



THE SEMI-ANNUAL PUBLICATION OF LUPUS LA

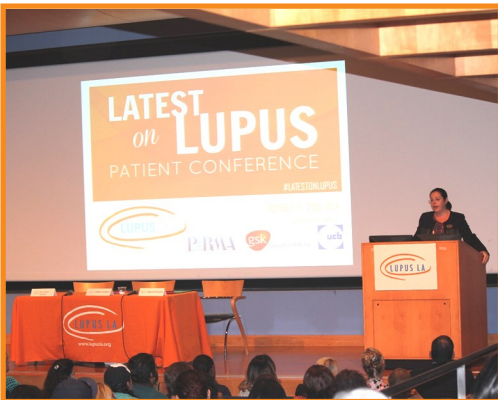
SPRING/SUMMER 2016

Educating Our Patients

The Latest on Lupus Patient Conference

By Katherine McMahon, Program Manager

"This was such a valuable, educational, and helpful conference." This sentiment was shared by a patient as she left the annual Los Angeles *Latest on Lupus* patient conference on October 17, 2015 at the UCLA Medical Center. Lupus patients gathered at the conference to learn more about the latest developments in lupus treatments and self-care.



Executive Director Toby L. Berkow addresses conference attendees.

The conference covered the most up-to-date research and treatments of lupus and commenced with a panel discussion that focused on the theme that "Motion Is Your Lotion: How Movement Helps Keep The Body Healthy." The panel included Dr. Jason Snibbe, orthopedic surgeon, who presented *Joint Health*; Karen Joubert,

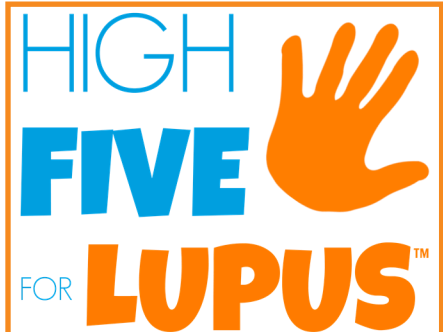
physical therapist who presented *Recovering from a Lupus Flare or Injury*;

Dena D'Angelo, certified yoga therapist who presented *Yoga Therapy for Lupus*; and Dr. R. Swamy Venuturupalli, Clinical Chief of Rheumatology at Cedars-Sinai Medical Center and Associate Clinical Professor of Medicine at the David Geffen School of Medicine at UCLA, who served as the moderator. The panel discussion was followed by a thorough and valuable question and answer session.

Next, Dr. Venuturupalli presented the *Latest on Lupus*. The informative
(Continued on pg. 3)



Dr. R. Swamy Venuturupalli discusses lupus.



Lupus Awareness Month Is Coming This May

Last May Lupus LA launched **HIGH FIVE FOR LUPUS™**, a text-to-give campaign to raise awareness and support for Lupus LA's programs and research.

We reached **over 20 million people** through social media, promoting awareness and support for lupus.

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Want more Lupus LA? Check out our new patient blog at WWW.LUPUSLA.ORG.

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Toby L. Berkow
Executive Director
Ext. 301

Katherine McMahon
Program Manager
Ext. 303

Megan Stubbs
Special Events Manager
Ext. 304

Celia Membreno
Special Events Associate
Ext. 305

Ruth Featherstone
Administrative Associate
Ext. 302

Lupus LA

8383 Wilshire Blvd.
Suite 232
Beverly Hills, CA 90211
310-657-5667

www.lupusla.org

Letter from the Chairman



At Lupus LA it seems like we go from one event to the next and hardly ever have time to catch our breath. We start the year with our Team Lupus LA 5K and Marathon teams and quickly transition into the Orange Ball in early May, then we jump into Get Lucky for Lupus LA in September and finish strong in November with the Hollywood Bag Ladies Luncheon. The variety of our events means that there is something for everyone and we try to appeal to as many lupus supporters as we can. We raise the majority of our budget from these events, and they are incredibly valuable in terms of media, public relations, awareness, and cultivation, but no organization can survive on events alone.

I want to take this opportunity to highlight our efforts to secure major gifts and why they are so important to our cause. Like almost all charities, the needs are greater than the resources we have and that forces us to make many decisions throughout the year as to what we are able to fund. Lupus LA is a full-service organization; we fund patient services including patient conferences, support groups, and emergency grants, as well as programs through our Medical Advisory Board. We help lupus patients find doctors and we send kids with lupus to camp every summer. We fund fellowships at local hospitals to bring new doctors into the fight against lupus and we fund groundbreaking research that we hope will eventually find a cure. We aren't able to fund all of these things every year, but that's always our goal.

The truth is, when a donor takes a special interest in one of our programs and when we can connect a donor to the intricate details of how that program works and why it is important to the lupus cause, a special connection is made and that donor can see his or her contribution come to life. Our research partners and our Medical Advisory Board have some really innovative ideas and programs that need funding and our goal is to make that connection to interested donors. We want to fund each and every solid idea and would like nothing more than to grow in our ability to provide money where it's needed, but our events can't do it alone and we need your help to push beyond the status quo.

What defines a major gift is different for every donor. You don't have to give millions of dollars to donate to one of these programs; we will work with any donor to direct whatever contribution he or she can make to the proper Lupus LA program as every contribution matters. I would encourage you to reach out to Lupus LA and talk to us about donating to one of our programs. We can provide more information and answer any questions you may have. And if this kind of giving doesn't appeal to you, we'll see you at the Orange Ball or Hollywood Bag Ladies Luncheon or Get Lucky for Lupus LA... you get the idea!

Thank you for your support of Lupus LA and for allowing us to break new ground with lupus patients and their families.

Adam Selkowitz, Chairman

Educating Our Patients

(Continued from pg. 1)

After lunch, Dena D'Angelo shared a powerful chair yoga demonstration and the conference attendees joined along in the movements. Participants shared that learning these yoga movements was very beneficial. Following the yoga demo, Mary Rosas, State Manager for GlaxoSmithKline (GSK), and Brandon Stephenson, Vice President for Cerrell Associates, helped empower the audience by sharing their expertise in advocacy work. The attendees were pleased to learn more about how they could get involved and felt motivated to create more opportunities for advocacy work.



Mary Rosas and Brandon Stephenson discuss advocacy with our patients.

The conference attendees shared that they left the conference feeling empowered and with a better understanding of lupus and the latest on lupus research. We would like to thank our sponsors, GSK, UCB Inc., and PhRMA, who enabled us to host the informative conference for patients and their families.

We are looking forward to our next *Latest on Lupus* patient conference, which will be held on June 25th at UC Irvine. For more information, please contact us via email at kmcmahon@lupusla.org, or call our office at 310-657-5667.



Left: Panelists (L to R): Dr. Jason Snibbe, Karen Joubert, Dena D'Angelo, and Dr. R. Swamy Venuturupalli.

Right: Conference attendees listen to the latest on lupus.



HAVE AN OLD CAR AND NEED TO GET RID OF IT?

Donate it to Lupus LA. You will get a tax write-off and Lupus LA will get a donation. Contact our partners at **www.donateforcharity.com** and schedule your pick-up today.



WE NEED YOU!

Lupus LA isn't an island, it's a village. A village of committed individuals, such as yourself, who pull together energy and resources to move Lupus LA forward. There are many ways to get more involved with Lupus LA. Here are our top 5:

1. Join our GO TEAM!

The "GO" in GO Team stands for Get Organized as the GO Team is a grassroots approach to organizing, raising awareness, and fundraising. Help get the word out and join the GO TEAM!

2. Volunteer

Lupus LA is always in need of extra hands either in the office or at an event. If you are interested in pitching in and lending your hand, let us know.

3. Donate

The generosity of our donors helps make our mission a reality – finding a cure for lupus. Support Lupus LA today.

4. Attend Our Patient Programs

Monthly support groups, patient conferences, and one-on-one counseling are just a few ways we help our patient population. Come check it out for yourself.

5. Spread the Word

A few great ways to enlist folks in learning more about lupus is by sharing our social media posts, being active in our HIGH FIVE for LUPUS™ campaign, and talking with others about this disease. One by one we can make a difference.

For more information about these and other ways to get involved, please visit our website at www.lupusla.org.

KISS LUPUS GOODBYE!



This past Valentine's Day weekend, over 90 walkers and runners came together as part of Team Lupus LA during the LA BIG 5K and Skechers Performance Los Angeles Marathon. Congratulations to all of the participants, who collectively raised over \$64,000! These funds will help support our patient services including the emergency grant program, Lupus LA local fellowships, and research for a cure. Special thanks to our top fundraisers: Team Immune Busters and Team Fogel. We are so thankful for all your support and dedication!



Kiss Lupus G-Bye (top to bottom): Team Lupus LA before the BIG 5K; Members of Team Fogel crossing the finish line; Mama Becky Ferrini and her family; Members of the Rotary Interact Club cheering on our runners.



Unbreak My Heart (top to bottom):

Lupus LA staffers with Toni; Cast members Skye P. Marshall and Lex Scott Davis; Dr. Jay Schapira, Toni, and Dr. Mariko Ishimori.



UNBREAK MY HEART L.A. PREMIERE

Stars were aligned for lupus on January 15th for the Lupus LA/Lifetime premiere party of *Toni Braxton: Unbreak My Heart*, a Lifetime original movie. Board member and Lupus LA Ambassador, Toni Braxton, was on hand along with the cast and many members of her family. Guests were treated to an early viewing of the film and partied late into the night. *Toni Braxton: Unbreak My Heart* is a story of love, perseverance and strength. The film chronicles Toni's journey to stardom through tremendous obstacles – including her lupus diagnosis. Both lupus and Lupus LA play important parts in the movie. *Toni Braxton: Unbreak My Heart*, which ran on Saturday, January 23rd, led the cable rankings with an impressive 3.62 million people watching, raising awareness and support for the disease.



SUCCESS WAS IN THE BAG

at the 13th Annual Hollywood Bag Ladies Luncheon

On Friday, November 20, over 500 guests joined together for Lupus LA's annual Hollywood Bag Ladies Luncheon. With cell phones in hand, these generous supporters bid on over 260 handbags, raising over \$98,000 in the silent auction alone. This year's committee focused on getting the best designers and boutiques in the city to donate, and Lupus LA was overwhelmed with all the donations received. Handbags were given by BVLGARI, Roberto Cavalli, Salvatore Ferragamo, Tom Ford, Ralph Lauren, Prada, Jake Gyllenhaal, Sharon Stone, Reese Witherspoon, and many more.

The luncheon kicked off with an exclusive Ted Baker fashion show and was hosted by Lupus LA Ambassador and TV personality, Terri Seymour. Jenni Pulos of *Flipping Out* served as auctioneer, and overall the event raised \$427,000 for lupus research and patient programs. Lupus LA was proud to honor three incredible women: Danielle Claman Gelber, Executive Vice President of Wolf Films and Executive Producer: Chicago Fire/Chicago P.D.; Eve Gerber, passionate philanthropist and lupus patient; and Peri Ellen Berne, longtime committee member.

Special thanks to sponsors 901 Too Salon, Cookie Casa, Fenix Cosmetics, Lancer Skincare, Massood Max, SmartyPants Vitamins, and Soupure.



In The Bag (top to bottom): Board member Janet Janjigian with honoree Danielle Claman Gelber; Lupus LA Founder Dr. Daniel J. Wallace and honoree Eve Somer Gerber; Model from the Ted Baker Fashion Show; Board members Michelle Kaye, Adam Selkowitz and Kathy Gallagher; Host and Lupus LA Ambassador Terri Seymour; Committee member Noah Alexander and honoree Peri Ellen Berne; Auctioneer Jenni Pulos shopping with Lupus LA supporters; and Marta Bloom and Kelly Stone Singer.



SELFIES FOR LUPUS LA!

HIGH FIVE for LUPUS™ is coming! Please plan on posting your own HIGH FIVE and asking others to do it too. The more high five selfies we can get onto social media, the larger the campaign will be. Remember, last year we reached over 20 MILLION people; this year we want to double that. Please consider posting a picture of your own HIGH FIVE for LUPUS™ this May.



**I'VE GOT A HIGH FIVE
WITH YOUR NAME ON IT!**



The Latest in Lupus Research

By Daniel J. Wallace, MD

The year 2016 opens with some very exciting new developments in the field of lupology. A few interesting examples are listed below.

It turns out that only 20% of lupus is due to a genetic component. Epigenetics, or how the environment influences the genome, is very important. Recent studies, for example, have suggested lupus patients have a unique microbiome, or bacterial makeup, in their gut. The ability to repair damaged DNA is by a process known as methylation. It is possible that certain foods 'hypomethylate' and these can make SLE worse, and other foods may be helpful, which in turn affect T cell function, and thus inflammation.

Lupus in the kidney, or nephritis, has often been confusing to follow because of the lack of consistency in how we measure it. A group in Chicago has made the revolutionary finding that the prognosis of nephritis relates more to a structure in the kidney known as the interstitium as opposed to the glomerulus. This implies that the way we have been reading kidney biopsies for the last 30 years is wrong. Using newer forms of imaging and biomarkers, in the next 2-3 years, without performing serial biopsies, we should be able to assess and learn how to better manage lupus nephritis.

The failure of several large Phase III trials has been the result of inadequate study design rather than the failure of the drug to work. For example, agents known to be useful for the disease, such as mycophenolate (Cell Cept) and rituximab, failed in several studies. Several groups are now looking at different primary end points, or outcomes, which make more sense, based on data from double blind studies to find out which type of testing does work. Also, a group working with the newly formed Lupus Research Alliance is studying repurposing, or using drugs already on the market for other diseases and known to be safe, for SLE. The first patients are going to be enrolled in the next few months.

Finally, new FDA guidelines for developing lupus drugs may appear in the next year. This will accelerate the development of new drugs and several new classes of agents, such as small molecules, anti-cytokine therapies and toleragens will be tested.

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You shop. Amazon gives.

Give to Lupus LA by making purchases through Amazon.com.

The AmazonSmile Foundation will donate .05% of the purchase price from customers' eligible purchases to Lupus LA. Simply log-on to Amazon through **www.smile.amazon.com** and choose Lupus LA as your designated charity. .05% of your purchase will be donated to Lupus LA to help find a cure for lupus.

Find a Group

Lupus LA's support groups are a great resource for people living with lupus and their loved ones. Join us at one of the following groups to learn more about lupus and how to live well with this chronic illness. Our support groups are free, confidential, and open to the public. For more information about the Lupus LA adult support groups and our pediatric support group at Children's Hospital Los Angeles, please contact Lupus LA at 310-657-5667 or via email at kmcMahon@lupusla.org.

Irvine Support Group
First Monday of the month
From 7:00 PM to 9:00 PM
University United Methodist Church
18422 Culver Drive
Irvine, CA 92612

Loom 4 Lupus Support Group
Second Saturday of the month
From 9:30 AM to 11:30 AM
Kaiser Permanente, Educational Outreach Program
4141 Maine Avenue
Baldwin Park, CA 91706

Spanish-Language Support Group
Primer Jueves del mes
De 7:00 PM a 8:30 PM
Clínica Oscar Romero, Sala 35
2032 Marengo Street
Los Angeles, CA 90033
(En frente del hospital general de USC)

Support Near You

Alhambra Support Group
Third Tuesday of the month
From 6:30 PM to 8:00 PM
 Alhambra Civic Center Library
 2nd floor Conference Room
 101 S. First Street
 Alhambra, CA 91801

UCLA Support Group
First Tuesday of the month
From 6:30 PM to 8:00 PM
 Rheumatology - Rehabilitation
 Center Building
 3rd Floor - Library
 1000 Veteran Avenue
 Los Angeles, CA 90024

**Howse Foundation &
 Lupus LA Support Group**
Second Saturday of the month
From 10:30 AM to 12:00 PM
 Olive Branch Diagnostic
 Imaging
 Women's Health Center
 10722 Arrow Route, Suite 520
 Rancho Cucamonga, CA 91730

Sherman Oaks Support Group
Second Tuesday of the month
From 6:30 PM to 8:00 PM
 Circle of Care Conference
 Room, Sherman Oaks Hospital
 4929 Van Nuys Boulevard
 Sherman Oaks, CA 91403

Long Beach Support Group
Fourth Tuesday of the month
From 6:30 PM to 8:00 PM
 Miller Children's Hospital Long
 Beach
 Children's Hospital Pavilion,
 Conference Room B
 2801 Atlantic Avenue
 Long Beach, CA 90806

NEW GROUP ANNOUNCEMENT
Crenshaw Support Group
Second Tuesday of the month
From 7:00 PM to 8:30 PM
 West Angeles Church
 Multipurpose Bldg. Rm 7
 3045 Crenshaw Blvd.
 Los Angeles, CA 90016

NEW

Will this drug help people and be safe to take?

Clinical trials help answer this question. At any given time, there are thousands of clinical trials being conducted. In the past several years, the number of lupus clinical trials has increased significantly.

Lupus LA is a proud member of the LRI National Lupus Coalition dedicated to finding new and safer options for treating and preventing lupus. Clinical trials are critical in the search for a better life for people with lupus. Participation of people with lupus in clinical research is the way to make this a reality. To learn more about clinical trials and to see if you are a possible candidate, check out www.lupustrials.org.



High Five For Lupus

(Continued from pg. 1)

We are asking our Lupus LA friends to use their personal social media to spread the word about lupus and help put an end to this debilitating disease.

To participate in this program, text the word **HIGHFIVE to 20222** and a \$5 donation will be given to Lupus LA through your cell phone bill. Simply look out for our **HIGH FIVE FOR LUPUS™** posts in the month of May and share them with your social media followers or write your own. We encourage you to post a picture of your own **HIGHFIVE** on your Facebook/Instagram pages with the hashtag #HIGHFIVE and we can share them too. For more information, please visit us at www.lupusla.org.



*MARK YOUR
CALENDAR!*

LATEST on LUPUS

PATIENT CONFERENCE

UC IRVINE | SATURDAY, JUNE 25 | REGISTER AT WWW.LUPUSLA.ORG



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8383 Wilshire Blvd., Suite 232
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P: 310-657-LOOP (5667)
E: info@lupusla.org

www.LupusLA.org

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Lupus LA is dedicated to finding the causes of and a cure for lupus, while offering support to people with lupus throughout Greater Los Angeles.

