

# the 100p

LUPUS LA

THE SEMI-ANNUAL PUBLICATION OF LUPUS LA



## MBJAM CHANGES THE GAME FOR LUPUS AWARENESS

Facing a standing-room-only audience at Dave & Buster's in Hollywood on July 28, Michael B. Jordan shared a lupus lesson that he learned from his mother: Some of its most devastating symptoms are invisible.

"Lupus really takes away from who you are, in a sense," said Jordan, a longtime Lupus LA Ambassador.

(Continued on pg. 4)

## In This Issue

Chairman's Message	2
Patient Conferences	3
Bag Ladies Preview	7



## SUSAN BAZARSKY, OUR NEW EXECUTIVE DIRECTOR, SHARES HER VISION FOR LUPUS LA

*This fall, we welcomed a new executive director to lead our staff and chart the future of Lupus LA. Now on the job for just over one month, Susan Bazarsky is proving herself to be an energetic, organized and spirited addition to the team. Susan came to Lupus LA from the American Technion Society and brings years of experience to the table in development and fundraising. We're all enjoying getting to know Susan at the office, and we wanted to introduce her to you here in Q&A form, so you can get to know her in her own words.*

**You've worked in nonprofit development for years, including at the American Technion Society. Tell us a bit about your background.**

I started my career in film and television, which I loved, but after my mother's passing I found a need to redirect my life and career to the nonprofit space. I had been consulting on a variety of fundraising events and felt it was the perfect fit for my producing, organizational, and management skills.

I've worked for a family foundation, at the Museum of Tolerance and most recently at the American Technion Society (ATS). At ATS I was responsible for educating a new generation of donors and raising large funds for fellowships, research, and faculty recruitment, along with event planning, program managing, and working very closely with the board. My team also created and developed annual events and a variety of program series, several of which were used nationally.

(Continued on pg. 5)

# Letter from the Chairman

## Lupus LA Board of Directors

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Michelle Kaye  
Phil Sun  
Nancy Utle  
Daniel J. Wallace, MD  
Janice Wallace

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Dear friends,

Fall is a season of change and that is exactly what's been happening at Lupus LA. After having led our team for over four years, Toby Berkow has left the organization for a new and exciting opportunity. We are very appreciative of all that Toby was able to bring to the table and her success at Lupus LA has benefited us all.



I want to be one of the first to introduce you to our new executive director, Susan Bazarsky. As you'll see in the article in this newsletter, Susan has already jumped in with both feet and is making an immediate impact on our work. Susan's leadership experience spans a wide range of roles across the nonprofit world, most recently as a leader in the development department at the American Technion Society. Susan is eager to meet as many lupus patients, families, doctors, and stakeholders as possible and to apply her tremendous expertise to our organization. Susan is a welcome addition to the Lupus LA team and we know incredible things lie ahead for Lupus LA and the greater lupus community.

One highlight of the last few months at Lupus LA that I want to draw extra attention to is the success of MBJAM. Michael B. Jordan and his family were able to help us create an event that has grown into one of our most special days. This year we were fortunate to be able to invite and host 200 lupus patients and family members at no charge, thanks to the generous support of our corporate sponsors. MBJAM '18 also proved to be our most successful lupus awareness initiative ever by garnering over 1.1 billion media impressions – that's billion with a B! That translates to worldwide attention for our cause and helps us across the board with our mission. We're excited to continue to grow this patient-focused event and I want to send my sincere thanks to Michael and the MBJAM team.

Here's to a healthy, productive, and successful fall!

Best wishes,



Adam Selkowitz  
Chairman

## “LATEST ON LUPUS” PATIENT CONFERENCES INFORM AND INSPIRE AT UCLA AND UC IRVINE

Lupus patients from across Southern California gathered for learning, inspiration, and community at two additional “Latest on Lupus” patient conferences this year, at UCLA and UC Irvine. Our patient conferences offer attendees the opportunity to ask their questions directly to lupus experts such as Lupus LA founder Daniel J. Wallace, MD – and these audience questions often lead to illuminating moments for everyone. Read on for highlights.

► Opening our UCLA patient conference on September 22, keynote speaker Daniel J. Wallace, MD, outlined a presentation so cutting edge, “none of this could have been given a year ago.” In an engaging and information-packed talk, the esteemed rheumatologist covered topics including new criteria for defining lupus, the role of the environment in lupus, current and upcoming clinical trials, and updates on treatment. After his presentation, Dr. Wallace took dozens of questions from the audience about all aspects of living with lupus. One memorable question dealt with whether lupus



patients should continue working. “My mantra is that lupus patients are not disabled; lupus patients are differently abled,” Dr. Wallace told attendees. “You’re smart, you can do things, and I want you to work.” That said, he added, lupus patients should work in jobs where they can pace themselves and take rest periods and breaks as needed. Dr. Wallace’s slides from this valuable day of learning are available for anyone who wants to read them. Please email Katherine at [kmcmahon@lupusla.org](mailto:kmcmahon@lupusla.org) to have them emailed to you.

Next, dermatologist Rachel Abuav, MD, presented on “Lupus and the Skin.” Some 55-90 percent of lupus patients develop a skin rash, she said, and she described various manifestations, triggers, and treatments. She also talked about female-pattern hair loss in lupus patients. Audience members took advantage of an engaging Q&A

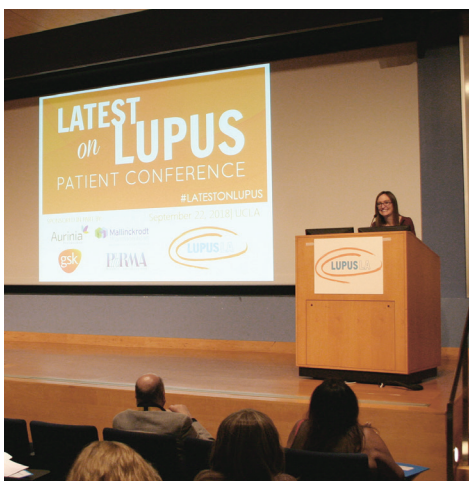
session with Dr. Abuav as well.

Patient conference guests then heard from Jennifer L. Caing, an immunology nurse educator with GSK, on how to communicate more effectively with doctors and other members of one’s care team. Last, Christine Lee, MD, presented on “Lab Tests and Lupus.” Lupus is not defined by a concrete set of laboratory markers, she said – instead, it takes a combination of antibody testing, symptoms, and exam findings to make an accurate diagnosis.

Videos from our UCLA patient conference are available on Lupus LA’s YouTube channel.

► At UC Irvine on June 9, Orange County lupus patients and their families gathered for a patient conference headed by rheumatologist Sheetal Desai, MD, who gave an in-depth keynote presentation explaining how lupus affects the body. Dr. Desai took

*(Continued on pg. 6)*



## MBJAM CHANGES THE GAME FOR LUPUS AWARENESS

(Continued from pg. 1)

“You’re always worrying about: How am I going to feel today? Am I going to have enough energy to do the things that I normally do? Am I going to be able to be who I am?” With every dollar raised for Lupus LA, he added, “You’re helping another lupus patient get back to being who they are.”

Moving speeches by the *Creed II* actor and his mother, Donna Jordan, were just a few of the highlights that made Lupus LA’s second annual MBJAM an event to remember. Some 450 guests gathered for a high-energy evening featuring arcade games, prizes, a buffet of hors d’oeuvres, and an interactive graffiti art station. Presented by Jordan

and hosted by returning MC Terrence J, MBJAM raised over \$265,000 to fund lupus research, patient services, and our advocacy work on behalf of the local lupus community.

Thanks to the generosity of event sponsors including American Airlines, Coach, Honey Nut Cheerios, Nike, and Warner Bros., Lupus LA was able to invite some 200 lupus patients and family members to enjoy MBJAM at no cost. Jordan told the crowd that he wanted to create an event where lupus patients could bring their families and “be a part of it together,” because “with lupus, it’s not just one person going through it – it’s the entire family. When

my mom is sick, we all feel it and go through it together.”

MBJAM also made a notable media splash that raised the bar for lupus awareness on a national scale. Celebrity attendees including Jamie Foxx, Storm Reid, Lena Waithe and Lupus LA Ambassadors Niles Fitch, Ali Hillis, and Meredith Monroe made waves on social media and helped garner press coverage that racked up over 1 billion views. That’s a lot of new people learning about lupus! We can’t wait to build on this success and welcome the lupus community to an even bigger MBJAM next year.



Clockwise from top left: MC Terrence J, actress Lena Waithe, and producer Olivia Charmaine Morris; Lupus LA Ambassador Ali Hillis enjoys games with her family; Jamie Foxx and Lupus LA Ambassador Michael B. Jordan face off in an intense game of Pop-A-Shot; Lupus LA Ambassador Niles Fitch with actress Storm Reid; Michael B. Jordan tells the crowd about his mother’s experience with lupus; Michael B. Jordan poses on the orange carpet with his father Michael A., mother Donna, sister Jamila, and brother Khalid; Lupus LA Ambassador and Extra host Terri Seymour with Board Chairman Adam Selkowitz; MBJAM volunteers let loose on the orange carpet.

## Q&A with Susan (continued)

(Continued from pg. 1)

### **What drew you to the opportunity to lead a healthcare nonprofit?**

I have personally experienced great loss, which drives me to work in a space that allows me to give back. Working with a healthcare nonprofit like Lupus LA that has so much respect from – and impact on – the local community, as well as national impact with their research dollars, spoke to me. After meeting with Adam Selkowitz [the chairman of the board], the board of directors and the staff, it was an easy decision. They are kind and dedicated and have built this nonprofit from a grassroots level to be something special, and I'm honored that they chose me to work alongside them.

### **What's your impression so far of the staff and board members who make up the Lupus LA team?**

In the short time I've been here, I'm already impressed. The staff has been extremely welcoming and supportive. They're dedicated to their work and committed to our organization. The board was a huge reason I wanted this position. Board partnership is an essential component for the success of any nonprofit and this board is quite exceptional. Many of them have been here since inception and their ongoing dedication and passion are inspiring. They truly are a family and I look forward to working with each of them.

### **What are your goals for your first year at Lupus LA? What are your long-term goals?**

My first goal is to learn about our community, the board, the Medical Advisory Board, and the staff to understand their goals and their needs,

and those of the organization. I attended our recent patient conference at UCLA and not only learned quite a bit about lupus, but also got to meet members of the local lupus community. I spoke to lupus patients and their families and heard personal stories that really touched me. I want to understand the needs of this community, learn more about the impact we have on them, and identify places where we could possibly do better. I'm excited to attend more of our annual events and learn why they're so highly anticipated. Long-term, I'd like to see our fundraising increase so that we can contribute even more money to research and grow our patient programs to reach an even wider audience. Over 60,000 people live with lupus in the greater Los Angeles area, and they all need access to care. Coming from a university, I understand the importance of research and clinical trials. Progress costs money and we need to contribute as much as we can nationally as well as locally. Our emphasis on research and patient services really touches my heart and motivates me.

### **Tell us more about your life outside the office. Where are you from? How do you spend your free time?**

After this month, I'm not sure I'm going to have a life outside of the office, but as a solo mom I'm used to being busy and continue to strive to create balance in my life. I was born and raised in New York. I moved to Los Angeles in the late '80s and while I love L.A., I will always be a New Yorker at heart. I have one daughter who is a senior in high school, so it's a stressful time right now in our home as she applies to college. She's a terrific young woman and I'm insanely proud of her. In my "free" time,



I love to cook, garden, watch movies, and spend time with my daughter – who, miraculously, at 16, still wants to spend time with me! We have two large rescue dogs, Rosie and Teddy, and I am blessed with an incredible group of smart, supportive, and loving friends whom I would not want to navigate my life without.

### **What books are currently on your bookshelf?**

While I wish I had more time to read, I always have a stack of books by my bed and do my best to read a bit every night (I am rarely successful). I've recently completed *Radical Candor* by Kim Scott, and *What I Told My Daughter* by Nina Tassler. I've just started *Thrive* by Arianna Huffington, and often revisit Maya Angelou's writings because her voice of reason speaks to me.

### **What's the most important thing you want people to know about you?**

I am dedicated and loyal to my family, my friends and my work. I have no room for intolerance and aspire to always be kind, which has a strong connection to my veganism and living a vegan lifestyle. Above all, I'd like them to know that I care.

## Conferences (continued)

*(Continued from pg. 3)*

a range of questions from audience members eager to hear from the noted rheumatologist, addressing topics including medications and pregnancy. “The ability to get pregnant is no different between women who have lupus and women who do not have lupus,” she said, although certain lupus medications can affect fertility and other factors may interfere with the body’s ability to carry a baby to term. Attendees shared that they found the presentation and Q&A very useful.

Rheumatologist Linh Truong, MD,

next presented a talk on factors that can trigger lupus flares and how to mitigate them, and Nina Narasimhalu, MD, gave a talk on lupus and one’s diet. While there is no lupus-specific diet, eating foods high in antioxidants and low in sodium will help manage the disease, she said. One food lupus patients should always avoid, she added, is alfalfa sprouts.

Rounding out the day was a presentation from Dojo Aguilar, an immunology nurse educator from GSK, who asked audience members to turn

to one another in their seats and say, “You are not alone.” It was a touching moment to end an inspiring day.

We would like to thank our sponsors, Aurinia, GSK, Mallinckrodt, and PhRMA, who enable us to host these informative conferences for patients and their families.

For more information about our patient conferences, please email Katherine at [kmcMahon@lupusla.org](mailto:kmcMahon@lupusla.org), or call (310) 657-5667.

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## FIND A SUPPORT GROUP NEAR YOU

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 [kmcMahon@lupusla.org](mailto:kmcMahon@lupusla.org) or (310) 657-5667.

### **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

### **Crenshaw Support Group**

Second Tuesday of the month  
From 7:00 PM to 8:30 PM  
West Angeles Church  
Multipurpose Bldg., Room 9  
3045 Crenshaw Boulevard  
Los Angeles, CA 90016

### **Howse Foundation & Lupus LA Support Group**

Second Saturday of the month  
From 11:30 AM to 1:00 PM  
Olive Branch Diagnostic Imaging  
Women’s Health Center  
10722 Arrow Route, Suite 520  
Rancho Cucamonga, CA 91730

### **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

### **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

### **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

### **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

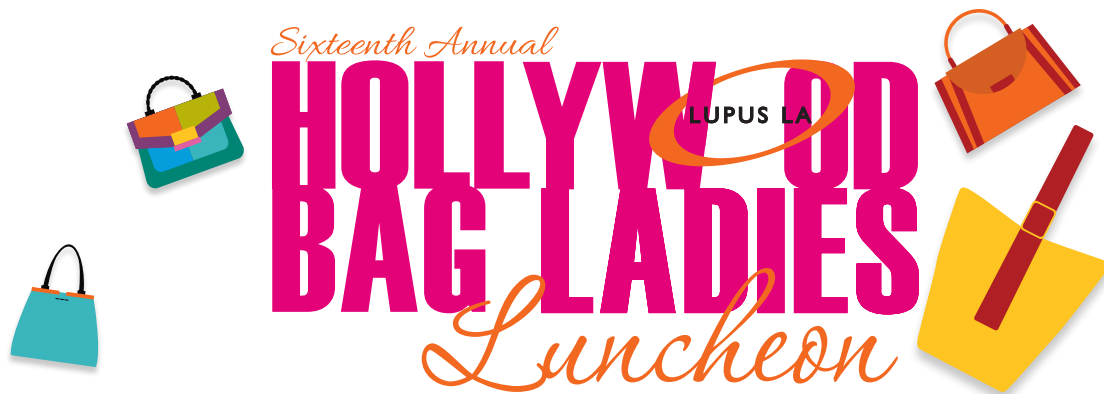
### **Spanish-Language Support Group**

Primer Jueves del mes  
De 7:00 PM a 8:30 PM  
Clinica Oscar Romero, Sala 101  
2032 Marengo Street  
Los Angeles, CA 90033  
(En frente del hospital general de USC)

### **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

### GEARING UP FOR THE 16TH ANNUAL HOLLYWOOD BAG LADIES LUNCHEON



The 16th annual Hollywood Bag Ladies Luncheon will once again return to the esteemed Beverly Hilton on Friday, November 16, 2018.

This year's event will honor Elayne K. Garber, MD, and her daughters Lindsay J. Forbess, MD, and Chelsey J. Forbess Smith, MD, a trio of rheumatologists who practice at Garber Forbess Rheumatology, with the 2018 Women of Achievement Award.

Contemporary brand Theory is joining Lupus LA this year as fashion partner

for the Bag Ladies Luncheon, and will feature select looks from their latest line during a stage show at the event, plus an exclusive pop-up store with a portion of proceeds benefiting Lupus LA.

Joining this year's event as host will be comedian and actress Caroline Rhea, who will also serve as auctioneer for a fantastic live auction featuring unique experiences and travel packages.

The real prizes of the event, however, are the designer bags donated by top

designers such as Gucci, Perrin, Louis Vuitton, Tory Burch, Chanel, and Coach, and from celebrities and dedicated supporters of the organization. All told, over 200 bags will be available for bid through a silent/online auction which closes at the event.

Since its inception, this signature Beverly Hills event has raised over \$5.4 million to fund the research and programs supported by Lupus LA. To purchase tickets online, please visit [BagLadies.GiveSmart.com](http://BagLadies.GiveSmart.com).

### THANKS FOR EVERYTHING, TOBY!

We want to thank our outgoing executive director, Toby Berkow, for four amazing years with Lupus LA! Toby accepted a new position this summer and we know she'll be just as successful in her new professional home as she was advocating for the lupus community. Best of luck in everything you do, Toby!






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*Sixteenth Annual*

# HOLLYWOOD BAG LADIES *Luncheon*

LUPUS LA

*Friday, November 16  
The Beverly Hilton*

Tickets: [BagLadies.GiveSmart.com](http://BagLadies.GiveSmart.com)