SPREADING OUR WINGS
A YEAR OF HISTORIC PROGRESS
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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  
Chair, LFA National Board of Directors

Sandra C. Raymond  
President and Chief Executive Officer
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.
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 Transplantation 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 Manipulation in a Novel Murine Lupus Nephritis Model
This grant award is made possible 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
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...

- 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.

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.
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).
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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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.

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

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

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.
ANNUAL REPORT 2010
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

**Expenditures**

**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

**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
# 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.

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