

LUPUS LA

Member of the Lupus Research Institute National Coalition • Spring 2015

YEAR OF THE HERO

As the saying goes, we all “need a hero” and 2015 is our year of the lupus superhero. For the past few months you have been receiving stories about Lupus LA heroes who inspire us, support us, and help to find a cure for lupus. We hope that you have been enjoying learning about each of these very special people.

Lupus LA believes that by the retelling of people’s stories, we can build upon our lupus community. We will continue to celebrate and share lupus superheroes of all kinds with you throughout the year. Coming up on June 6, 2015, Lupus LA will present the Orange Ball: A Night of Superheroes, honoring four wonderful members of our community: actor, Michael B. Jordan; pulmonologist, Dr. C. Andrew Schroeder; and philanthropists, Michelle and Alan Kaye. To learn more about this fun-filled night on the Fox Studios “New York Street” set, check out www.lupusla.org.



Coalition Members of the LRI gather together for a group picture before heading to the Hill.

Advocacy on the Hill

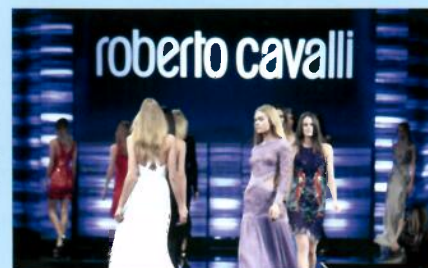
On March 23-24, 2015, three members of the Lupus LA team went to lobby on Capitol Hill in Washington, D.C. The trip was organized by the Lupus Research Institute (LRI), our research partner, and included lupus groups from all over the country. We were able to meet with a number of legislative aids from our 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 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.

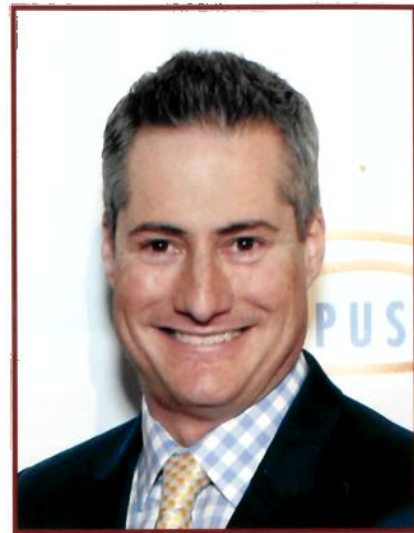
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You know it's spring when the Lupus LA marathon and 5K teams start walking and running for lupus. This year they walked and ran their way to raise over \$95,000 for Lupus LA! Led by Team Wallace and Team Fogel, our impressive group of over 130 participants had a strong presence at the event and garnered significant press along the way.



Spring also means we're about to produce our biggest event of the year, the Orange Ball. This year we decided to shake things up, provide a fresh take to our audience and do something out-of-the-box to generate even more excitement for the event. We think we've come up with something sensational. With the help of our primary corporate sponsor, 20th Century Fox, and our dinner chairs, Lauren Shuler Donner, Nancy Utley, and Jim Gianopulos, we have landed on the Fox lot on the famed "New York Street" set. A new theme, an Evening of Superheroes, is the backdrop as we will celebrate our stellar group of honorees, Michael B. Jordan, Michelle and Alan Kaye, and C. Andrew Schroeder, MD. If you've never been to the Orange Ball or haven't been in a few years, I urge you not to miss this superhero street party for lupus.

Spring is also a time to celebrate Lupus Awareness Month. Each May we work to find new ways to engage the public and spread the word about lupus. Lupus Awareness Month is significant because it shines a spotlight on those living with lupus and provides an opportunity to educate non-lupus patients about this disease and its symptoms. This year we are launching a nationwide text2give campaign where we will enlist our celebrity ambassadors and other friends of Lupus LA to use their social media following to raise money and awareness. This program, High Five for Lupus, provides an easy way for people to text "HIGHFIVE" to a designated number to donate \$5 to Lupus LA. Our goal is to reach over 50 million people over the course of Lupus Awareness Month—that's awareness at its best. I would encourage all of you to join our campaign and do what you can this May to help us educate, engage, and enlighten the world about lupus.

On behalf of the entire board of directors of Lupus LA, I wish you a wonderful start to your summer season and hope that you'll be able to come celebrate the superheroes of lupus at the new and improved Orange Ball on June 6th.

With thanks,

A handwritten signature in black ink, appearing to read 'Adam Selkowitz'.

Adam Selkowitz

Lupus Awareness Month

May is Lupus Awareness Month and Lupus LA has an exciting new project we are launching on May 1st called **HIGH FIVE FOR LUPUS™**.

HIGH FIVE FOR LUPUS™ is a text-to-give campaign to raise awareness and support for Lupus LA's programs and research.

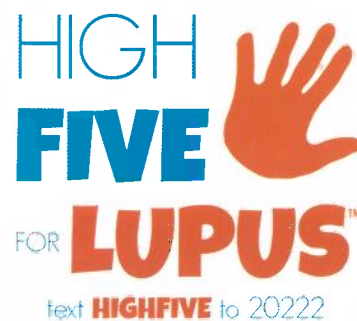
We are asking our ambassadors, friends, and supporters to use their personal social media platforms to spread the word about lupus and help put an end to this debilitating disease.

To participate in this program, people can text the word **HIGHFIVE to 20222** and a \$5 donation will be given to Lupus LA through their 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 also post a picture of your own **HIGH FIVE** on your Facebook/Instagram pages.

How are you going to show your support for the month of May? Please let us know at info@lupusla.org, and you might just find yourself on our next social media post.

For more information about this campaign, please visit us at www.lupusla.org.



Welcome New Board Member Denise Winner



Denise Winner

Denise Winner joined the Lupus LA Board of Directors this past March. Denise has significant experience in finance and is the President of Winner Squared, Inc., a consulting firm providing financial engineering and analytics, research and technology solutions for banks, insurance companies, hedge funds and startups. In her free time, Denise

is also an avid tennis player, an elite ultra-marathon runner, a mom, and a lupus patient.

In addition to her professional expertise and her passion for Lupus LA, Denise brings years of nonprofit leadership experience to the table as she sits on a number of boards and committees, including a domestic violence agency and her alma mater, the University of Pennsylvania.

Denise has already jumped in with both feet by serving on the Hollywood Bag Ladies Luncheon committee. As a board member, she is looking forward to serving on our audit committee and helping with technology.

ADVOCACY, continued from page 1

- 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.

Now you can help make sure **every member of Congress** hears how they can help lupus patients by becoming a virtual advocate. Use LRI's automated Legislative Action

Center (<http://www.congressweb.com/lri>) to email your federal legislators and ask them to help find a cure for lupus.



Meeting on the Hill with Congresswoman Lucille Roybal-Allard. (From L to R: ED Toby Berkow, program director Katherine McMahon, Congresswoman Roybal-Allard, board member Bridget Hood)

Success Was in the Bag!

At the 2014 Hollywood Bag Ladies Luncheon at the Beverly Hilton this past November, over 500 guests were treated to a bevy of beautiful purses, a jaw-dropping fashion show by Roberto Cavalli, and our amazing women of achievement honorees, award-winning producer Bruna Pappendrea and philanthropist and board member Kathy Gallagher.



Honoree Kathy Gallagher accepting her award.

Hosted by longtime supporter and Lupus LA Ambassador Paula Abdul, the star-studded crowd welcomed Reese Witherspoon to celebrate and honor her dear friend and producing partner Bruna Pappendrea. Witherspoon knew little about lupus prior to meeting Bruna. In her remarks, Witherspoon commented that "watching my friend battle this disease with such grace and strength has inspired and awed me. Bruna shows us all that anything is possible with the right attitude and determination." Pappendrea, who juggles many roles as producer, mother of twins, wife, and lupus patient, shared that "if everything happens for a reason, then I believe I was meant to be an advocate and voice to help find a cure for this disease. It means so much to me that all of

you have come out today to help lend a hand."

Board member Kathy Gallagher sparkled in Cavalli as she accepted an award for her hard work and commitment to finding a cure for lupus. Fellow board member Michelle Kaye presented Gallagher with her award, sharing that Gallagher's "go-getter" attitude has helped to advance our organization and our ability to help to find a cure for lupus. Gallagher shared that she "can think of no other organization that does so much for those who need it. In such a relatively short time, a mere 14 years since Dr. Wallace founded it, Lupus LA has become the single most vital resource for information, research, awareness, support groups and, of course, hope."

Lupus LA is grateful for the generous support of our sponsors and donors to help make this luncheon a major success. Over \$385,000 was raised to support the programs and research of Lupus LA.



Walking the red carpet together were author Cheryl Strayed, honoree Bruna Pappendrea, and presenter Reese Witherspoon.



Ladies who lunched together included (L-R) Joan Robbins, Carolyn Folks, Event Co-Chair Janice Wallace, and Janice Arouh.



Board members (L-R) Denise Winner, Janet Janjigian and Michelle Kaye enjoy looking at the bags together.

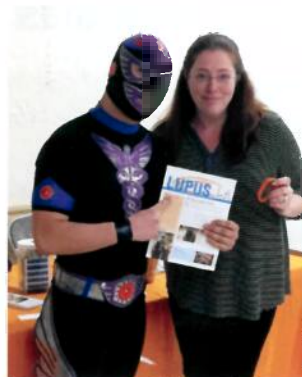


Host Paula Abdul

Wrestling for Lupus LA

Lupus LA supporter Bill Chew wanted to host an event in his community of Van Nuys to benefit patient programs and lupus research. As a sports promoter with a passion for WWE wrestling, Bill arranged for a night of professional wrestling at the Knights of Columbus Hall in Van Nuys with proceeds benefiting Lupus LA. Executive Director Toby Berkow was on hand to see the action and talk with people about lupus. It was a night to remember with over 130 people in attendance.

Interested in throwing your own Lupus LA fundraiser, become a member of the Lupus LA **GO TEAM** and check out the "Host An Event" page on our new website launching in May.



Main event winner Mercurio Jr. and Toby Berkow pose for a picture before the big match.



Wrestling producer and event promoter Bill Chew holds the winner's award in honor of Lupus LA.

Running for Team Lupus LA

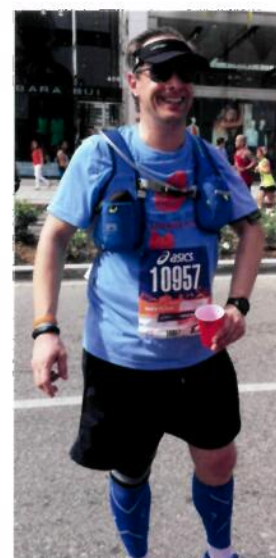
Over 130 runners joined forces as TEAM LUPUS LA took part in the ASICS LA Marathon and Big 5K on March 14-15, 2015. The weekend of festivities started at our carb-laden pasta dinner on Thursday, March 12th, at Maggiano's at The Grove, where 50 of our participants got ready for the race. On Saturday, Lupus LA met at the Ketel One Club at Dodger Stadium to run the 5K. Participants included *Jane the Virgin* star, Brett Dier, and girlfriend, *Ravenswood* star, Haley Lu Richardson; Santana Dempsey of *Life's a Drag*; Josh Brennan of *Silicon Valley*; and Lupus LA Ambassador Kristen Renton from *Sons of Anarchy*. On Sunday, the Interact Club of Beverly Hills High School joined Lupus LA staffers at our cheer station on Rodeo Drive to rally for our marathon runner, Christophe Stahl. Congratulations to all of the participants, with a special BIG thank you to the members of Team Fogel and Team Wallace who collectively raised \$66,000. Together the weekend raised over \$96,000 for Lupus LA.



Melitta Johnson and friends at the 5K.



Team Lupus LA members (L-R) Liz Morasso, Elle Jones, Megan Stubbs Hatch and Nicole Fogel at the 5K.



LA Marathon runner Christophe Stahl taking a break at our Rodeo Drive cheer station.



Proud 5K runner for Lupus LA.

Medical Advisory Board is GROWING!

We are pleased to announce the addition of five new doctors to our Medical Advisory Board (MAB). Please welcome Dr. Paul Noble, Chair of the Department of Medicine (Cedars-Sinai - Pulmonology), Dr. Hart Cohen (Cedars-Sinai - Neurology), Dr. Jennifer Grossman (UCLA - Rheumatology), Dr. C. Andrew Schroeder (Cedars-Sinai - Pulmonology), and Dr. Jason Snibbe (Cedars-Sinai - Orthopedic Surgeon).

The MAB is comprised of medical and healthcare professionals dedicated to supporting the important work of Lupus LA, including expanding patient services and funding novel research. Headed by Co-Chairs, Dr. Andreas Reiff of Children's Hospital Los Angeles and Dr. R. Swamy Venuturupalli of Cedars-Sinai, our MAB met this past fall and discussed a variety of topics including

new lupus research, collaborations between local institutions and the work of our current research fellow.

The MAB has also agreed to create a series of video blog

posts called "Ask an Expert" for our patients. This blog will be unveiled in late May along with our new website. If you have a specific question that you would like to ask one of our experts, please email kmcmahon@lupusla.org. Please note that we will not be able to answer everyone's questions through the blog, but we will do our best to follow-up via phone or email.



Clinical Trials – A Call for Action

Clinical trials help to answer the question, "Will this drug help people and be safe to take?" 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 National Coalition of state and local lupus organizations through the Lupus Research Institute. The National Coalition is dedicated to finding new and safer options for treating and preventing

lupus. It is the National Coalition's belief that together with you and thousands of lupus patients around the country, we can make a difference.

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.

And the Golden Globe Goes to...

Lupus LA was once again the official charity at the DPA gifting suite run by Nathalie Dubois-Sissoko at the Luxe Hotel on Rodeo Drive—this time for the Golden Globes. Attending these types of events is a great way to promote lupus awareness and the work of Lupus LA. At the suite, we met with many celebrities from both television and movies, shared information about lupus, and asked folks to help by proudly wearing their Lupus LA orange bracelets. We look forward to continuing our relationship with DPA and raising awareness for lupus and Lupus LA.



Tasha Smith and Angela Bassett don orange bracelets for lupus awareness with staffers Megan Stubbs Hatch and Celia Membreno.

Los Angeles Patient Conference

The annual Los Angeles Latest on Lupus patient conference was held on December 6, 2014, at the UCLA Medical

Center. The conference brought together a wide range of lupus patients who were eager to learn more about the latest developments in lupus treatments. The 150 attendees reported that the conference served as an exciting opportunity for them to hear from the best and the brightest in the field of lupus research and care.



Attentive participants listened to our speaker.

The conference consisted of four presentations that broadly covered the most up-to-date research and treatments for lupus.



Dr. Dan J. Wallace spoke on the latest trends in lupus treatment and care.

The conference commenced with a panel led by rheumatologist Dr. Jennifer Grossman, who discussed *Lab Tests & Lupus*; rheumatologist Dr. Maureen McMahon, who discussed *Lupus & the Heart*; and

pulmonologist Dr. C. Andrew Schroeder, who discussed *Lupus & the Lungs*. Following the panel, Dr. Daniel J. Wallace, rheumatologist and Lupus LA founder, presented *Latest on Lupus*. An informative question-and-answer period followed both presentations.

After lunch there were two more sessions. The first one was given by board-certified dermatologist, Dr. Rachel Abuav. Her discussion on *Lupus and the Skin* focused on patients with complex dermatologic conditions (often recalcitrant to first-line therapies), autoimmune blistering

disorders, rheumatologic diseases, and the cutaneous manifestations of systemic disease. The last presentation of the day was led by Lupus LA board member Bridget Hood. Hood discussed the importance of patient advocacy and helped empower the audience by sharing her personal journey in advocacy work and how others can get involved. The attendees reported that they left the conference with a better understanding of lupus and the latest on lupus research.



Lupus LA staffers with volunteer Sylvia Masera (center).



ED Toby Berkow with board members: Bridget Hood, Alan & Michelle Kaye, and Kate Kelly.

We would like to thank our sponsors, GlaxoSmithKline (GSK) and UCB Inc., 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 27th at UC Irvine. For more information, please email us at kcmahon@lupusla.org or call our office at (310) 657-5667.



Fellowship Update

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. In light of these staggering numbers, Lupus LA is committed to the training of new doctors in the field of rheumatology in Southern California.

In 2013, Lupus LA began a two-year fellowship at Cedars-Sinai Medical Center. Our current fellow, Vaneet Sandhu, MD, is about to finish her second year. Dr. Sandhu's work focused on both research and patient care. About 50% of her fellowship was dedicated to 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 remainder of her time was spent on lupus research projects. We wish to thank Dr. Sandhu for her energies in helping make lupus care and treatments more accessible. Dr. Sandhu will move on to a junior faculty

position with the Loma Linda School of Medicine in the Division of Rheumatology. Dr. Sandhu's major clinical and research interests involve lupus and related autoimmune disorders. She will be setting up clinics at the medical school that emphasize the diagnosis, treatment and management of these diseases, as well as teaching medical students, interns, residents and fellows. She will start July 15, 2015, and represents a much needed resource who will provide clinical excellence in San Bernardino and Riverside counties. We wish her much success and look forward to our continued relationship.

Lupus LA will start its next fellowship in July 2015 at Children's Hospital Los Angeles. This is a three-year fellowship specializing in pediatric rheumatology. The focus of this fellowship will be patient care. For more information on our fellowship program, please contact us at info@lupusla.org.

LUPUS LA SUPPORT GROUPS

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 and/or 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

Looms 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

Clinica Oscar Romero, Sala 35
2032 Marengo Street
Los Angeles, CA 90033
(En frente del hospital general de USC)

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

Kids of All Ages at the CHLA Holiday Party

Lupus LA co-hosted the 2014 Children's Hospital Los Angeles' Department of Rheumatology Holiday Party. The families celebrated the holidays and their successful year of support groups as they snapped pictures in the photo booth, enjoyed food, and mingled with Disney characters Elsa, Anna and Sven from *Frozen*. Joining the fun were Lupus LA Ambassador Phill Lewis and actress Taylor Spreitler, who helped hand out presents to every child. The presents were graciously donated by a Lupus LA family.

The guests of the party are part of the Pediatric Support Group at Children's Hospital Los Angeles. Meetings are held once every two months from 9:00 am to 11:30 am at Children's Hospital Los Angeles. There are separate discussion groups for younger children, older teens, and parents (including a group for Spanish-speaking parents). Each session focuses on a specific aspect of life with a rheumatic illness. Your family is welcome to attend one or all of the sessions. Siblings older than 5 years may participate in supervised arts and crafts during the meetings.

For more information, contact Katherine McMahon at kcmahon@lupusla.org or at (310) 657-5667.



Teens thank the support group sponsors and CHLA staff.



Lupus LA Ambassador Phill Lewis helps distribute gifts to guests.



Guests were greeted by *Frozen* characters, Anna, Elsa and Sven.



(L-R) Lupus LA Medical Advisory Board Co-Chair and Head of Pediatric Rheumatology at CHLA, Dr. Andreas Reiff poses with CHLA Social Worker Maggie Sepkowitz, Lupus LA Chairman Adam Selkowitz, Phill Lewis, Taylor Spreitler and guest.



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LUPUS LA'S ORANGE BALL
PRESENTS
**A
NIGHT
OF
SUPERHEROES**

HONORING

MICHAEL B. JORDAN
LOOP AWARD

MICHELLE AND ALAN KAYE
DANIEL J. WALLACE FOUNDER'S AWARD

C. ANDREW SCHROEDER, MD
MEDICAL VISIONARY AWARD

SATURDAY, JUNE 6
6:30 PM - 10:30 PM

FOX STUDIOS

"NEW YORK STREET"
10201 WEST PICO BLVD., LOS ANGELES

PURCHASE TICKETS AT WWW.LUPUSLA.ORG

CITY CHIC ATTIRE
EMBRACE YOUR ORANGE SIDE!

COME JOIN THE SUPERHERO STREET PARTY
FEATURING LIVE MUSIC, SURPRISE ENTERTAINMENT,
EXCITING FOOD STATIONS, AWARDS, AND MORE!

EVENT CHAIRS

Jim Gianopulos Lauren Shuler Donner Nancy Utley

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