



# LUPUS LA

## 2014/15 ANNUAL REPORT



# FROM OUR CHAIRMAN

Dear Friends,

Lupus LA began raising money for lupus research in 2000 and we've come a long way since that first event. We're now a full-service, multi-dimensional lupus organization with worldwide reach and influence. Almost two years ago we separated from our parent organization and obtained our own 501(c)(3) in order to increase growth and streamline our operation. As you'll see in this annual report (the first Lupus LA has produced), we've been incredibly successful in this, our first full year as our own entity. We continue to support the research initiatives of our partners and work with other lupus organizations to increase the reach of our message, but make no mistake, we have created a unique and powerful approach to fighting lupus, helping patients, and raising awareness.

Our global reach through our Lupus LA Ambassador program has allowed celebrities like Toni Braxton, Sharon Stone, Paula Abdul, Melissa Joan Hart, Michael B. Jordan, Seal, and many others to bring attention to lupus like never before. If you look at the full list of Ambassadors in this report, you'll see an incredible variety of dedicated personalities, all deeply passionate about the work they do with Lupus LA.

What lies ahead for Lupus LA? Our primary goal has always been to do what's best for lupus patients and we believe our comprehensive approach will continue to produce results. We will be bringing an increased focus to raising research dollars to fund the promising developments in the research landscape. We will be increasing our outreach to lupus patients and their families through our ever-growing and impressive Medical Advisory Board. And we will continue to be a leader in bringing media attention to the struggles of people affected by lupus. We could not do any of this without the support of our constituents. You are incredibly passionate and devoted and on behalf of the board of directors, you have my utmost appreciation and respect. Together, we hope to win this fight for all those who have known this disease.



Adam Selkowitz  
Chairman



*"Lupus LA is a strong and vibrant organization because of the deep commitment of its supporters. Continuing this commitment is vital."*

- Adam Selkowitz, Lupus LA Board Chairman and Lupus Patient



# OUR CORE VALUES

Created in 2000, Lupus LA is a 501(c)(3) non-profit healthcare organization dedicated to finding the causes of and a cure for lupus while serving the needs of people with lupus and their families in Los Angeles County and across Southern California. With an operating budget of approximately \$1.5M and a full-time staff of five, Lupus LA raises funds for our three core values: supporting medical research, providing patient services and programs, and promoting awareness and advocacy.

## MEDICAL RESEARCH

- FUNDING MEDICAL RESEARCH
- SPONSORING FELLOWSHIPS AT LOCAL INSTITUTIONS
- SUPPORTING LOCAL PROJECTS THROUGH OUR MEDICAL ADVISORY BOARD

## PATIENT PROGRAMS

- ONE-ON-ONE CONSULTATIONS
- DOCTOR REFERRALS
- SUPPORT GROUPS
- EMERGENCY GRANTS
- PATIENT EDUCATION

## ADVOCACY & AWARENESS

- GOVERNMENT LOBBYING
- EXPANDED SOCIAL MEDIA
- AWARENESS CAMPAIGNS
- CELEBRITY AMBASSADOR PROGRAM



*"Since its inception in 2000, Lupus LA has made a huge impact for lupus and they are growing exponentially in making a difference for lupus patients globally. With focused efforts toward research, patient services and medical fellowship programs, this organization is about finding solutions that effect positive, long-lasting change for this chronic, potentially life-threatening disease. I am honored to be on the Board of Directors amongst members who truly care and whose goal is to find a cure."*

*- Bridget Hood, Lupus LA Board Member and Lupus Patient*

# 2014/15 MEDICAL RESEARCH HIGHLIGHTS

- ***Lupus LA exceeded its expected fundraising goal by \$100,000 this past year in support of medical research.***

Lupus LA supports ground-breaking medical research each year by working with our partners at the Lupus Research Institute and the Alliance for Lupus Research. In 2014/2015, due to the generosity of our donors, Lupus LA was able to give away an additional \$100,000 to help find the causes of and a cure for lupus.

- ***Lupus LA completed funding a 2-year rheumatology fellowship with hospital partner, Cedars-Sinai Medical Center.***

The American College of Rheumatology Workforce Study estimated that about half of practicing rheumatologists will retire within eight years, and that by 2025, there will be a shortage of 2,600 rheumatologists in the U.S. Because of this, the Lupus LA Board of Directors made a strategic decision in 2013 to establish a Rheumatology Fellowship Program with local institutions.

This program supports the training of a clinician/scientist over a two or three year period. Part of the fellow's responsibilities will be training doctors at various free clinics and hospitals in Los Angeles on how to recognize and diagnose lupus and how to treat lupus patients. The fellow will spend approximately 50% of their time on a lupus research project. 2014/2015 saw the completion of our first 2-year fellowship at Cedars-Sinai Medical Center. Our second fellow just began her three-year fellowship at Children's Hospital Los Angeles this past July 2015.

- ***Lupus LA Medical Advisory Board expands and advances its goals.***

The Medical Advisory Board (MAB) is comprised of medical and healthcare professionals dedicated to supporting the work of Lupus LA. Members hail from four of the leading Greater Los Angeles medical institutions: Cedars-Sinai Medical Center, UCLA Medical Center, UC-Irvine and Children's Hospital Los Angeles. Chaired by rheumatologists Andreas Reiff, MD, and R. Swamy Venuturupalli, MD, FACR, the MAB is a dedicated and passionate group of clinicians whose common goal is to find better treatment options for patients and eventually find a cure for lupus.

LUPUS LA *medical*  
advisory  
board

The MAB has put forth new initiatives during the 2014/2015 year. One of the group's primary goals is to encourage our hospital partners to come together and think about joint projects that can have a larger impact on the lupus landscape. It is our belief that when institutions work together the outcomes are more impactful to the greater good.

There were five new MAB members during the 2014/2015 fiscal year. They are: Jennifer Grossman, MD (Rheumatology), Paul W. Noble, MD (Pulmonology), Vaneet K. Sandhu, MD (Rheumatology), C. Andrew Schroeder, MD (Pulmonology), and Jason Snibbe, MD (Orthopedic Surgery).



*"To me, Lupus LA is the point where patient support melds with expert care and cutting edge research."*

- C. Andrew Schroeder, MD, Pulmonologist and Lupus LA Medical Advisory Board Member

# 2014/15 PATIENT SERVICES HIGHLIGHTS

- ***Lupus LA awarded 43 Lupus Emergency Grants totaling over \$18,000 to lupus patients in Greater Los Angeles.***

One of the cornerstones of our program department is our Lupus LA Emergency Grant program (LEG). Patients can receive up to \$500 annually to help cover costs of a lupus-related emergency. For example, this enables families affected by lupus to purchase life-saving medication and pay overdue bills. Since the LEG program's inception in 2009, Lupus LA has helped support 152 local lupus patients with grants totaling over \$60,000.

- ***Lupus LA sponsored 7 campers with lupus to attend The Painted Turtle to enjoy a summer camp experience.***

Lupus LA believes that every child deserves to experience "normal kid things" even when facing an illness like lupus. Lupus LA supports children with lupus and their families by offering campership grants to attend The Painted Turtle summer camp. The Painted Turtle is a specialty camp where children with lupus and other serious medical conditions celebrate just being kids. Lupus LA started this program in 2010 and has sponsored a total of 67 children.

- ***Lupus LA helped over 650 people this past year through individual consultations with our Program Services team.***

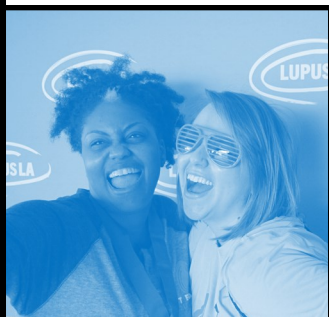
Having lupus can be overwhelming. Our Lupus LA program services team helps individuals and families figure out healthcare, find the right doctors, and can offer suggestions on dealing with a flare or other life issues. Since Lupus LA began, we estimate that over 2,400 patients have been helped through our individual consultation program.

- ***Lupus LA reached more than 480 people through our 8 adult support groups.***

Knowing that there are others dealing with the same issues as you are can be comforting. Our peer-to-peer and professionally led adult support group programs are run in 8 locations throughout Greater Los Angeles. Since the beginning of the Lupus LA adult support groups program in 2007, more than 2,300 lupus patients have participated throughout Southern California. Our current locations are: Alhambra, Baldwin Park, Irvine, Long Beach, Los Angeles, Ontario and Sherman Oaks, and a Spanish-language group in Boyle Heights.

- ***Lupus LA provided in-person patient education and advocacy training to 300 individuals this year through two "Latest on Lupus" patient conferences.***

Each year Lupus LA hosts two patient education conferences. One is in Irvine, and the other is in Los Angeles. The "Latest on Lupus" conferences include updates on the latest research and presentations by top doctors and clinicians in California, including members of the Lupus LA Medical Advisory Board. Patients and caregivers are able to ask questions and learn more about how to successfully manage their disease and advocate for themselves on important lupus issues. Over 1,800 people have attended the "Latest on Lupus" conferences since they began in 2008.



*"It is Lupus LA's patient programs, emergency grant fund, and commitment to raise funds for research that reaches far beyond the Los Angeles area that drew me to Lupus LA. Their commitment and focused dedication to the lupus community is unmatched on a national level."*

- K. Elle Jones, Lupus Patient

# 2014/15 ADVOCACY HIGHLIGHTS

- **Lupus LA advocates for our patient population by signing on to important letters and meeting with government officials and their officers to discuss pressing topics such as healthcare reform, patients' access to treatment, and prescription pricing regulations.**

This past year, Lupus LA signed onto 8 letters on behalf of lupus patients. Topics included: FDA inclusion of lupus in the Patient-Focused Drug Development Initiative, Supporting the 21st Century Cures Act, Non-interference in Medicare Part D, and asking the U.S. Department of Health and Human Services to adequately review plans for 2016 and to pass the Affordable Care Act.

Additionally, Lupus LA staff and representatives met with members of Senators Dianne Feinstein and Barbara Boxer's offices, Representative Xavier Becerra, and Congresswoman Lucille Roybal-Allard and her Field Deputy Talía León.

- **Lupus LA reaches out to the community through participation in health fairs, trainings and the California Partnership for Access to Treatment (CPAT) seminars.**

In 2014/2015, Lupus LA took part in six events throughout Greater Los Angeles and Southern California.



- **Lupus LA went to the Hill on behalf of lupus patients everywhere. Members of the Lupus LA staff and board advocated for better access to healthcare and other hot topics.**

On March 23-24, 2015, three members of the Lupus LA team went to lobby on Capitol Hill in Washington, D.C. The trip was organized by one of our research partners, the Lupus Research Institute (LRI), and included lupus groups from all over the country. Delegates met with a number of legislative aids from our Southern California region's leadership, including a one-on-one meeting with Congresswoman Lucille Roybal-Allard. There were four issues that our group discussed on the Hill:



- Speeding up new drug approvals and working to include the patient in the process by passing the 21st Century Cures Act legislation to improve how new drugs are tested and approved.
- Asking our leaders in Washington, D.C. to write to the FDA to recommend including lupus in public meetings on drug development.
- Asking to increase NIH funding to \$32 billion in 2016 for biomedical research to improve treatment for lupus patients.
- Encouraging legislators to support the Patient Access to Treatments Act (PATA) bill to make biologic drugs more affordable for patients.



*"When you have family members and friends with lupus you can't help but just want to learn and support your loved ones. That's what I did over 20 years ago when my identical twin sister was diagnosed with lupus. Now we advocate together and spread lupus awareness together in our hometowns, counties, state and nationally. Lupus advocacy and awareness is critical to finding a cure!"*

*- Kirsten Gee Maeda, Lupus Caregiver and Support Group Facilitator*

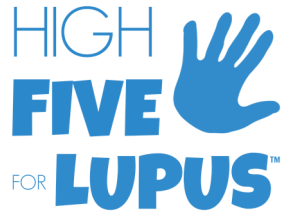


# 2014/15 AWARENESS HIGHLIGHTS

- **Lupus LA celebrated a new year with a new look with our revamped and expanded website.**

In May 2015, Lupus LA launched a brand new website ([www.lupusla.org](http://www.lupusla.org)). Our goals were to make the website visually appealing, easier to navigate, and more informative to patients, caregivers, and the lupus community everywhere.

- **The Lupus LA HIGH FIVE FOR LUPUS™ Campaign reached over 20 million people.**



Each May we celebrate Lupus Awareness Month. In May 2015, Lupus LA embarked on a new endeavor – the *HIGH FIVE FOR LUPUS™* campaign. *HIGH FIVE FOR LUPUS™* was a text-to-give campaign to raise awareness and financial support for Lupus LA's programs and research.

We asked our ambassadors, friends, and supporters to use their personal social media platforms to spread the word about lupus and help put an end to this debilitating disease. During the *HIGH FIVE FOR LUPUS™* campaign, we not only brought in much needed dollars, but through the magic of social media, we also reached over 20 million people.

- **In May 2015, the Lupus LA community helped to secure six Lupus Awareness Month proclamations across Greater Los Angeles.**

- **We added two new Lupus LA Celebrity Ambassadors to our roster in 2014/2015.**



Scott Michael Campbell, Mekhi Phifer, and Seal joined the ranks of the Lupus LA Ambassador Program. Dedicated celebrity ambassadors help Lupus LA spread messages about lupus awareness, new scientific discoveries, and Lupus LA happenings. The committee is charged with acting as a platform through which their fans and fellow celebrities can learn more about lupus and Lupus LA.



- **Lupus LA is making its mark on social media.**

Lupus LA is reaching more people through the magic of social media. Facebook, Twitter and Instagram feeds have grown substantially during the 2014/2015 fiscal year. Some of our social media highlights are:

- We have gained over 1,000 followers on Facebook over the past year with over 1,600 impressions per day.
- On Twitter, we have 6,200 followers with a daily average of 2,000 impressions per day.
- We have a total of 1,763 followers on Instagram.



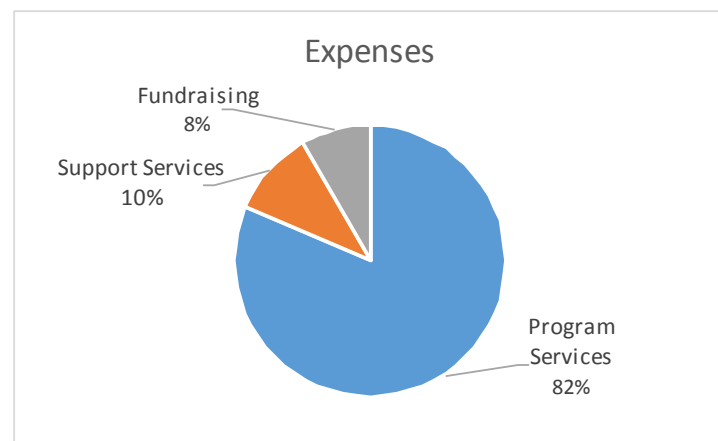
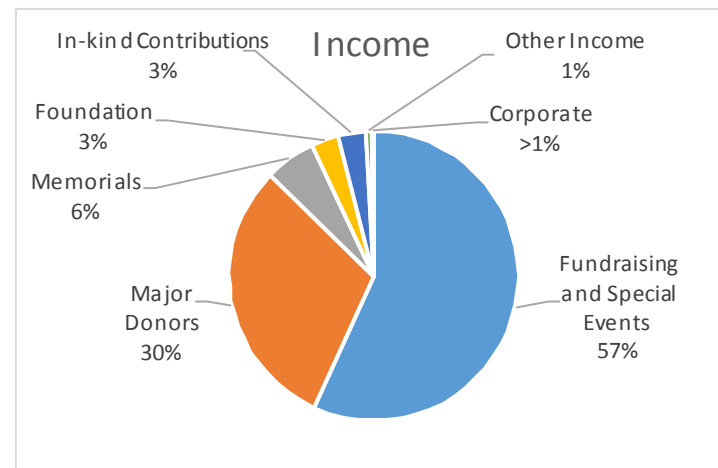
*"I knew my mother had lupus, and I wanted to find an organization to support that meant something to me personally and that organization is Lupus LA. My mission is to spread the word about lupus and further the research to help find a cure for my mom and others."*

- Michael B. Jordan, Actor and Lupus LA Celebrity Ambassador

# FINANCIAL STATEMENT

## LUPUS LA STATEMENT OF ACTIVITIES For the year ended June 30, 2015

	Unrestricted	Temporarily Restricted	Total
<b>Revenue and Support</b>			
Fundraising and Special Events	\$ 683,544		\$ 683,544
Major Donors	105,000	260,000	365,000
Memorials	71,023		71,023
Foundation	0	37,000	37,000
In-kind Contributions	35,000		35,000
Other Income	9,976		9,976
Corporate	1,750		1,750
Net Assets released from purpose restrictions	286,368	(286,368)	
<b>Total Revenue and Support</b>	<b>1,192,661</b>	<b>10,632</b>	<b>1,203,293</b>
<b>Expenses</b>			
Program Services	878,773		878,773
Support Services	109,330		109,330
Fundraising	88,511		88,511
<b>Total Expenses</b>	<b>1,076,614</b>		<b>1,076,614</b>
<b>Change in Net Assets</b>	<b>116,047</b>	<b>10,632</b>	<b>126,679</b>
<b>Net Assets, Beginning of Year</b>	<b>199,659</b>	<b>80,000</b>	<b>279,659</b>
<b>Net Assets, End of Year</b>	<b>\$ 315,706</b>	<b>\$ 90,632</b>	<b>\$ 406,338</b>



Selected financial data was derived from audited financial statements. Lupus LA is audited annually by independent auditors and complete audited financial statements are available upon request.



"I would especially like to express my sincere gratitude to the donors for my Lupus LA emergency grant. They are a true blessing in my life. I have always taken care of myself and my two children. I worked hard, sometimes having two jobs. I went from being a human resources director to a limousine driver to a very successful scrap metal trader to lupus. What a health and financial shock. I just want the donors to know that this is a wonderful gift and I do not take it or them for granted. Thank you for your help and support."

- Leslie, Lupus Patient



# OUR LEADERSHIP & STAFF

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*Founder:* Daniel J. Wallace, MD, FACP, FACR (Rheumatologist)

*Members: Rheumatologists:* Sheetal Desai, MD, MEd, Lindsay Forbess, MD, Jennifer Grossman, MD, Bevra Hahn, MD, Mariko Ishimori, MD, Maureen McMahon, MD, Renee Rinaldi, MD, Marilyn Solsky, MD, Vaneet K. Sandhu, MD, Michael H. Weisman, MD

*Other Specialties:* Rachel Abuav, MD (Dermatologist), C. Noel Bairey Merz, MD, FACC, FAHA (Cardiologist), Hart Cohen, MD (Neurology), Paul Hackmeyer, MD (Gynecologist), Caroline Jeffries, Ph.D. (Researcher), Paul W. Noble, MD (Pulmonologist), Jay N. Schapira, MD (Cardiologist), C. Andrew Schroeder, MD, FCCP (Pulmonologist), Jason Snibbe, MD (Orthopedic Surgeon)

## LUPUS LA STAFF

Toby L. Berkow (*Executive Director*), Katherine McMahon (*Program Manager*), Megan Stubbs (*Special Events Manager*),

Celia Membreno (*Special Events Associate*), Ruth Featherstone (*Administrative Associate*)



*"Lupus LA is a wonderful resource for anyone with lupus, or family members of those with lupus, to acquire information and support."*

*- Michelle & Alan Kaye, Parents of a Lupus Patient and Lupus LA Board Members*

# 2014/15 DONORS

Thank you to our donors for supporting the efforts of Lupus LA during our 2014/15 fiscal cycle. Through the generosity of the many people listed below and on the following pages, Lupus LA continues to help those who suffer from this devastating disease & strengthen their hope that life without lupus will soon be a reality.

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# CONTACT Us

To learn more about Lupus LA, please contact us at:

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Email: [info@lupusla.org](mailto:info@lupusla.org)

Or visit us on the web at [www.lupusla.org](http://www.lupusla.org).

