TOGETHER, WE CAN SOLVE THE CRUEL MYSTERY.
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*Lupus Foundation of America*

*Lupus Foundation of America & National Network*

National Network

National Board of Directors & Management

Medical-Scientific Advisory Council
In recent years there has been unparalleled progress in lupus research and awareness, from the approval of the first treatment developed specifically for lupus, to the first-ever Ad Council national lupus awareness campaign. But our work is far from over.

We remain steadfast in our efforts to improve the quality of life for all people affected by lupus. We execute our mission through a comprehensive program of research, education, awareness, and advocacy. Each component of our mission is an integral piece of the puzzle to solve the cruel mystery of lupus.

In 2012, the Lupus Foundation of America redoubled its efforts to fight lupus. Our Annual Report celebrates the Foundation’s many achievements, bringing us closer to creating a world free from lupus. Our national medical research grant program is even more important today due to the draconian cuts in federal funding for medical research for all diseases. Lupus research suffers from these cuts more than most, since national funding for medical research on lupus has not kept pace with diseases of similar morbidity and mortality. We continue to fund researchers at academic medical centers across the United States in areas of importance in lupus research, including: lupus nephritis, cutaneous lupus, adult stem cells, neuropsychiatric lupus, and male lupus. We must expand this program!

In addition, our ongoing efforts to ensure we have an arsenal of safe and effective lupus treatments is exemplified in the expansion of our program to standardize the way in which lupus disease activity is measured during the conduct of clinical trials.

Our widely regarded, gold standard web-based training for instruments used in clinical trials to assess people with lupus is known as the Lupus Foundation of America Professional Online Instrument Training Program (LFA POINT®). LFA POINT® is an important step forward in improving clinical trial outcomes, bolstering our goal to put new medicines in the hands of people with lupus faster.

Another highlight this year was the establishment of our new rallying cry, Help Us Solve the Cruel Mystery®. We must speak in unison about the disease and paint a clear picture of the devastating realities of lupus to garner the attention and resources it deserves. Along with this, we launched a comprehensive education and awareness initiative for physicians, patients, and the public. The centerpiece of the program is a 45-foot bus with eight interactive lupus education exhibits and displays. The bus is traveling across the country promoting greater awareness and understanding of lupus.

We are inspired by you, the millions living with lupus, the people caring for a loved one, physicians, government leaders, and researchers. We are poised to bring about dramatic change in lupus diagnosis, treatment, and awareness. We invite you to read on. Join us. Together, we will solve the cruel mystery of lupus in our lifetime and end its devastating impact on millions of lives.

Thank you.
TOGETHER, WE CAN SOLVE THE CRUEL MYSTERY THROUGH RESEARCH.

There is good and bad news related to the medical research effort on lupus. The bad news is that there have recently been devastating cuts in the federal funding of medical research. The federal government is the largest funder of medical research. As a result of the cuts, the medical research enterprise in the U.S. is suffering. The biopharmaceutical industry relies upon the basic research conducted by the National Institutes of Health (NIH) and other agencies for clues to the development of new medications. Without this research, the development of new, safe, tolerable treatments for lupus will continue to be delayed.

The good news is that, due to more robust national research funding in the past, we now have recent research findings that have spurred new and exciting activity in the field. Today, more than two dozen pharmaceutical and biotechnology companies are developing potential therapies for lupus. We also have a better understanding of the underlying causes and who is at-risk. Researchers have identified more than 40 genes associated with the disease. Through a comprehensive research effort, we work with stakeholders from the government, research, and industry to expand the medical research effort on lupus and drive meaningful advances in our understanding and treatment of the disease.
This past year our peer-reviewed grant program continued to fund important areas of research at leading academic medical centers across the United States. The centers include: Oklahoma Medical Research Foundation; Brigham and Women’s Hospital; Allegheny-Singer Research Institute; Hospital for Sick Children; The Ohio State University; Yale University; University of California at Irvine; University of Virginia; and State University of New York at Buffalo.

Our funding supported research in the areas of pediatric lupus, lupus nephritis, cutaneous lupus, adult stem cells, neuropsychiatric lupus, and male lupus. Our grants aim to fill gaps in lupus research and are awarded to researchers conducting studies that are critically important in advancing the science and medicine of lupus. We also established the Michael Jon Barlin Pediatric Research Program in 2006, the first-ever dedicated pediatric lupus research initiative, which has led to the creation of urgently needed treatment plans for children with lupus, especially those with kidney disease. In 2012, the program funded an important study that aims to determine whether levels of microRNA in the urine can indicate lupus nephritis-related disease activity and damage in the kidneys of children with lupus.

OTHER RESEARCH MILESTONES ACHIEVED IN 2012:

MAJOR BREAKTHROUGH TO DRIVE NEW THERAPIES
We marshaled the resources of seven major biopharmaceutical companies to unlock clues hidden in data from early trials of potential lupus treatments, which will improve future trials and stimulate development of new treatments.

The initial results from the Lupus Foundation of America Collective Data Analysis Initiative (LFA CDAI) were presented during the 2012 American College of Rheumatology scientific conference. Three new research projects began in 2012. They expect to deliver results as well as more valuable data to the LFA CDAI in 2013.

FIRST-OF-ITS-KIND LUPUS INSIGHT PRIZE
In collaboration with the Alliance for Lupus Research and the Lupus Research Institute, the Foundation established a first-of-its-kind national prize in lupus to honor the achievements of an outstanding investigator in lupus. The recipient received an award of $200,000.

The Lupus Foundation of America has taken the lead on challenges that have impeded the development of new lupus treatments for decades. The LFA POINT Program is now the gold standard reference for how outcome measures are performed in international trials and in the training of new clinical investigators worldwide.

— JOAN T. MERRILL, MD - LUPUS FOUNDATION OF AMERICA MEDICAL DIRECTOR & MEMBER & HEAD, CLINICAL PHARMACOLOGY RESEARCH PROGRAM, OKLAHOMA MEDICAL RESEARCH FOUNDATION
PEDiATRIC QUALiTy OF LiFE
MIRIAM KAUFMAN, MD
Hospital for Sick Children
Toronto Ontario, Canada
Creation of a Mobile Application to Support Self-Management
This is the Lucy Vodden Research Grant Award, established by the Lupus Foundation of America and musician/philanthropist Julian Lennon.

LUPUS AFFECTING THE BRAiN
JOSEPH M. AHEARN, MD
Allegheny-Singer Research Institute
Pittsburgh, PA
Mechanistic Role for PC4d in the Pathogenesis of Stroke in Lupus
This grant award is presented in memory of Kassie McMillin Biglow and is made possible in part by funds provided by the Philadelphia Tri-State Chapter of the Lupus Foundation of America.

LUPUS SKiN DIsEASE
VICKY R. KELLEY, PHD
Brigham and Women’s Hospital, Inc.
Boston, MA
Aberrant Macrophages: Pivotal in Discoid Lupus
This grant award is provided through a trust created in memory of Stephen and Catherine Pida.

STEM CELLS
CAROL F. WEBB, PHD
Oklahoma Medical Research Foundation
Oklahoma City, OK
The Role of ARID3a Expression in Hematopoietic Stem Cells in SLE Patients
This grant award is named in honor of The Cooper Family Foundation and is made possible in part by funds provided by the Oklahoma Chapter of the Lupus Foundation of America.

MICHAEL JON BARLIN PEDIATRIC LUPUS RESEARCH PROGRAM:
PEDIATRIC LUPUS KIDNEY
STACY P. ARDOIN, MD, MHS
The Ohio State University
Columbus, OH
Micro RNA in Pediatric Lupus Nephritis
This grant award is made possible in part by funds provided by The Louis Berkowitz Family Foundation and from the Greater Ohio Chapter of the Lupus Foundation of America.

GINA M. FINZI MEMORIAL STUDENT FELLOWSHIP PROGRAM:
CAROLINE ALBERT
Yale University School of Medicine
Can Hydroxychloroquine Prevent Adverse Pregnancy in Women with APS?
Mentor: Vikki M. Abrahams, PhD

ELIZABETH CLARKE
University of California at Irvine
Impact of C1q on Macrophage Modulation of T Cell Function in Autoimmunity
Mentor: Andrea J. Tenner, PhD

CHRISTINE COQUERY
University of Virginia School of Medicine
The Role of Neutrophils in Controlling the Development of Plasma Cells in Autoimmune-Prone Mice
Mentor: Loren D. Erickson, PhD

THOMAS J. COVEY
State University of New York at Buffalo School of Medicine and Biomedical Sciences
MRI, Electrophysiology and Working Memory Impairment in SLE
Mentor: David W. Shucard, PhD

ANNE SONG
Yale University School of Medicine
Competition between TLR7 and TLR9 for UNC93B in a Murine Model of Lupus
Mentor: Mark J. Shlomchik, M.D., PhD

MARY BETTY STEVENS MD, YOUNG INVESTIGATOR PRIZE:
DIANE L. KAMEN, MD, MSCR
Medical University of South Carolina

EVELYN V. HESS MD, MACP, MACR RESEARCH AWARD:
ELLEN M. GINZLER, MD, MPH
State University of New York
TOGETHER, WE CAN SOLVE THE CRUEL MYSTERY THROUGH EDUCATION.

While we continue to advance the science and medicine of lupus and drive the search for cures, we must ensure that all people affected by lupus have access to the tools and resources they need today to manage their health and maintain a good quality of life. Whether you have just been diagnosed with lupus, have been living with the disease for 10 years, or are a family member or caregiver, we are there with you every step of the way. We know that not everyone has the same needs.

We are continually expanding our services and developing new and innovative ways to provide you the latest research findings and resources that will help people with lupus and their health care providers better treat and manage the disease. Our education programs have a national reach with a local presence. The Lupus Foundation of America’s national network conducts its outreach into local communities to bring education and support programs to people affected by lupus.
I have dealt with lupus for 20 years and I don’t think my family really understood what I was going through until they went through the bus.

— PERSON WITH LUPUS AND NATIONAL BUS TOUR VISITOR

In 2012, we launched our multi-city Help Us Solve the Cruel Mystery® National Tour to help reveal the cruel mystery of lupus and its impact on the lives of millions of people around the world. The centerpiece of this comprehensive education initiative for the public, patients, and physicians is a 45-foot bus with eight interactive exhibits and displays. Visitors can learn more about the symptoms of lupus and how it affects the body, as well as hear personal stories from individuals with lupus and their caregivers.

The tour includes a patient education program through which individuals with lupus and their families can learn from and interact with world-renowned lupus medical and wellness experts. It also includes a continuing medical education (CME) program to educate physicians and health professionals about lupus treatments and diagnosis.

Advertising, media, and celebrity engagement around the tour helps educate communities about lupus and resources available to individuals with lupus and their families.

Distributed our award-winning magazine, Lupus Now® to 135,000 people with lupus and their families, policy makers, and health professionals. Visit lupusnow.org.

Responded to more than 60,000 inquiries from people looking for information and support through the Foundation’s National Health Educator Line and National Network.

Created the Lupus Foundation of America Caregiver Taskforce, a voice for the diverse needs of family members and caregivers of those living with lupus, providing guidance on resources, services, and education to better manage the health of their loved ones and themselves.
TOGETHER, WE CAN SOLVE THE CRUEL MYSTERY THROUGH AWARENESS.

Ten years ago no one spoke about lupus. Today, lupus is featured in prime-time television, celebrities are getting behind the cause, there are public service announcements, and more news stories about lupus than ever before.

We are making progress, but it’s not enough.

We are continuing this momentum by aggressively conducting outreach efforts to increase public understanding of lupus through national public awareness campaigns, celebrity engagement, and online and social marketing. Increased awareness among the public and health professionals is critical to getting people diagnosed early. We must engage and generate support from broader audiences so lupus gets the attention and resources required to develop a robust medical research effort and ensure all people affected by lupus have access to the information and resources they need.
Each person’s story with lupus is so unique, and I urge everyone to share their stories and use their voice. We can all do our part. Awareness starts with us and we have to educate our family, friends, and communities about lupus.

— SHANNON BOXX - PROFESSIONAL SOCCER PLAYER AND U.S. OLYMPIC GOLD MEDALIST
With the recent cutbacks at the federal level, it is more important than ever that we are vigilant in our efforts to make our voices heard and urge our nation’s leaders to make lupus a health care priority. We are the leading voice for people with lupus, advocating for expanded investment in research and education on Capitol Hill and in state capitols across the country. In recent years, Congress has responded to activists’ call for an expanded federal effort on lupus by opening new sources of federal funding for biomedical research and critically needed public and clinical education initiatives.
This disease, disproportionately affecting women, needs greater attention. Our goal is to increase understanding of this chronic disease and examine ways to support researchers’ efforts to identify, treat, and to hopefully one day find a cure.

--- REPRESENTATIVE JIM MORAN (D-VA)

In 2012, the Lupus Foundation of America spearheaded the formation of a Congressional Lupus Caucus in the U.S. House of Representatives. Representatives Tom Rooney (R-FL), William Keating (D-MA), Ileana Ros-Lehtinen (R-FL), and Jim Moran (D-VA) serve as co-chairs.

A Congressional Caucus is central to our advocacy efforts to raise awareness of lupus and bring it to the forefront of the nation’s health care agenda. The establishment of the Caucus would not have been possible without our nationwide grassroots network of tens of thousands of lupus activists, supporters, and volunteers from every state, who continue to speak up, share their stories, and urge Congress to make lupus a priority.

- Secured an additional $3.6M in Fiscal Year 2013—$26.5M total—for the National Lupus Patient Registry under the direction of the Centers for Disease Control and Prevention (CDC). The study will provide a more accurate estimate of the number of people with lupus in the United States, revealing the burden of disease on individuals and their families.

- Generated an additional $1 million in Fiscal Year 2013 through the U.S. Department of Health and Human Services Office of Minority Health for the development of an education curriculum and other materials to help current and future medical professionals diagnose lupus early and deliver improved treatment and disease management.

- Established the Coalition for Accessible Treatments to address the rising out-of-pocket costs associated with vital, life-saving medications used to treat chronic diseases and conditions.

- Sustained funding from the U.S. Department of Defense Peer Reviewed Medical Research Program, currently funded at $50M. We established funding for lupus in 2005 and continue to advocate for its inclusion as one of the diseases eligible for funding.

(Opposite) Representative Jim Moran (D-VA) at the 2012 Butterfly Gala in Washington, DC.
TOGETHER, WE CAN SOLVE THE CRUEL MYSTERY THROUGH YOU.

We thank our supporters, volunteers, and activists across the country who join with us year after year in the fight to end lupus. Without you, our work would not possible. We are partners with a shared mission to improve the quality of life for all those affected by lupus, and ultimately find a cure.
As a mother who lost her beloved daughter to lupus, and a long-time supporter of the Lupus Foundation of America, I am personally committed to ensuring that LFA meets the needs of the lupus community far into the future. To accomplish this goal, and to honor my daughter’s memory, I have included the LFA in my estate plans. I urge everyone to consider LFA as part of their estate plans, and join me in taking action to end the suffering and devastation caused by this disease.”

— PATTI CULPEPPER - LUPUS FOUNDATION OF AMERICA LUPUS LEGACY SOCIETY CHARTER MEMBER

WAYS YOU CAN SUPPORT THE WORK THAT IMPROVES THE LIVES OF PEOPLE WITH LUPUS:

Make a Secure Tax Deductible Donation. Visit lupus.org/donate or mail your check made payable to the Lupus Foundation of America, 2000 L Street NW, Suite 410, Washington, DC 20036.

Start a Team and Register for Walk to End Lupus Now®. The nation’s largest lupus walk raises money for lupus research, increases awareness of lupus, and rallies public support. Find a walk in your community. Visit WalkToEndLupusNow.org.

Create a Page of Hope. Share your personal story, and invite family and friends to give in honor or in memory of someone in lieu of giving or getting gifts. Visit lupus.org/pagesofhope.

Make Your Voice Heard on Capitol Hill. Sign up to become an e-advocate. To learn more, visit our Legislative Action Center at lupus.org/advocacy.

Remember us in your will and estate planning. To discuss options for leaving a lasting legacy, e-mail plannedgiving@lupus.org or call 202-212-6779. Visit lupus.org/plannedgiving for more information and language to use for bequests.

Raised more than $20 million to support our global research, education, awareness, and advocacy programs.

Raised approximately $6 million for lupus research and education through more than 60,000 walkers in the Walk to End Lupus Now® in nearly 60 cities.

Raised more than $1.2 million and honored champions for lupus, including Whoopi Goldberg, Dr. Michael Lockshin, and the Congressional Lupus Caucus Co-Chairs during the Foundation’s Galas in Washington, DC and New York City.
STATEMENT OF FINANCIAL POSITION
September 30, 2012

ASSETS (in thousands of dollars)
- Cash and Investments $7,297
- Accounts Receivable, Net 379
- Pledges Receivable, Net 778
- Property and Equipment, Net 1,279
- Other Assets 236
- **TOTAL ASSETS** $9,969

LIABILITIES AND NET ASSETS

Liabilities
- Accounts Payable and Accrued Expenses $1,527
- Research Grants Payable 917
- Deferred Lease Incentives 1,038
- Other Liabilities 103
- **Total Liabilities** 3,585

Net Assets
- Unrestricted 2,787
- Temporarily Restricted 3,490
- Permanently Restricted 107
- **Total Net Assets** 6,384

**TOTAL LIABILITIES AND NET ASSETS** $9,969

A complete copy of the audited financial statements is available upon request from the Lupus Foundation of America National Office by calling 202.349.1155 or by writing to Lupus Foundation of America, 2000 L Street NW, Suite 410, Washington, DC 20036

STATEMENT OF ACTIVITIES
For the Year Ended September 30, 2012

ASSETS (in thousands of dollars)
- Contributions and Grants $10,960
- Special Events, Net of Direct Benefit Costs 2,101
- Program Revenue 946
- Dues and Other Income 670
- **TOTAL SUPPORT AND REVENUE** 14,677

EXPENSES

Program Services
- Public Information and Education 4,803
- Professional Relations and Education 918
- Network Support and Services 1,672
- Patient Education and Support 577
- Research 947
- **Total Program Services** 8,897

Supporting Services
- Management and General 626
- Fundraising 2,379
- **Total Supporting Services** 3,005

**TOTAL EXPENDITURES** 11,902

CHANGE IN NET ASSETS $2,775

A complete copy of the audited financial statements is available upon request from the Lupus Foundation of America National Office by calling 202.349.1155 or by writing to Lupus Foundation of America, 2000 L Street NW, Suite 410, Washington, DC 20036

SUPPORT & REVENUE

- **Contributions & Grants** 75%
- **Special Events** 6%
- **Program Revenue** 14%
- **Dues & Other Income** 5%

EXPENSES

- **Program Services** 75%
- **Supporting Services** 25%
### Financial Highlights

**Lupus Foundation of America & National Network**

#### Statement of Financial Position

**September 30, 2012 (Unaudited)**

<table>
<thead>
<tr>
<th>Assets (in thousands of dollars)</th>
<th>Amount</th>
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<td>Pledges Receivable, Net</td>
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<td><strong>$14,112</strong></td>
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<table>
<thead>
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<th>Liabilities and Net Assets</th>
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<td>Liabilities</td>
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<td>Accounts Payable and Accrued Expenses</td>
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<td>Permanently Restricted</td>
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**Total Liabilities and Net Assets** $14,112

#### Statement of Activities

**For the Year Ended September 30, 2012 (Unaudited)**

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<thead>
<tr>
<th>Assets (in thousands of dollars)</th>
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<td>Contributions and Grants</td>
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<td>Special Events, Net of Direct Benefit Costs</td>
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<td>Program Revenue</td>
<td>967</td>
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<td>Dues and Other Income</td>
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<td><strong>Total Support and Revenue</strong></td>
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<th>Expenses</th>
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<td>Program Services</td>
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<td>Public Information and Education</td>
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<td>Professional Relations and Education</td>
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<tr>
<td>Network Support and Services</td>
<td>1,496</td>
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<td>Patient Education and Support</td>
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<td>Research</td>
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<td><strong>Total Program Services</strong></td>
<td><strong>12,995</strong></td>
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<th>Supporting Services</th>
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<td>Management and General</td>
<td>1,374</td>
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<td>Fundraising</td>
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<td>Total Supporting Services</td>
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<tr>
<td><strong>Total Expenditures</strong></td>
<td><strong>17,704</strong></td>
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**Change in Net Assets** $2,814

### Support & Revenue

- **Contributions & Grants** 63%
- **Special Events** 31%
- **Program Revenue** 5%
- **Dues & Other Income** 1%
- **Dues & Other Income** 1%

**Expenses**

- **Program Services** 73%
- **Supporting Services** 27%
The Lupus Foundation of America National Network is composed of chapters, offices, and 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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