LEADING THE FIGHT TO END LUPUS...
LUPUS: AN URGENT NATIONAL PUBLIC HEALTH ISSUE

Every day, lupus exacts a brutal toll on the lives of people affected by this misunderstood and unpredictable disease — physically, emotionally and financially. It ravages different parts of the body, and has no known cause and no known cure. 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.

Lupus is serious and relentless — and so are we. People who have the disease are always under the threat of a new health crisis and must be brave in the face of what can be daunting and overwhelming. For them, we offer the best answers available, the support of caring people, and referrals to expert physicians. We are their allies in the search for a cure and in the quest for resources to fund research. We work with lupus experts to help us identify the most pressing scientific challenges and aggressively pursue and fund a research agenda to find the answers to the most important and challenging questions in lupus.

We are determined to bring an end to lupus while providing answers, support and hope to all impacted by lupus. We advance our mission through a comprehensive program of research, advocacy, education and awareness.
This year, we took another bold step forward with the development of the Lupus Foundation of America Rapid Evaluation of Activity in Lupus (LFA-REAL™), a first of its kind system that will allow people with lupus and their rheumatologists to assess, evaluate treatment decisions and improve data collection in clinical trials testing new lupus treatments.

The LFA-REAL™ system was the brainchild of the Foundation’s medical director and researcher at the Oklahoma Medical Research Foundation, Joan T. Merrill, MD and Columbia University researcher and physician, Anca D. Askanase, MD, MPH. While discussing how existing lupus assessment tools were complex, unreliable and time-consuming, they agreed there was a significant need to have a simplified tool to assess disease activity and importantly, one that engaged people with lupus as partners in their care.

The tool has two parts that the clinician and the patient each complete. Its purpose is to monitor disease activity over time, encourage treatment decisions to be made together and reduce unnecessary treatment and costs. It will be the only tool for lupus to go through a special qualification and approval process by the Food and Drug Administration (FDA) for use in lupus clinical trials. This means greater consistency in data from clinical trials of potential new lupus therapies, so that the trials can be completed more successfully, allowing new medicines to get into the hands of patients and physicians faster.

“The LFA-REAL™ system is unique because, for the first time, a tool is being developed that will capture the patient voice, address quality of life, track disease activity AND work in companion with the rheumatologists’ assessment. It ensures that the patient is engaged in the treatment and decision making process alongside their physician.”

ANCA D. ASKANASE, MD, MPH
COLUMBIA UNIVERSITY MEDICAL SCHOOL

Since 2009, our direct grant programs, combined with our advocacy efforts, have led to a total investment of $37 million in new dollars for lupus research. Our national research program is focused on bringing down barriers to the development of new treatments for lupus. This includes developing the first-ever global definition of a lupus flare for use in clinical trials and practice, spearheading an initiative to evaluate data from past lupus clinical trials to improve how future trials are conducted, and creating an innovative online tool to provide training to clinical investigators on the instruments used in global lupus clinical trials to improve how data is collected and analyzed. All of these initiatives help bring us closer to achieving our goal of having an arsenal of treatments for lupus and the tools and resources to achieve the best possible quality of life for people with lupus.
BRINGING DOWN THE BARRIERS™

NATIONAL RESEARCH PROGRAM GRANTEES & INITIATIVES

NEUROPSYCHIATRIC LUPUS
MARK W. DIFRANCESCO, PHD
Cincinnati Children’s Hospital Medical Center
Cincinnati, OH
Imaging the Blood-Brain Barrier in Childhood-Onset Neuropsychiatric Lupus
Presented in memory of Kassie McMullin Biglow and made possible in part by funds provided by the Lupus Foundation of America Greater Ohio Chapter.

ADULT STEM CELLS
LAURENCE M. MOREL, PHD
University of Florida College of Medicine
Gainesville, FL
Genetic Regulation of Stem Cell Dysfunction in a Mouse Model of Lupus
This grant is in honor of the Cooper Family Foundation and is provided through a trust created in memory of Stephen and Catherine Pida.

MICHAEL JON BARLIN PEDIATRIC LUPUS RESEARCH PROGRAM:
LISABETH V. SCALZI, MD, MS
Pennsylvania State University Milton S. Hershey Medical Center
Hershey, PA
Impact of Social Media and Online Support for Self-Management in Adolescents with Lupus
This is the Lucy Vodden Research Grant Award, which was established in memory of Lucy Vodden by the Lupus Foundation of America and Julian Lennon. This grant is made possible in part by funds provided by the Lupus Foundation of America Philadelphia Tri-State Chapter.

CAREER DEVELOPMENT AWARD:
CANDACE H. FELDMAN, MD, MPH
Brigham and Women’s Hospital
Boston, MA
Comparative Risks of Infections in Lupus Patients on Immunosuppressants
Created to help fellows interested in pursuing lupus research meet their financial needs.

GINA M. FINZI MEMORIAL STUDENT SUMMER FELLOWSHIP PROGRAM:
ELISABETH ADKINS
The Jackson Laboratory
Bar Harbor, ME
The Sackler School of Graduate Biomedical Sciences at Tufts University
Boston, MA
Origins of Follicular T cells and Interleukin 21 Signaling in Systemic Lupus Erythematosus

STEFAN M. GYSLER
Yale University School of Medicine
New Haven, CT
Role of microRNAs in Trophoblast Responses to Antiphospholipid Antibodies

DANUSHA JEBAJANESAN
University of Toronto and The Hospital for Sick Children
Toronto, ON, Canada
Multiple Targets of Maternal Autoantibodies in Lupus Pregnancies

HANS KIM
State University of New York Upstate Medical University
Syracuse, NY
Nuclear Magnetic Resonance-Based Metabolomic Study for Systemic Lupus Erythematosus

MORGAN MORELLI
Allegheny-Singer Research Institute
Pittsburgh, PA
Association of PC4d with Thrombosis and Cardiovascular Disease in Systemic Lupus Erythematosus

LUPUS INSIGHT PRIZE:
MARK J. SHLOMCHIK, MD, PHD
University of Pittsburgh
Pittsburgh, PA
Dr. Shlomchik investigated the connection between the death of neutrophils, the body’s most abundant white blood cells, and lupus.

LFA RAPID EVALUATION OF ACTIVITY IN LUPUS (LFA-REAL™):
ANCA D. ASKANASE, MD, MPH
Columbia University
New York, NY
DIANE L. KAMEN, MD, MSCR
Medical University of South Carolina
Charleston, SC
JOAN T. MERRILL, MD
Oklahoma Medical Research Foundation
Oklahoma City, OK
S. SAM LIM, MD, MPH
Emory University
Atlanta, GA

GINA M. FINZI MEMORIAL STUDENT SUMMER FELLOWSHIP PROGRAM:
ELISABETH ADKINS
The Jackson Laboratory
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Medical University of South Carolina
Charleston, SC
JOAN T. MERRILL, MD
Oklahoma Medical Research Foundation
Oklahoma City, OK
S. SAM LIM, MD, MPH
Emory University
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LFA COLLECTIVE DATA ANALYSIS INITIATIVE (CDAI):
MIMI KIM, SCD
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.
LEADING THE FIGHT TO END LUPUS THROUGH ADVOCACY.

Our investment in advocacy efforts has generated huge dividends for lupus research. In 2013 alone, the Foundation’s activists successfully stimulated more than $11 million in new funding for lupus research and education programs. The Foundation has an amazing track record of success, stimulating $28 in federal lupus research and education for every $1 invested in advocacy.

We are determined to make lupus a national health care priority. We fight to improve access to health care and expand funding for lupus education and research initiatives so we can find better treatments and get the answers we need to solve the cruel mystery of lupus.

SECURED MORE THAN $11 MILLION FOR LUPUS RESEARCH AND EDUCATION

Kidney failure. Months of rehabilitation and therapy. Loss of employment. These are just a few ways lupus has affected 42 year old Toni Grimes from Arizona. During the Lupus Foundation of America’s National Advocacy Lupus Summit, Toni and more than 250 lupus activists from 31 states shared with members of Congress and their staff the countless and sometimes devastating ways lupus has affected them and their families. Along with other activists, she delivered the Foundation’s National Research petition, containing more than 30,000 signatures.

We are committed to telling the stories of people affected by lupus to underscore the urgent need to increase funding for lupus research. We will keep the pressure on our nation’s leaders on Capitol Hill and in state houses across the country until we achieve our goal of improving the quality of life for Toni and the millions of others who struggle with this terrible disease every day.

MORE ADVOCACY SUCCESS:

— Advocating successfully for the continued support of lupus research through the Department of Defense Peer Reviewed Medical Research Program, which awarded $1.6 million to two biotechnology companies to develop potential life-saving treatments for lupus. Another $3.4 million in grants was provided to three research institutions to learn more about lupus.

— Secured an additional $2 million for a total of $6.5 million for The Lupus Initiative, which launched in 2013 to train more doctors on recognizing the signs and symptoms of lupus to improve early diagnosis and treatment.

— Secured an additional $5.5 million to support the largest national epidemiology study conducted on lupus through the Centers for Disease Control and Prevention, bringing total funding to $32 million. The study will provide a more accurate estimate of the number of people with lupus and provide a clear picture of the burden of disease on individuals and their families.

“Participating in the National Lupus Advocacy Summit was empowering and inspiring. Sharing my story with my representatives and being with hundreds of other activists made me feel like we were in this together, and we could make a difference.”

TONI GRIMES
LUPUS ACTIVIST FROM PHOENIX, ARIZONA
MORE EDUCATION SUCCESS:

— Conducted live and online Continuing Medical Education (CME) programs for health professionals, to explore advances in lupus management and treatment.

— Completed the first phase of the Help Us Solve the Cruel Mystery National Tour, which featured a 45 foot bus with interactive exhibits designed to showcase how lupus impacts the daily lives of individuals and their families. The tour included a patient education program and a state-of-the-science continuing medical education (CMG) program for healthcare professionals. The Tour reached more than 90 million people through the media and impressions generated during its time on the road.

— Celebrated the tenth anniversary of Lupus Now®, the only national magazine exclusively for people with lupus, their caregivers and health care professionals.

PROVIDED CARING SUPPORT AND PROGRAMS FOR 200,000 PEOPLE AFFECTED BY LUPUS

With the support of our National Network of chapters, offices, and support groups, we are out in the community every day, hosting more than 2,400 support group meetings and education programs and participating in more than 600 health fairs last year alone. Through our National Health Educator Call Center and programs conducted by our National Network, we provided education, support and referrals for more than 60,000 people.

Twenty-five year old Brittney McBath reached out to the Foundation looking for answers and help after years of debilitating symptoms including joint pain, fevers and neurological and gastrointestinal issues. The Foundation provided resources and referred her to one of the leading experts in lupus, who helped Brittney regain control of her health and provided her with hope for the first time in years.

The resources and support of the Lupus Foundation of America changed my life. After years of being sick and finding no relief from my symptoms, I finally was able to regain control of my health and have hope that I could live a long and happy life.”

BRITTNEY MCBATH
DIAGNOSED WITH LUPUS AT AGE 18

LEADING THE FIGHT TO END LUPUS THROUGH EDUCATION.

Whether an individual has had lupus for six weeks or six years, we know that a lupus diagnosis can be overwhelming, confusing and at times frightening. We’re here to listen and to make sure that everyone gets the answers and support they need. Our work has earned public confidence, and our advice is credible and authoritative. We have years of experience and deep roots with leading researchers and medical specialists. We collaborate with top lupus experts to provide the latest information about developments in lupus education and treatment.
Since his diagnosis of lupus kidney disease (lupus nephritis) in 2012, entertainer and host of America’s Got Talent, Nick Cannon, has added another title to his resume: lupus activist. By sharing his story with the media, including CNN and Good Morning America, he continues to bring greater attention and awareness to the impact of lupus.

Cannon is also featured in an educational video which promotes the importance of clinical trials and awareness about clinical trial options for lupus nephritis. He served as Grand Marshal for our Walk to End Lupus Now™ events in Washington, D.C. and Los Angeles, which attracted more than 10,000 people to join the fight in those communities. Cannon also brings additional awareness through social media, reaching his more than 4 million followers.

“We are all in this fight against lupus together. Awareness starts with us. Each of us can do our part, raise our voice and educate our families, neighbors, friends and communities.”

Nick Cannon
Actor, Entertainer and Host of America’s Got Talent

We are committed to bringing lupus to the forefront of the public’s consciousness, so that it can receive the attention and resources needed to find its causes and cures. Celebrities play a critical role, shining a light on lupus, educating the public about its impact, and injecting lupus into the national dialogue. Julian Lennon, Nick Cannon, actor Ian Harding and Olympic soccer player Shannon Boxx have all stepped up in recent years to help raise awareness of lupus. The Foundation is leading the charge to rally public support from all corners, including stars of film, television and sports, to increase awareness of lupus.

**SHINING A LIGHT ON LUPUS**

**MORE AWARENESS SUCCESS:**

- Exceeded 5 million annual visits to our website, lupus.org.
- Surpassed 150,000 likes on Facebook, becoming the largest lupus community online.
- Walk to End Lupus Now became the world’s largest lupus walk, with events in more than 60 communities and 70,000 participants, generating visibility, public understanding and support for people with lupus.

Opposite: Nick Cannon (C) joined by actress Margaret Avery, Being Mary Jane (L) and Ian Harding (R), Pretty Little Liars at Walk to End Lupus Now in Los Angeles.
WAYS YOU CAN JOIN THE FIGHT

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 202-349.1153. Visit lupus.org/plannedgiving for more information and language to use for bequests.

Become a Corporate Sponsor. Each year, many companies join the movement to solve the cruel mystery. Align your brand and company with our cause and those living with lupus. To learn more, contact Donna Grogan at grogan@lupus.org or 202-349-1152.

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 be possible. We are partners with a shared mission to improve the quality of life for all those affected by lupus.

LEADING THE FIGHT TO END LUPUS WITH YOU.
FINANCIAL HIGHLIGHTS

17% FUNDRAISING
78% PROGRAM SERVICES**
4% MANAGEMENT & GENERAL

12% RESEARCH & SCIENTIFIC INITIATIVES
52% ADVOCACY & AWARENESS

LUPUS FOUNDATION OF AMERICA**

STATEMENT OF ACTIVITIES
For the Year Ended September 30, 2013

REVENUE AND SUPPORT $ 11,201,340

EXPENSES
Program Services 10,485,487
Management and General 590,275
Fundraising 2,298,326
TOTAL EXPENSES 13,374,088

CHANGE IN NET ASSETS (2,172,740)
NET ASSETS, BEGINNING OF YEAR 6,383,798
NET ASSETS, END OF YEAR $ 4,211,050

LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

STATEMENT OF ACTIVITIES
For the Year Ended September 30, 2013

REVENUE AND SUPPORT $ 17,687,201

EXPENSES
Program Services 14,801,945
Management and General 1,273,525
Fundraising 3,456,575
TOTAL EXPENSES 19,532,045

CHANGE IN NET ASSETS (1,844,844)
NET ASSETS, BEGINNING OF YEAR 9,954,017
NET ASSETS, END OF YEAR $ 8,109,173

** These are the program expenses for the Lupus Foundation of America national office.

We are focused and aggressive in our efforts to increase understanding of lupus among the public and our nation’s leaders so lupus gets the attention and resources it needs. We achieve this through:

— Advocating for expanded investment in lupus research, securing $9 million in new government funding this year (a total of $37 million since 2009).
— Advocating for increased funding for lupus awareness and education programs, generating a total of $2 million this year in new government funding (this year a total of $9 million since 2009).
— Ongoing outreach and education for government leaders and the public.
— Engaging the media and celebrities to shine a light on lupus.

Our comprehensive National Research Program leads scientific initiatives to stimulate the development of new treatments, funds grants to lupus researchers and advocates for expanded public and private investment in research on lupus. (See advocacy and awareness section above). We achieve this through:

— Funding research where there is a gap in our understanding or the topic has been underfunded.
— Improving the design of lupus clinical trials so they can be completed successfully.
— Creating an online training tool for researchers on the instruments used in lupus clinical trials.
— Developing a new disease assessment and treatment management tool.

While on the quest for treatments and cures we provide answers, support and hope to people with lupus, their families and the physicians who care for them. We achieve this through:

— Patient education programs and support groups.
— Physician education and training.
— Our Health Educator Network that provide answers and referrals.
— Health management tools and resources, including Lupus Now® magazine.

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.
NATIONAL NETWORK

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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