

LUPUS LA

West Coast Division of the S.L.E. Lupus Foundation • Member of the Lupus Research Institute National Coalition • Fall/Winter 2013

Lupus LA Partners with Saks 5th Avenue

On the evening of Sept. 26, more than 150 Lupus LA guests listened to tunes spun by a DJ, drank champagne, indulged in desserts, had their lip prints read and their nails done, sat for complimentary treatments and makeovers with renowned make-up artists and shopped at the Saks 5th Avenue Beverly Hills store.

They were all at “Master the Look,” a fun and lively ladies night out (with a few good men) in the cosmetics department of Saks 5th Avenue. The event hosts, Lupus LA board members Janet Janjigian, Janice Wallace and Michelle Kaye, and supporters Janice Arouh and Sheila Milstein, were thrilled to see so many of the guests they

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Lupus LA is Running on Full

2014 marks the fifth year that Team Lupus LA will be participating in the ASICS LA Marathon. Formerly known as Team Life Without Lupus, Team Lupus LA has a new name and a new attitude. Runners and walkers from different backgrounds are joining the team and are already training and fundraising for the March event. Members of Team Lupus LA will run and walk in the LA 5K, Charity Relay and the ASICS LA Marathon, to be held March 8-9, 2014.



Lupus LA is a premier charity in the ASICS LA Marathon and has been a top ten fundraiser in the marathon for the last three years. This premier status is also a big benefit to the team members. On the morning of the marathon, members of Team Lupus LA will gather in their own suite at Dodger Stadium as they gear up for the big race. The organization will be highlighted by the ASICS LA Marathon on its website, in an email blast and at the marathon expo.



Lupus LA board member Kathy Gallagher at mile 16.

This year, Team Lupus LA's goal is to raise \$85,000! Team members commit to raising funds by asking for donations in support of their run. Lupus LA provides the team with certified trainers and offers lots of fun incentives along the way. Special events manager, Megan Hatch says,

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LETTER FROM THE CHAIRMAN

Dear Friends,

Everywhere you look these days it seems like you're seeing and hearing about lupus. That is great news. Whether it's the new public service ads running on television, the national media attention received by celebrities like Toni Braxton and Michael B. Jordan, or the interwoven storylines that contain lupus on some of television's most-watched shows, the word "lupus" is growing.

One of the most important aspects of the Lupus LA mission is to foster that growth and to do everything we can to get the word out. Sometimes those efforts take years to pull off and sometimes they come out of the blue, but each and every press mention or Facebook post or celebrity tweet helps to educate the public about lupus, and each time we educate someone new that opens the door to more money being raised, more research being funded, and more people getting the help they need.

The Lupus LA Ambassador Program is a big part of our effort to educate the public, and thanks to Ambassadors like Michael B. Jordan, Melissa Joan Hart, Parminder Nagra, Scott Grimes, and Paula Abdul, we are able to reach a diverse group of people around the world. And these Ambassadors are getting involved! Bob Guiney recently hosted the Get Lucky for Lupus LA poker event, and Phill Lewis is working with our corporate partner, Coffee Bean & Tea Leaf, on the exciting roll-out of a children's book, proceeds of which go to Lupus LA's research effort. Meredith Monroe and Ali Hillis have helped the poker event thrive, and Kellie Martin hosted a special benefit for a lupus patient in need.

Our events are incredibly successful, but what makes them truly valuable to the lupus community is how we use those events to reach well beyond the borders of Los Angeles and how that translates into exponential progress for the lupus community. We've also begun another exciting program called SAVI (Social Awareness Volunteer Initiative). SAVI is a team of dedicated social media influencers who are doing their part to dramatically raise our online presence, and they have already greatly increased our social media footprint.

I encourage all of you to be a part of this movement. Follow us on Twitter (@LupusLA) and "like" us on Facebook, support our Ambassadors, and help the SAVI team spread the word about lupus and Lupus LA.

Before I close, I want to give a special welcome to our newest Lupus LA board member, Phil Sun. Phil is an extremely successful talent agent at William Morris Endeavor (WME) whose mother is a lupus patient. Phil is lending his skills to our board and I know he will make a big impact for the organization.

Please enjoy the newsletter and feel great!



Adam Selkowitz
Chairman



Sun Shines Bright on Lupus LA Board

Lupus LA is very pleased to welcome Phillip Sun to the Lupus LA board of directors. Phil is an agent in the motion picture department at WME, where he works with a diverse list of clients, including Sophia Bush (*Chicago PD*), Idris Elba (*Long Walk To Freedom*), Lance Gross (*House of Payne*), Michael B. Jordan (*Fruitvale Station*), Sung Kang (*Fast & Furious 6*), and Sullivan Stapleton (*300: Rise of an Empire*). He is also part of the teams that represent Tyler Perry (*Alex Cross*), Jack Reynor (*Transformers 4*), Adam Sandler (*Grown Ups 2*), Charlize Theron (*Mad Max: Fury Road*), John Travolta (*Savages*) and Robin Williams (*The Crazy Ones*).

Sun began his career in the William Morris Agency mailroom. He worked as an assistant in the television and

film departments at WMA before being promoted to agent. Additionally, Sun works closely with the WME Foundation as a camp counselor and mentor to children in the Compton community.

On joining Lupus LA, Phil said, "It is an honor to officially join the Lupus LA board. My mother suffers from lupus so I have seen firsthand the effects that this disease can have on loved ones and families. I am so impressed with the work of Lupus LA, and I am excited to help raise awareness for this devastating disease."



The Savvy Women Behind SAVI

As mentioned in the letter from the Lupus LA chairman, we've also begun another exciting program - SAVI (Social Awareness Volunteer Initiative). The SAVI team leaders are Bridget Hood, K. Elle Jones, Kirsten Maeda, and Lizza Monet. They are savvy, dedicated social media influencers who are doing their part in a volunteer capacity to increase Lupus LA's online presence. Thank you team SAVI!

SAVI team from left to right: Kirsten Maeda, Bridget Hood, K. Elle Jones and Lizza Monet at the 2013 Get Lucky for Lupus LA event.



Lupus LA Takes Action

As part of Lupus LA's Community Awareness Program (CAP), we have been meeting with elected officials to increase their awareness of lupus. We also educate them on issues that reduce healthcare disparities, the need for more innovative medical research and better treatment options.

Pictured upper right is Cynthia Zarate, Lupus LA program manager, speaking before the LA City Council. Council President Herb Wesson is to her right, and behind Cynthia is Lupus LA board member, Janice Wallace. Additionally, Lupus LA updated Congresswoman Lucille Roybal-Allard on the activities of Lupus LA. The Congresswoman has demonstrated strong leadership in supporting biomedical research at the NIH, and for championing a national effort – the Lupus Initiative – to educate healthcare professionals about the disease and its diagnosis. Pictured from left to right are Lupus LA executive director Patti Koltnow, Congresswoman Lucille Roybal-Allard, Cynthia Zarate and Lupus LA board member Dorothy Ellis.



MORE MEMORABLE EVENTS

Lupus LA has a well-earned reputation for producing successful events, and this year we have continued the tradition with three more events - our annual gala, the Orange Ball, a reception and screening of *Fruitvale Station* at WME and our yearly rooftop party and poker tournament, Get Lucky for Lupus LA.

Orange Ball

Thanks to our many friends and supporters, we raised over \$500,000 at the Orange Ball held on May 9 at the Beverly Wilshire. Comedian and actor Bob Saget did a superb job hosting the evening. Our outstanding honorees were actor Jason Alexander, Dr. Stanley J. Naides, R&D at Quest Diagnostics Nichols Institute, and cardiologist Dr. Jay N. Schapira. Guests were entertained by Mindy Abair and Jay Gore, Tracie Bennett and our own Toni Braxton. The event also raised national awareness for lupus, with stories reaching nearly half a billion readers and viewers.



Clockwise from top left: Actress Elisabeth Harnois of *CSI* on the orange carpet; Broadway's Tracie Bennett performs; Orange Ball Host Bob Saget (left) with honoree Jason Alexander on the orange carpet; Lupus LA board member & superstar Toni Braxton sings to honoree Dr. Schapira; Live auction donors Gary & Stacey Uberstine with winners board members Debbi & Roger Cowan at the 49ers game in Seattle; The Cowans with Seahawks coach Pete Carroll (center).

Fruitvale Station

In July, WME hosted a special cocktail reception and private screening of *Fruitvale Station* starring WME client and Lupus LA Ambassador Michael B. Jordan. Everyone was visibly moved by the film. Both Michael and the film are considered among the frontrunners for Oscar nominations. Lupus LA guests were then treated to a Q&A with Michael, who answered questions about the role, his acting career and his personal connection to lupus.

Clockwise from top: Seventy guests attended a pre-screening cocktail reception, including: Sheila & Roger Milstein; Michael B. Jordan and friends.



Get Lucky for Lupus LA

Last, but not least, on September 12, 450 guests took over the rooftop of the Petersen Automotive Museum. While 180 guests played poker, another 270 partied the night away enjoying the food, drinks, silent auction, raffle and more. Congratulations to tournament winner actor Roger Cross, who won a \$10,000 seat for the PokerStars Caribbean Adventure Main Event at the Atlantis Resort and Casino in the Bahamas, donated by PokerStars. A big thank-you to Coffee Bean & Tea Leaf, Fenix Cosmetics, Lash Fary, Polite in Public, Skinnygirl, SodaStream, Sweets & Treats, Inc., Venice Beach Beer Company and Wente Vineyards. And thanks to the many silent auction donors who contributed to the success of the event.

Clockwise from top left: Actress and poker player Shannon Elizabeth and SodaStream; Lou Diamond Phillips enjoying the game; Mixed martial artist Tito Ortiz with tournament winner actor Roger Cross.

LATEST ON PATIENT CONFERENCES

Our 3rd annual *Latest on Lupus* Irvine patient conference was held on Sept. 28 at the University of California, Irvine. With 100 attendees, this was twice as large as 2012, and the largest Irvine patient conference to date. The program was top notch from beginning to end as evidenced by the participants' evaluations.

The keynote speaker, Dr. Sheetal Desai, presented the *Latest on Lupus*. Dr. Desai is a board-certified rheumatologist, who specializes in the diagnosis and treatment of osteoarthritis, rheumatoid arthritis, polymyalgia rheumatica, fibromyalgia, scleroderma, and lupus. Her presentation was followed by a Q&A, but at break-time there was a long line of patients who had additional questions. Sarah Goozeé, Ph.D., is a lupus patient and has her Ph.D. in Clinical Psychology. She spoke on mental health and lupus. This is the first time we had this topic at a patient conference, and it was very well received. The final presentation consisted of a panel of lupus patients who shared their stories, talked about why they engage in advocacy, and how the audience could get involved. The audience was touched and inspired by their stories.

Patients and their families left the conference more knowledgeable and hopeful.

As always, we are very grateful to our sponsors, GlaxoSmithKline (GSK) and UCB

Inc., who enabled us to host the conference free of charge to patients and their families.

The next *Latest on Lupus* patient conference is scheduled for December 7 at Cedars-Sinai Medical Center. For more information email us at info@lupusla.org, or call our office at 310-657-5667. To register online, please register at our website, www.lupusla.org.

Clockwise from bottom left: Participants listen to speaker; Patient advocates, Andrea Carrion, Kimberly Howse, K. Elle Jones, Kirsten Maeda & Bridget Hood; Lupus LA board member Kate Kelly & Mary Rosas of GlaxoSmithKline.



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"Joining Team Lupus LA is a great way to get your friends and family involved in this important cause. You can run on a team together, or friends can run on your behalf. This event has a wonderful community feel to it and we are looking forward to growing our team this year!"

You can get more information and join the team by going to www.lupusla.org. If you would like to support Team Lupus LA, you can make a donation at www.firstgiving.com/lupusla.



Left, above: KTLA's Gayle Anderson interviews Lupus LA Chairman Adam Selkowitz; Left, below: Lupus LA board members Michelle & Alan Kaye wave to cheering station; Above: Team members, including the Beverly Hills High Interact Club.

It's Tea Time for Lupus LA

On September 3, The Coffee Bean & Tea Leaf®, launched its first children's book and kid-friendly caffeine-free herbal infusion tea inspired by the book, "Master Davey and the Magic Tea House." The book is co-authored by The Coffee Bean & Tea Leaf® Director of Tea, David DeCandia, and children's literature author Susan Chodakiewitz.

Lupus LA is especially close to DeCandia's heart, as his daughter has lupus. Because he is passionate about funding research for lupus, The Coffee Bean & Tea Leaf® is donating a portion of sales of the Magic Tea House Gift Set to Lupus LA, for our research partner the Lupus research Institute.

"Master Davey and the Magic Tea House" is being sold with a blue tiger tea tin in The Magic Tea House Gift Set at select The Coffee Bean & Tea Leaf® store locations, CoffeeBean.com, and Amazon.com while supplies last. The hardback book will also be sold separately at CoffeeBean.com and Amazon.com.

SAKS, continued from page 1

personally invited. Lupus LA will receive 10% of the total sales. A big thank-you to Robyn Horowitz of Saks 5th Avenue Beverly Hills for being a true partner to Lupus LA.

Clockwise from top:
On the right, Lupus LA board member Nancy Utley with her guests; Lip print reading; Lupus LA board members Debbi Cowan & Janet Janjigian are all smiles after shopping.



LUPUS LA SUPPORT GROUPS

Being truly "supported" is a powerful feeling that many people with lupus long to have, and that can help enormously in riding out the emotional rollercoaster of life with this exhausting and unpredictable chronic illness. But there is support out there – Lupus LA's support groups are here to help you learn more about lupus and how to cope with all of the stress that comes along with it. Each month covers a different topic with different speakers. For more information about the Lupus LA adult support groups listed below, and our pediatric support group at Children's Hospital of Los Angeles, please contact Lupus LA at 310-657-5667 and/or info@lupusla.org

Irvine Support Group

First Monday of every month
7pm – 9pm
Irvine, CA

Spanish-Language Support Group

Primer jueves del mes de
7pm a 8:30pm
Los Angeles, CA

Howse Foundation & Lupus LA Support Group

Second Saturday of every month
10am – 11:30am
Ontario, CA

Loom 4 Lupus Support Group

Second Saturday of every month
9:30am – 11:30am
Baldwin Park, CA

Cedars-Sinai Support Group

Second Wednesday of every month
7pm – 9pm
Los Angeles, CA

Alhambra Support Group

Third Tuesday of every month
6:30pm – 8:30pm
Alhambra, CA

San Fernando Valley Support Group

Fourth Monday of every month
6:30pm – 8pm
Sherman Oaks, CA

Long Beach Support Group

Fourth Tuesday of every month
10:30am – 12pm
Long Beach, CA



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Join us on Facebook and Twitter

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www.twitter.com/lupusla

Lupus LA, the West Coast division of the S.L.E. Lupus Foundation, promotes lupus research, awareness, and education, and serves the needs of people with lupus and their families in the greater Los Angeles area.

Lupus LA Board of Directors

Adam Selkowitz, *Chairman*

Debbi Cowan, *Vice Chairman*

Alan Kaye, *Treasurer*

Dorothy Ellis, *Secretary*

Toni Braxton

Roger Cowan

Kathy Gallagher

Janet Janjigian

Michelle Kaye

Kate Kelly

Lauren Shuler Donner

Phil Sun

Nancy Utley

Janice and Daniel J. Wallace, M.D

Patti Koltnow, *Executive Director*

YOU'RE INVITED

ELEVENTH ANNUAL
HOLLYWOOD BAG LADIES
Luncheon

Woman of Achievement Honorees
Janice Wallace
Dorothy, Kelly and Sharon Stone

Hosted by Louise Roe

Friday, November 15, 2013
Beverly Wilshire Hotel • 9500 Wilshire Boulevard, Beverly Hills

11:00 AM – Silent Auction
Shop for exclusive bags from the collections and closets of top designers and celebrities.

12:30 to 2:00 PM – Luncheon, Live Auction, Entertainment and Awards

YOU'RE INVITED