

SPREADING OUR WINGS

A YEAR OF
HISTORIC PROGRESS



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HOW YOU CAN CONTINUE TO SUPPORT THE LUPUS FOUNDATION OF AMERICA

- ▶ Make a secure tax-deductible donation.
Visit www.lupus.org/donate or mail your check made payable to the Lupus Foundation of America (LFA), 2000 L Street, N.W., Suite 410, Washington, DC 20036.
- ▶ Register for *Walk for Lupus Now*®, the LFA's signature national walk program that raises funds to support programs of research, education, and advocacy. To find an LFA Walk in your community, visit WalkForLupusNow.org.
- ▶ Create a Page of Hope and share your personal story, then invite family and friends to give in honor or in memory of someone in lieu of giving or getting gifts.
Visit www.lupus.org/pagesofhope.
- ▶ Sign up to become an e-advocate, and make your voice heard on Capitol Hill. To learn more, visit the LFA's Legislative Action Center at www.lupus.org/advocacy.
- ▶ Remember the LFA in your will and estate planning; visit www.lupus.org/plannedgiving for more information and language to use for bequests. To discuss options for leaving a lasting legacy to the LFA, email plannedgiving@lupus.org or call 202.212.6779.
- ▶ Donate your gently used household goods to the LFA. Your donated items will be sold to for-profit wholesale buyers. Proceeds support the mission of the LFA. To schedule a pickup, visit www.lfapickup.org.

LETTER FROM THE CHAIR AND PRESIDENT AND CEO

This is an exciting time for people with lupus, their families, and the health professionals who care for them. We have seen historic progress in recent years, and helped lay the foundation for a new paradigm in lupus that includes increased awareness and understanding of lupus, greater investment in lupus research, and the development of new, effective, safer, and more tolerable treatments.

The Lupus Foundation of America (LFA) is leading efforts to create momentum in the field by establishing new research initiatives and implementing creative solutions to address the tough issues related to advancing the science and medicine of lupus. These initiatives include the Lupus Research Registry provided through the LFA Center for Clinical Trials Education (LFA CCTE) Web site, for individuals interested in participating in future lupus clinical trials, and a Web-based service (LFA POINT program) through which physicians and clinical investigators receive uniform training on instruments used to assess disease activity in clinical studies and medical practice. The LFA is also partnering with key stakeholders from industry, government, and the scientific community to evaluate data from previous lupus clinical trials to improve the design of future studies. Already the LFA's review of data from past clinical trials is yielding important information on how best to structure future lupus clinical trials.

Last year, the LFA launched the pilot program *Lupus: Learn from the Experts*™ that enables people with lupus and their families to gain valuable information and insight on managing their disease from leading lupus experts. The LFA is committed to developing new and innovative education programs to ensure that all people touched by lupus have access to the support services and information they need.

Securing greater visibility and public understanding of lupus are among the LFA's highest priorities. By engaging celebrity support for lupus from individuals, such as musician and philanthropist Julian Lennon and Eduardo Xol from *ABC's Extreme Makeover: Home Edition*, we are increasing

awareness and elevating this urgent public health issue on the nation's health care agenda.

Through our advocacy efforts, the LFA has stimulated more than \$18.4 million in funding for the first-ever comprehensive national epidemiological study which will determine the number of people in the United States living with lupus. Initial results are expected in late 2011. Confirming how many people have lupus and determining how many new cases occur each year will help researchers and policy makers gain a better understanding of the individual, social, and economic impact of the disease.

We will continue to urge the federal government and industry to increase investment in lupus research, develop a full arsenal of treatments, increase public awareness, and educate our health professionals so lupus may be diagnosed and treated early.

On behalf of everyone at the LFA, we thank our supporters, volunteers, and lupus advocates across the nation who band together to help support our efforts on behalf of all those living with lupus. We recognize and value you as our partners in advancing the LFA's mission and improving the quality of life for all those affected by lupus, and ultimately finding a cure.



Cindy Coney

Cindy Coney
Chair, LFA National
Board of Directors



Sandra C. Raymond

Sandra C. Raymond
President and
Chief Executive Officer

LFA Global Ambassador Julian Lennon performs at the **2010 LFA National Butterfly Gala** in Washington, DC. Lennon and the LFA established the **Lucy Vodden Research Grant Award**, which will fund lupus research through the LFA's **National Research Program, Bringing Down the Barriers™**.



SPREADING OUR WINGS

Our commitment is to support a comprehensive research program that will advance the science and medicine of lupus and stimulate development of new treatments by directly funding lupus research, increasing public and private investment in lupus research, and leading collaborative efforts with key stakeholders on special research initiatives.

YEAR IN REVIEW

RESEARCH

We know more about lupus than we did 10 years ago. Advances in lupus research have provided us with a better understanding of the possible underlying causes of the disease, and unprecedented opportunities to greatly expand our knowledge base on lupus. Only through a comprehensive, targeted medical research effort will we be able to find a cure for this complex disease. Accelerating medical research on lupus and engaging all relative public and private sources of support in this effort are among the LFA's highest priorities.

In 2010, the LFA accomplished goals in these areas:

- ▶ Developed the LFA Professional Online Instrument Training Program™ (LFA POINT program), a Web-based service through which physicians and clinical investigators receive uniform training on instruments used to assess disease activity in clinical studies and medical practice.
- ▶ Established the *Lucy Vodden Research Grant Award* with musician and philanthropist Julian Lennon. The research initiative is named after Lucy Vodden, a childhood friend of Lennon's who lost her battle with lupus in September of 2009 at the age of 46.
- ▶ Achieved an 18 percent increase in visits to the LFA Center for Clinical

Trials Education (LFA CCTE), the comprehensive trusted resource for all people with lupus considering participation in a clinical research study.

- ▶ Launched the Lupus Research Registry through the LFA Center for Clinical Trials Education (LFA CCTE), which uses information provided by the registrants to help connect them to local clinical studies enrolling volunteers.
- ▶ Awarded nearly \$24 million since the program's inception to more than 400 investigators at 100 institutions throughout the United States. The LFA is directing its support toward areas of research where gaps exist in the understanding of lupus and toward promising areas of study where other public and private organizations have not focused their efforts. In 2010, the LFA provided grants in the following areas: pediatric lupus, reproductive health, lupus nephritis, neuropsychiatric lupus, stem cells, and male lupus. Visit the LFA's National Research Program for a complete list of 2010 award recipients.
- ▶ Hosted a meeting in cooperation with the National Institutes of Health (NIH) of nearly 200 lupus researchers, clinicians, and representatives from government, industry, academia, and nonprofit organizations to look at ways to best apply research findings from lupus mouse models to human lupus.

Dr. Gary Gilkeson (right), Chair, of the LFA Medical-Scientific Advisory Council and LFA, MSAC Member, **Dr. Susan Manzi** (left) discuss the importance of federal funding for lupus research at the advocate training for the LFA's Twelfth Annual Advocacy Day.



BRINGING DOWN THE BARRIERS™

LFA NATIONAL RESEARCH PROGRAM 2010 RESEARCH GRANTEES

Michael Jon Barlin Pediatric Lupus Research Program

Kathleen M. O'Neil, MD

University of Oklahoma College of
Medicine

*Effect of Pubertal Hormone
Changes on Systemic Lupus
Erythematosus*

This grant award is made possible
through support of the Wallace H.
Coulter Foundation in memory of
Michael Jon Barlin.

Male Lupus Research

Bruce C. Richardson, MD, PhD

University of Michigan School of
Medicine

*Genetic/Epigenetic Modeling of
Male Lupus Risk*

This grant award is made possible
through support of the Wallace H.
Coulter Foundation in memory of
Michael Jon Barlin.

Stem Cell Research

Richard K. Burt, MD

Northwestern University School of
Medicine

*Hematopoietic Stem Cell Transplan-
tation Induces Remission in Lupus*

This grant award is made possible

with funds contributed by the LFA,
Illinois Chapter.

Lupus Nephritis

Richard J. Quigg, MD

The University of Chicago Medical
Center

*Therapeutic Complement Manipula-
tion in a Novel Murine Lupus
Nephritis Model*

This grant award is made pos-
sible through support of the Louis
Berkowitz Family Foundation and
with funds contributed by the LFA,
Illinois Chapter.

Neuropsychiatric Lupus

Martin G. Pomper, MD, PhD

Johns Hopkins Medical Institutions
*Imaging Microglial Activation in
Neuropsychiatric Lupus*

This grant award is presented in
memory of Kassie McMullin Biglow
and with funds contributed by the
LFA, Akron Area Chapter and
the LFA, DC/ Maryland/ Virginia
Chapter.

Gina M. Finzi Memorial Student Fellowship Program

Dana DiRenzo

Temple University School of

Medicine *Effect of Mer Tyrosine
Kinase on Pristane-Induced SLE*

Adam F. Ilowite

Albert Einstein College of Medicine
*VCAM-1, TWEAK, and CXCL-16
as Early Biomarkers for Lupus
Nephritis*

Melanie Khosravi

University of California, Los Angeles
*The Role of Complement Factor H
Gene Variants in Risk for SLE*

Rachael L. Philips

University of California, Los Angeles
*Cutaneous Formation of a
Tertiary Lymphoid Organ in Lupus
Erythematosus*

Hang Shi

Toronto Western Research Institute
*Steroid-related Damage in an
International Inception Cohort of
SLE Patients*

Evelyn V. Hess, MD, MACP, MACR Research Award

David Isenberg, MD, FRCP, FAMS

University College Hospital, London

Mary Betty Stevens, MD, Young Investigator Prize

Sasha Bernatsky, MD, PhD

McGill University

Jada Pinkett Smith, Will Smith, and Karen B. Evans, aunt to Jada, Executive Director of the Will and Jada Smith Family Foundation, and Immediate Past Chair of the LFA National Board of Directors, accepted the LFA's *Butterfly of Hope Award* at the inaugural **LFA Butterfly Gala** in New York City.



SPREADING OUR WINGS

Our commitment is to have lupus recognized as a serious and life-altering disease by implementing public awareness campaigns, employing social media tools, building celebrity support for lupus, and increasing the number of stories about lupus in the media.

AWARENESS AND ADVOCACY

Public awareness and advocacy go hand in hand. Through increased awareness, we can elevate lupus on the nation's health care agenda and bring national attention and resources to lupus. The LFA is aggressively conducting outreach efforts to increase public understanding of lupus through national awareness campaigns, media outreach, and online and social marketing. 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 2010, the LFA accomplished goals in these areas:

AWARENESS

- ▶ Continued support of The Advertising Council's multi-media lupus awareness campaign, which generated nearly \$60 million in donated media since the launch of the campaign in 2009. The LFA is the Founding Partner on the campaign sponsored by the U.S. Department of Health and Human Services Office on Women's Health (OWH).
- ▶ Collaborated with musician and philanthropist Julian Lennon and James Scott Cook to promote the song "Lucy," which resulted in significant media coverage including: *USA Today*, *Billboard Magazine*, *Washington Post*, *WebMD* magazine, and the *CBS Early Show*.
- ▶ Expanded the LFA's social media presence and created new online tools to educate and engage constituents and to recruit new LFA supporters. This expansion included a new interactive Facebook Fan page and new

videos featured on the LFA's Web site, www.lupus.org, and YouTube page.

- ▶ Attracted more than 40,000 individuals in 67 cities to participate in the LFA's signature national walk program, *Walk for Lupus Now®*.
- ▶ Increased traffic to the LFA's Web site by 13 percent, generating more than 3 million visits worldwide.
- ▶ More than 24,000 people signed a pledge committing to raise awareness during Lupus Awareness Month in May. Eduardo Xol from *ABC's Extreme Makeover: Home Edition* kicked off the campaign with a personal message encouraging people to *Band Together for Lupus™* and raise awareness their own way in their communities.

Representative Glenn 'GT' Thompson, Jr. (D-PA, 5) (center) with lupus advocates, **Kathryn Witimer** and family at the LFA's Eleventh Annual Advocacy Day.



ADVOCACY

- ▶ Secured \$4.5 million for the National Lupus Patient Registry operated through the Centers for Disease Control and Prevention (CDC) for Fiscal Year 2010. This study will determine the number of people with lupus in the United States. To date, Congressional support for the study is \$18.4 million.
- ▶ Stimulated \$1 million to continue the national lupus education campaign in conjunction with the U.S. Department of Health and Human Services



SPREADING OUR WINGS

Our commitment is to elevate lupus on the nation’s health care agenda by: developing policies that support the needs of people with lupus; stimulating additional federal funds for research education, and support services; and expanding the number of people who make their voice heard on Capitol Hill and in state capitals across the country about the challenges of living with lupus.



Office of Minority Health, (OMH), the Office on Women’s Health (OWH), and the Office of the Surgeon General.

- ▶ Gathered more than 2,000 advocates to share their personal stories during the LFA’s Twelfth Annual Advocacy Day about the many ways lupus has affected their lives. Two hundred advocates personally met with Members of Congress on Capitol Hill and another 1,800 emailed or called to urge support for more funding for lupus research, awareness, and health care provider education.
- ▶ Conducted meetings with key officials at the National Institutes of Health (NIH), Centers for Disease and Control and Prevention, (CDC) U.S. Food and Drug Administration (FDA), and Members of Congress to educate policy makers on the needs of people with lupus. This included: the urgent need to expand the medical research effort on lupus, affordable health care for all, and increased public understanding and awareness of lupus.
- ▶ Led MAPRx, a coalition of more than 48 patient, family, caregiver and health professional organizations committed to safeguarding the well-being of people with chronic disease and ensuring prescription access under Medicare Part-D and the private insurance sector.
- ▶ More than \$11.8 million has been awarded since 2005 to support important lupus research studies through the U.S. Department of Defense (DoD) Congressionally Directed Peer Reviewed Medical Research Program (PRMRP). Through its advocacy efforts, the LFA made a persuasive case to DoD officials that described the relevance of lupus research to military personnel and their dependents.
- ▶ Expanded the LFA’s state and local advocacy efforts by introducing lupus awareness and education legislation and hosting state advocacy days. To date, 37 states have pursued Lupus Awareness Month initiatives for May, 10 states have held advocacy days, and eight states have introduced LEAP bills (Lupus Awareness and Education Programs).

North Carolina lupus advocate and support group facilitator, Tameka Mitchell, attends a health fair in Charlotte, North Carolina.



SPREADING OUR WINGS

Our commitment is to provide the most up-to-date and accurate lupus information, and expand our support and services to reach all people with lupus and their caregivers where they live, work, and play.

EDUCATION AND SUPPORT

As the authoritative voice for people with lupus, the LFA collaborates with international lupus experts to translate the latest research findings in medically sound and innovative educational materials, programs, and tools for people with lupus and health care providers. Our goal is to ensure that all people affected by lupus have access to the information and services they need.

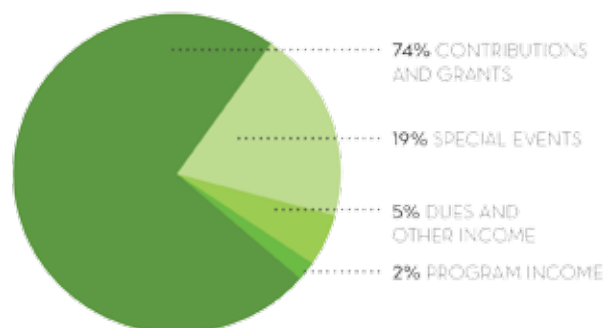
In 2010, the LFA accomplished goals in these areas:

- ▶ Distributed 135,000 copies of the LFA's award-winning magazine *Lupus Now*® to individuals with lupus and their families, policy makers, and health professionals. *Lupus Now* contains the latest information on clinical research, lifestyle, and coping strategies.
- ▶ Created new educational materials and expanded content on the LFA's Web site in Spanish and Chinese.
- ▶ Launched the pilot program *Lupus: Learn from the Experts*™, a series of telephone conferences and online presentations hosted by leading lupus experts that cover topics of interest to people at different points in living and coping with their lupus, including diagnosis, treatments, and the emotional and physical aspects of the disease.

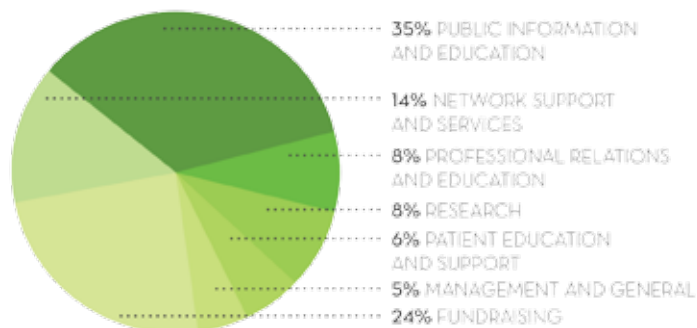
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- ▶ Generated a 20 percent increase in inquiries through the LFA's Health Educator Network, responding to nearly 55,000 inquiries in English, Spanish, and Mandarin.
 - ▶ Provided education, support, and referrals to approximately 200,000 individuals through outreach and education efforts, including sponsoring more than 200 support groups, and conducting more than 400 patient education programs.
 - ▶ Launched "15 Questions With..." a new online "ask the experts" forum for people living with lupus and their caregivers which covers topics including: kidneys and lupus, men and lupus, skin lupus, and disability. The transcripts have been viewed more than 40,000 times.

LUPUS FOUNDATION OF AMERICA, INC.

LUPUS FOUNDATION OF AMERICA SUPPORT AND REVENUE



LUPUS FOUNDATION OF AMERICA EXPENDITURES



Statement of Financial Position

September 30, 2010

(In Thousands of Dollars)

Assets

Cash and Investments	\$ 3,179
Accounts Receivable, Net	300
Pledges Receivable, Net	1,186
Property and Equipment, Net	48
Other Assets	163
Total Assets	4,876

Liabilities and Net Assets

Liabilities

Accounts Payable and Accrued Expenses	885
Research Grants Payable	784
Deferred Lease Incentives	27
Other Liabilities	41
Total Liabilities	1,737

Net Assets

Unrestricted	2,849
Temporarily Restricted	183
Permanently Restricted	107
Total Net Assets	3,139

Total Liabilities and Net Assets **\$ 4,876**

Statement of Activities

For the Year Ended September 30, 2010

(In Thousands of Dollars)

Support and Revenue

Contributions and Grants	\$ 7,523
Special Events, Net of Direct Benefit Costs	1,986
Program Income	177
Dues and Other Income	541
Total Support and Revenue	10,227

Expenditures

Program Services

Public Information and Education	3,426
Professional Relations and Education	810
Network Support and Services	1,389
Patient Education and Support	535
Research	783
Total Program Services	6,943

Supporting Services

Management and General	529
Fundraising	2,293
Total Supporting Services	2,822

Total Expenditures **9,765**

Change in Net Assets **\$ 462**

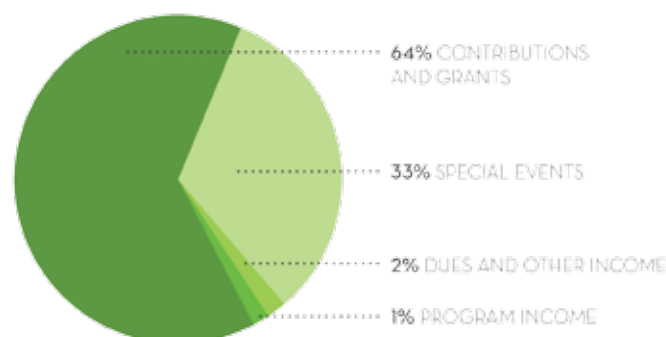


Program services represent 74% of total expenses. A complete copy of the audited financial statements is available upon request from the Lupus Foundation of America, Inc. National Office by calling 202-349-1155 or by writing the Lupus Foundation of America, Inc, 2000 L Street NW, Suite 410, Washington, DC 20036.

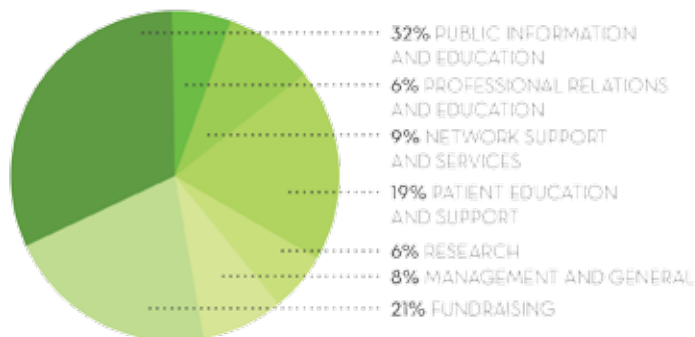
The Lupus Foundation of America, Inc. has received the Better Business Bureau Wise Giving Alliance Seal, and continues to meet all standards of the National Health Council.

LUPUS FOUNDATION OF AMERICA, INC. AND ITS NATIONAL NETWORK

LUPUS FOUNDATION OF AMERICA AND NETWORK
SUPPORT AND REVENUE



LUPUS FOUNDATION OF AMERICA AND NETWORK
EXPENDITURES



Statement of Financial Position

September 30, 2010 (Unaudited)

(In Thousands of Dollars)

Assets

Cash and Investments	\$ 6,526
Accounts Receivable, Net	478
Contributions Receivable, Net	1,314
Property and Equipment, Net	267
Other Assets	183
Total Assets	8,768

Liabilities and Net Assets

Liabilities

Accounts Payable and Accrued Expenses	1,466
Research Grants Payable	784
Deferred revenue	203
Other Liabilities	126
Total Liabilities	2,579

Net Assets

Unrestricted	5,336
Temporarily Restricted	703
Permanently Restricted	150
Total Net Assets	6,189

Total Liabilities and Net Assets **\$ 8,768**

Statement of Activities

For the Year Ended September 30, 2010 (Unaudited)

(In Thousands of Dollars)

Support and Revenue

Contributions and Grants	\$ 9,813
Special Events, Net of Direct Benefit Costs	4,999
Program Income	208
Dues and Other Income	319
Total Support and Revenue	15,339

Expenditures

Program Services

Public Information and Education	4,808
Professional Relations and Education	814
Network Support and Services	1,285
Patient Education and Support	2,801
Research	872
Total Program Services	10,580

Supporting Services

Management and General	1,139
Fundraising	3,081
Total Supporting Services	4,220

Total Expenditures **14,800**

Change in Net Assets **\$ 539**



Program services represent 74% of total expenses. A complete copy of the audited financial statements is available upon request from the Lupus Foundation of America, Inc. National Office by calling 202-349-1155 or by writing the Lupus Foundation of America, Inc, 2000 L Street NW, Suite 410, Washington, DC 20036.

The Lupus Foundation of America, Inc. has received the Better Business Bureau Wise Giving Alliance Seal, and continues to meet all standards of the National Health Council.

LFA NATIONAL NETWORK

The LFA and its National Network consists of chapters, national and regional field offices, and community representatives who provide education and support programs to people with lupus, their families, and health care professionals.

Alaska Chapter
Anchorage, AK

Arkansas Chapter
Hot Springs, AR

Arizona Chapter
Glendale, AZ

California Regional Office,
Los Angeles, CA

Connecticut Chapter
Farmington, CT

DC/MD/VA Chapter
Washington, DC

Southeast Florida Chapter
Delray Beach, FL

Georgia Chapter
Smyrna, GA

Iowa Chapter
Des Moines, IA

Illinois Chapter
Chicago, IL

Indiana Chapter
Indianapolis, IN

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Wichita, KS

Heartland Chapter
St. Louis, MO

Piedmont Chapter
Charlotte, NC

Winston-Triad Chapter
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