupus and employment.

And each year on World Lupus Day in May, hundreds of activists and their families gather in front of Philadelphia City Hall to bring attention to the impact that this devastating disease has on people in their communities.

Lupus is tough enough already. By providing invaluable support and resources to people on the local level, our Philadelphia Tri-State Chapter and all of our chapters work every day to ensure that no one with lupus has to go through it 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.

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Georgia Chapter
Smyrna, GA
Greater Ohio Chapter
Brecksville, OH
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New York Regional Office
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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
AWARENESS: KNOW LUPUS

The road to no lupus starts with knowing lupus. This is the heart and message of the KNOW LUPUS campaign launched during May of 2015. Building awareness is essential to improve early diagnosis and treatment.

We have made progress, but it’s not enough. We need to continue to engage support from all corners—corporations, media, celebrities, community organizations, and individuals like you who are impacted every day by this devastating disease.

In less than a year, the campaign has generated more than 250 million impressions and $10 million in donated media across television, radio and billboards. The campaign has been seen in train stations, airports and subways across the country.

Amelia is just one of the millions of people across the country who has been touched by the campaign. After months of seeing the KNOW LUPUS ads and years of experiencing symptoms, Amelia is finally on the road to getting the answers and support she needs.

A centerpiece of the campaign is an online, animated and interactive challenge to engage audiences to KNOW LUPUS and make a donation to lupus research.

The campaign also features some of the best known stars of television and movies—including Whoopi Goldberg, the cast of Marvel’s Agents of S.H.I.E.L.D., Felicia Day, Ian Harding, and Project Runway host, Tim Gunn, and other Lifetime network stars.

“I saw the KNOW LUPUS advertisements on the train every day for months. After visiting your website I realized, I had every single lupus symptom and had been experiencing them for years. Thanks to your campaign, I may finally get the treatment I need. Thank you so much.”

— Amelia
ADVOCACY: A NATIONAL BLUEPRINT FOR ACTION

We are the leading voice for people with lupus and remain vigilant in our efforts to make lupus a national healthcare priority. Thanks to the thousands of lupus activists across the country our efforts have paid off. We have a track record of success in opening new sources of federal funding, and in recent years have stimulated a total of $74 million for lupus research and education.

This year, we saw unprecedented recognition from our nation’s leaders of the need for a comprehensive approach to lupus care and treatment. The Foundation partnered with the United States Centers for Disease Control and Prevention (CDC) and the National Association of Chronic Disease Directors (NACDD) to create the National Public Health Agenda for Lupus—the first ever national blueprint for all stakeholders to guide action in the fight against lupus.

While we have seen progress over the past decade, we still have much work to do to ensure a robust public health and well-funded biomedical research effort. The National Public Health Agenda serves as an action plan for the next decade and beyond. The Agenda provides far-ranging recommendations from improving data collection and research, to developing self-management programs and robust care coordination models and increasing public awareness.

In 2015, the Lupus Foundation of America was also awarded a multi-year, multi-million dollar grant from the CDC to implement recommendations outlined in The Agenda that will improve symptom recognition, diagnosis and quality of life for people living with lupus.

“Lupus is a complex disease that requires a coordinated and multifaceted approach. CDC is committed to enhancing the health and quality of life of people with lupus by supporting the strategies and recommendations outlined in the National Public Health Agenda for Lupus.”

— Casey J. Hannan, MPH, Arthritis, Epilepsy and Well-Being Branch Chief, United States Centers for Disease Control and Prevention (CDC).
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2000 L Street NW, Suite 410
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Toll Free: 1.800.558.0121
Main: 202.349.1155
lupus.org