



# LUPUS LA

## 2015/16 ANNUAL REPORT



# FROM OUR CHAIRMAN

Dear Friends,

Thank you for taking the time to read the Lupus LA Annual Report. As you'll see, we've had quite a busy year and have accomplished great things. You'll also see that financially, we had a challenging year and I'd like to address that head on.

Fundraising for a disease that many people have, but few know about, has always been a substantial obstacle. Lupus LA was founded to raise money solely for research and to use our influence in Hollywood to raise awareness. Over our 17-year history we have done both those things and more. We added a full-scale patient services division and through that division have helped literally thousands of lupus patients and their families. We've lobbied from Sacramento to Washington, D.C., and we've created a Medical Advisory Board loaded with the best in the business.

Having a multi-faceted organization that fills many needs is expensive and throughout the years we've raised the money we've needed to grow. This year, we fell short of the goals we set for ourselves. We still provided all of the services and functions of the past and we expanded in some areas as well. We revamped all of our major fundraising events and still managed to fund a fellowship and some research, but not enough. Research is what drives hope for lupus patients and their doctors and it's critical we fund as much as possible. This year, we plan to redouble our efforts to procure major gifts, specifically those with a focus on research, and we urge you to work with us to achieve that goal.

There has never been a greater need for an organization as diverse, nimble, and dedicated as Lupus LA and we intend to rise to the challenges before us and meet the needs of our community. Please join me as we Rocket to the Cure (the theme for our 2017 Orange Ball at the California Science Center) and be part of the Lupus LA fight.



Adam Selkowitz  
Chairman



*"Lupus LA strives to help all people with lupus through our innovative programs, commitment to medical research, and sharing of information and awareness to all."*

- Adam Selkowitz, Lupus LA 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 \$1.4M 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 advocacy and awareness.

## 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



*"Supporting Lupus LA is important to me because it raises awareness about this chronic illness that is not well understood by so many people, provides services to patients who need support, and funds cutting edge research that is so important to finding the cause and cure."*

- Julie Tesser, Lupus LA Hollywood Bag Ladies Committee Member and Lupus Patient

# 2015/16 LUPUS LA HIGHLIGHTS

- **Lupus LA began a 3-year pediatric rheumatology fellowship with hospital partner, Children's Hospital Los Angeles.**

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.

Our fellowship 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.



In July 2015, Lupus LA began its second fellowship with the pediatric rheumatology division at Children's Hospital Los Angeles specializing in pediatric rheumatology patient care. There are **approximately 200 pediatric rheumatologists in the country** and most are concentrated in large urban areas. Pediatric rheumatological disease diagnosis is growing exponentially and the need for trained doctors and clinicians is desperate throughout the U.S.



- **Lupus LA funded over \$150,000 in support of our medical research programs.**

Lupus LA continued its work in supporting ground-breaking medical research each year by working with our national partners at the Lupus Research Institute and the Alliance for Lupus Research and with our local hospital partners at Children's Hospital Los Angeles and Cedars-Sinai Medical Center. Since 2000, Lupus LA has funded \$10.5 million to research endeavors.

- **The Lupus LA Medical Advisory Board continued its goals and expanded by two.**

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. This past year we added Loma Linda Hospital to our list.

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.

There were two new MAB members during the 2015/2016 fiscal year. They are Paul Hackmeyer, MD (Obstetrics and Gynecology), and Caroline Jeffries, PhD (Immunology Research).

LUPUS LA *medical*  
advisory  
board

*"It will be a great moment when a cure is found for this disease!"*

- Daryl Boren, Lupus LA Supporter



# 2015/16 PATIENT SERVICES HIGHLIGHTS

- **Lupus LA awarded 29 Lupus Emergency Grants totaling over \$12,400 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. Since the LEG program's inception in 2009, Lupus LA has helped support 181 local lupus patients with grants totaling over \$72,000.



- **Lupus LA reached more than 550 people through our 9 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, a Spanish-language group in Boyle Heights and our NEW group in the Crenshaw area.

- **Lupus LA sponsored 10 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 77 children.

- **Lupus LA helped over 1,332 people this past year through individual consultations with our patient services team.**



Having lupus can be overwhelming. Our Lupus LA patient services team helps individuals and families figure out healthcare and 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 3,700 patients have been helped through our individual consultation program.

- **Lupus LA provided in-person patient education and advocacy training to 292 individuals this past 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.



*"Lupus LA has given me support through the friendships that I have made, the conferences which I always attend, and the support group Alexis [her daughter and patient] attends."*

*- Bunny Pappas-Markowitz, Lupus LA Supporter and Mother*



# 2015/16 ADVOCACY HIGHLIGHTS

- ***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.***

In March of 2016, two 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 Karen Bass. There were three issues that our group discussed on the Hill:



- To support Funding to Strengthen Biomedical Research at the National Institutes of Health.
- To support the 21st Century Cures/Medical Innovation Legislation.
- To support the Creation of a DoD Lupus Medical Research Program.
- ***Lupus LA advocates for our patient population by signing on to important letters, taking a public stance on key issues 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 17 letters and 2 initiatives on behalf of lupus patients. Hot topics included: The Department of Defense Peer Reviewed Medical Research Program (PRMRP), the Lupus Initiative in the

Senate Appropriations Bill, the 21st Century Cures Bill, increased NIH Funding, increased funding for the National Lupus Patient Registry program at the Centers for Disease Control and Prevention, the Patient Focused Drug Development Initiative, and support of better ethics of Step Therapy & Autoimmune Disease Modernization.

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



In 2015/2016, Lupus LA took part in seven events throughout Greater Los Angeles and Southern California including the Urban League, the Irvine Yoga and Awareness event, a Wise and Healthy Aging event, and three California Partnership for Access to Treatment (CPAT) seminars.

- ***Lupus LA community members helped secure 6 proclamations in honor of Lupus Awareness Month in May 2016.***

Proclamations were awarded in the following areas: California State, Beverly Hills, Baldwin Park, La Puente, Simi Valley, and Los Angeles.



*"The social media aspect is hugely important because awareness is the key. Awareness is information, information is power."*

- Jill Blackstone, Lupus Patient



# 2015/16 AWARENESS HIGHLIGHTS

- **With the help of our Celebrity Ambassadors and guests, Lupus LA made a big impact in the media this past year with over 530,000,000 media impression surrounding our events. Publications included:**



People Magazine, OK! Magazine, Us Weekly, Extra TV, New York Daily News, Beverly Hills Courier, MSN.com, Just Jared, E-online, LA Confidential, Angeleno, Essence, The Huffington Post, The Doctors (TV), Celebuzz.com, Yahoo.com, LAGuestList.com, HollywoodLife.com, USMagazine.com, Beverly Hills Weekly, and many more...

- **The Lupus LA HIGH FIVE FOR LUPUS™ campaign reached over 15 million people.**

Each May we celebrate Lupus Awareness Month. In May 2015, Lupus LA continued its social media and text-to-give HIGH FIVE FOR LUPUS™ campaign.

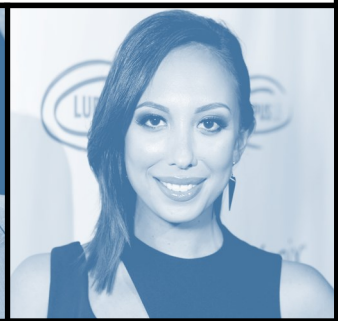
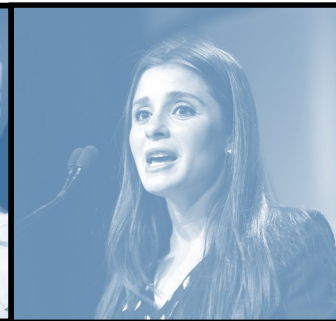


- **Lupus LA continued to expand our virtual presence by adding a patient-focused blog to our website and growing by leaps and bounds on social media.**

Lupus LA is reaching more people through the magic of social media and our website this year. Facebook, Twitter and Instagram feeds have grown substantially as well our overall website visitors. Some of our social media highlights are:

- We have gained over 2,000 followers on Facebook over the past year with over 2,500 impressions per day. That's almost double the growth we had the previous year.
- On Twitter, we have 7,230 followers with a daily average of 2,000 impressions per day.
- We have a total of 2,826 followers on Instagram.
- Our weekly blog posts have a wide reach into the lupus community and include posts by doctors, patients and other lupus-related professionals.
- **Lupus LA held 4 successful red-carpet events, helping to reach our fundraising goals for the 2015/2016 fiscal year.**

Lupus LA holds 4 large-scale events each year to raise both needed dollars and awareness through national and local media coverage. Over 1,800 people participated in our 2015/2016 events, which raised a combined total of over \$1,000,000.

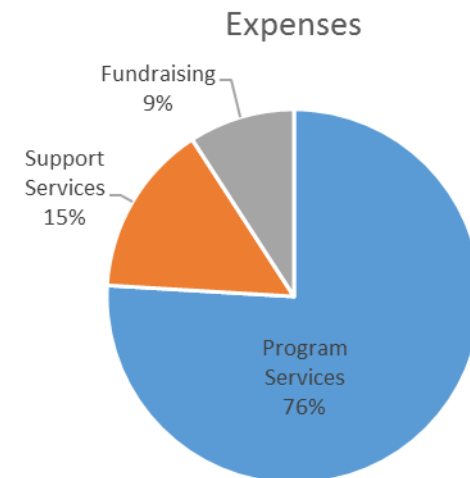
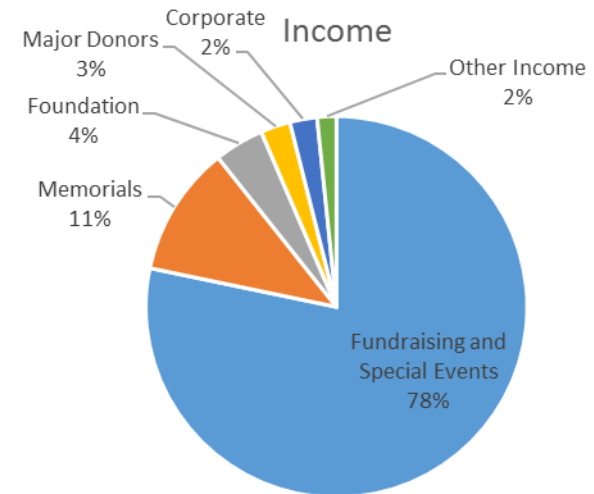


# FINANCIAL STATEMENT

## Lupus LA Statement of Activities

For the year ended June 30, 2015

	Unrestricted	Temporarily Restricted	2016
<b>REVENUE AND SUPPORT</b>			
Fundraising and Special Events	\$ 559,412	\$ -	\$ 559,412
Memorials	79,047		79,047
Foundation		30,100	30,100
Major donors	15,000	3,000	18,000
Corporate	16,500		16,500
Other income	11,666		11,666
In-kind contributions			-
Net assets released from purpose restrictions	123,732	(123,732)	-
<b>TOTAL REVENUE AND SUPPORT</b>	<b>805,357</b>	<b>(90,632)</b>	<b>714,725</b>
<b>EXPENSES</b>			
Program services	618,792		618,792
Support services	121,380		121,380
Fundraising	74,590		74,590
<b>TOTAL EXPENSES</b>	<b>814,762</b>	<b>-</b>	<b>814,762</b>
<b>CHANGE IN NET ASSETS</b>	<b>(9,405)</b>	<b>(90,632)</b>	<b>(100,037)</b>
<b>NET ASSETS, BEGINNING OF YEAR</b>	<b>315,706</b>	<b>90,632</b>	<b>406,338</b>
<b>NET ASSETS, END OF YEAR</b>	<b>\$ 306,301</b>	<b>\$ -</b>	<b>\$ 306,301</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.*



# OUR LEADERSHIP & STAFF

## BOARD OF DIRECTORS

Adam Selkowitz (*Chairman*), Debbi Cowan (*Vice Chair*), Denise Winner (*Treasurer*), Dorothy Ellis, (*Secretary*), Toni Braxton, Roger Cowan, Kathy Gallagher, Bridget Hood, Janet Janjigian, Alan Kaye, Michelle Kaye, Lauren Shuler Donner, Phil Sun, Nancy Utley, Daniel J. Wallace, MD, Janice Wallace

## MEDICAL ADVISORY BOARD

*Co-Chairs:* Andreas Reiff, MD (Rheumatologist), R. Swamy Venuturupalli, MD, FACP (Rheumatologist)

*Founder:* Daniel J. Wallace, MD, FACP, FACP (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, 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 has given me hope and support in not feeling alone in this journey."*

*- Nicole Fogel, Lupus Patient*

# 2015/16 DONORS

Thank you to our donors for supporting the efforts of Lupus LA during our 2015/16 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 and strengthen their hope that life without lupus will soon be a reality.

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 office at (310) 657-5667 or email us at [info@lupusla.org](mailto:info@lupusla.org).



# 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).

