

the 1000

LUPUS LA

THE SEMI-ANNUAL PUBLICATION OF LUPUS LA



ORANGE BALL TOASTS LUPUS HEROES

“As I’ve lived with this diagnosis for the last 27 years, it took some time to grow from fear and despair to acceptance and optimism,” said Nancy Utley, President of Fox Searchlight Pictures, in a frank and moving speech about her experience with lupus on May 3 at the 2018 Orange Ball. Nancy accepted the Daniel J. Wallace Founder’s Award after a personal

(Continued on pg. 6)

In This Issue

| | |
|---------------------------|-----|
| Chairman’s Message | 2 |
| Advocacy Successes | 3 |
| Conferences & Fellowships | 4-5 |
| Lupus LA Events | 6-7 |
| Patient News | 9 |



Cure 1000 Pushes Research Forward

Since our founding, Lupus LA has been dedicated to our core mission: to find the causes of and a cure for lupus. To accomplish this goal, we support the dedicated doctors and researchers who study the mysteries of lupus in the hope that they can break the code of this complex disease.

In keeping with this goal, Lupus LA has launched Cure 1000 – a giving program where 100% of all donations go directly to fund research initiatives, including: funding a local research project at one of our partner hospital institutions; funding local rheumatology fellows who are tasked with both patient care and research projects; and funding national novel research through our partners at the Lupus Research Alliance.

Cure 1000 members are an elite group of individuals who are committed to finding a cure through medical research. To join, members make an ongoing annual commitment of \$1,000 or more for direct research funding. This is outside of any other gifts to programs or events at Lupus LA.

Members receive semi-annual reports on the latest in lupus research, are invited to exclusive events to hear firsthand from leaders in the immunology/rheumatology field and know that they are personally making a difference in the fight to find a cure. To learn more about how you can join Cure 1000, please contact Lupus LA at info@lupusla.org or call (310) 657-5667.

Letter from the Chairman

Lupus LA Board of Directors

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Dear Friends,

Welcome to our newsletter's new look and feel! What you're seeing may just look like font changes and a new masthead but what's really going on at Lupus LA is a new focus on our brand. Thinking of a charity, especially one that focuses on such a serious health issue, as a brand may sound odd, but that's an important part of what we have to do in order to successfully connect with our audience of lupus patients, researchers and advocates.



Lupus LA tackles the fight against lupus from many angles – funding research and fellowships, supporting doctors, lobbying our government, and offering services to improve patients' quality of life. Since we serve so many constituencies, the tone of our voice is critical. We're making a renewed effort to speak with a clear, informative and unique voice that conveys the quality of work we do on behalf of lupus patients and their families.

I want to introduce you to Lupus LA's newest addition, Rachel Zaimont. In her newly created role of Communications Associate, Rachel is now responsible for our voice. She will be creating, curating and circulating our message through all of our available channels. Rachel has already begun to make her mark through our social media outreach, through our e-blasts and with this newsletter. She will be focusing more on telling patient stories, expanding the reach of our Medical Advisory Board and working with our Ambassador Program to amplify the voices of the celebrities and influencers who support Lupus LA.

We've always been focused on delivering high quality patient services, raising significant money to support research and making the world more aware of what lupus is all about. Now we are even more focused on telling that story in a consistent way.

I hope the subtle changes you'll see in the coming months will give you a better view into the heart of Lupus LA and what we stand for. We are here for, and because of, you. I invite you to share your thoughts, get more engaged and see Lupus LA as your source for information and community. Together, our voices are stronger.

Warm regards,

A handwritten signature in black ink, appearing to read 'Adam Selkowitz'. The signature is stylized and fluid.

Adam Selkowitz
Chairman

Washington, D.C. Lobbying Success Leads to New Research Grants

Caroline Jefferies, MD, a lupus researcher at Cedars-Sinai Medical Center and member of Lupus LA's Medical Advisory Board, won one of 13 grants awarded by the U.S. Department of Defense (DoD) on May 17, 2018 as part of its new Lupus Research Program. The DoD announced \$5 million in funding for innovative research projects that will lead to breakthroughs in lupus detection, diagnosis and treatment.

This series of grants marks the successful culmination of years of lobbying by lupus advocates including Lupus LA.

This past March, Lupus LA's Executive Director Toby Neiman Berkow and Program Manager Katherine McMahon lobbied legislators in Washington, D.C. as part of the Lupus Research Alliance's Advocacy Days. Toby and Katherine met with the offices of Congress members Adam Schiff, Lucille Roybal-Allard, Ted Lieu and Karen Bass, and Senators Kamala D. Harris and Dianne Feinstein. They asked for support for the DoD's Lupus Research Program, as well as support for a \$2.2 billion increase to strengthen biomedical research at the National Institutes of Health (NIH).

Dr. Jefferies and her 12 fellow awardees were among 121 researchers who applied for the highly-selective DoD grants. Congratulations to Dr. Jefferies – we can't wait to see what promising new research comes out of this program!



Celebrating Our Star of Advocacy: Katherine McMahon

Lupus LA Program Manager Katherine McMahon was honored this past January as a Star of Advocacy at the California Chronic Care Coalition's (CCCC) Gala held on January 25, 2018 in Sacramento.

The CCCC is a unique alliance of more than 30 leading consumer health organizations including physician and provider groups representing Californians living with chronic conditions. The CCCC advises and promotes the collaborative work of policy makers, industry leaders and patient-centered stakeholders emphasizing access to affordable, quality healthcare focusing on all levels of prevention, coordinated care, and the wellness and longevity of patients.

Lupus LA is a member of the CCCC and is extremely proud of Katherine for this well-deserved honor.



UCLA and Loma Linda Patient Conferences Explore the “Latest on Lupus”

Lupus LA’s “Latest on Lupus” patient conferences continue to inform and inspire attendees while giving lupus patients and their families a special opportunity to ask their questions directly to doctors who specialize in treating lupus.

► Our annual “Latest on Lupus” Los Angeles patient conference was held on December 16, 2017 at the UCLA Medical Center. The conference covered the most up-to-date research and treatments of lupus.

Rheumatologist Daphne Scaramangas-Plumley, MD, presented “What is New in Lupus.” Dr. Scaramangas-Plumley’s informative presentation was followed by a helpful Q&A session. Cardiologist Jay Schapira, MD, provided an educational presentation on the important topic of “Lupus and the Heart.” Next, retina specialist David Lazar, MD, presented a useful talk on “Retinal Toxicity Associated with Plaquenil Use.” Participants and their loved ones shared that the event was a helpful chance for them to hear from the best and the brightest in the field of lupus research and care.

The patient conference concluded with an inspiring advocacy presentation. Lupus advocates K. Elle Jones and Sheba Family presented “Use



the Power of Your Voice for Lupus Advocacy.” The presenters helped empower the audience by sharing their personal journeys with lupus and advocacy work, helpful self-care tips, and information about their YouTube show, “A Cup of Tea TV.” The show offers a community of experts, lupus patients and their loved ones a ‘sip’ of truth, education and awareness about living with lupus. The attendees shared that they felt empowered and inspired by the very moving presentation. We would like to thank our sponsors, GSK, Aurinia, Mallinckrodt and PhRMA, who enabled us to host this informative conference for patients and their families.

► Thanks to a very generous sponsorship from GSK, Lupus LA

was able to host a new conference on March 15, 2018 at Loma Linda University Health. The conference attendees were very grateful that a new location in the Inland Empire was added. Rheumatologist Vaneet Sandhu, MD, presented the “Latest on Lupus.” Rheumatology fellow Arezoo Haghshenas, MD, presented on “Lupus Nephritis.” Lupus advocate K. Elle Jones presented “Use the Power of Your Voice for Lupus Advocacy.” The attendees shared that they learned valuable information about living with lupus and enjoyed being able to ask their questions directly to doctors.

For more information, please email us at kmcmahon@lupusla.org or call (310) 657-5667.

Investing in Our Future: Funding New Rheumatology Fellows

Over 1.5 million people in the U.S. live with lupus, yet there are only 5,595 rheumatologists serving adults and just 300 treating children in the whole country. Those numbers are shrinking, while the need rapidly grows.

Twenty-two states have fewer than 3 pediatric rheumatologists. Eight states have zero. By 2030, one-third of all practicing rheumatologists will retire. This drastic drop in providers will create a shortage that leaves patients in critical need.

Lupus LA is working to change that. Our board of directors established a fellowship program with local teaching hospitals to train more rheumatologists in our community who specialize in treating lupus patients. Our first fellow, Vaneet Sandhu, MD, completed her fellowship at Cedars-Sinai Medical Center in June 2015. Our second fellow, Julie Cramer, MD, is finishing her training this month at Children's Hospital Los Angeles (CHLA). (See the article below for more about this exceptional doctor and her future plans.)

Next, we are ready to fund a new rheumatology fellow beginning in July 2018 at Cedars-Sinai Medical Center. Looking to the future, Lupus LA has already committed to fund a new three-year fellowship at CHLA beginning in July 2019. We are excited to see how these skilled doctors change the game for lupus patients during their careers.

If you would like to learn more about how you can help Lupus LA train more rheumatologists, please contact Lupus LA at info@lupusla.org or (310) 657-5667.

Lupus LA's Second Rheumatology Fellow Graduates: Congrats, Dr. Julie Cramer

For the past three years, Lupus LA has proudly funded a pediatric rheumatology fellow at Children's Hospital Los Angeles (CHLA). As of this June, Julie Cramer, MD, has finished her training. We wish her a hearty congratulations!

As Dr. Cramer's tenure at CHLA comes to an end, her next chapter is just beginning. She will go on to serve pediatric rheumatology patients at Valley Children's Hospital in Madera, California, providing services to an underserved population. We are so proud of her accomplishments and look forward to hearing about all of the people she will help in her new community.



Lupus LA Events

Orange Ball Toasts Lupus Heroes

(Continued from pg. 1)

and often funny introduction by presenter Laura Dern, who described Nancy as “my friend, my dance partner and the last person to leave any party.”

This engaging pair of speeches by the longtime Lupus LA board member and her close friend was just one highlight of a beautiful and uplifting gala, taglined “A Modern Supper Club,” at the Beverly Wilshire Hotel. Over 400 guests mingled over cocktails, enjoyed a steakhouse-style dinner and then cut loose on the dance floor as West Coast Music’s IMPULSE delivered a high-energy set of party favorites.

Also honored was Marc Chevrier, MD, PhD, FACR, Head

of Lupus Strategy at Janssen Research and Development. Dr. Chevrier accepted the Medical Visionary Award for his pioneering lupus research. “If there were no Marc Chevrier, there would be no new lupus drugs on the market,” said Lupus LA founder Daniel J. Wallace, MD, in presenting the award.

“A Modern Supper Club” raised more than \$525,000 to fund Lupus LA’s research initiatives, patient programs and advocacy, led by dinner chairs Lauren Shuler Donner, Bruna Papandrea and Jim Gianopulos. Lupus LA was also thrilled to give away six pairs of tickets to lupus patients from across Southern California. We’re thankful for a successful evening and can’t wait to do it again next year!



Clockwise from top left: Former Lupus LA Rheumatology Fellow Julie Cramer, MD, Nikita Goswami, MD, Cynthia Salvant, MD, and Board Chairman Adam Selkowitz on the dance floor; Honoree Marc Chevrier, MD, PhD, FACR, accepts the Medical Visionary Award; West Coast Music’s IMPULSE rocks the house; Board member Janice Wallace and Lupus LA founder Daniel J. Wallace, MD; Presenter Laura Dern paints a warm portrait of honoree Nancy Utley; Dinner chair Jim Gianopulos with honoree Nancy Utley on the orange carpet; Laurie Selkowitz, Kim Fertman, and Lupus LA Ambassador Scott Michael Campbell; Actress Storm Reid is all smiles with Lupus LA Ambassador Niles Fitch; Board member Denise Winner and Andre Winner dance; a guest cuts loose on the dance floor.

BAG OF TRICKS

15th Hollywood Bag Ladies Luncheon Designed for Success

On November 17, 2017, over 500 fashion and handbag enthusiasts spent the afternoon at The Beverly Hilton for Lupus LA's 15th annual Hollywood Bag Ladies Luncheon. Showcasing the designs of Roberto Cavalli and featuring over 300 handbags, the luncheon also recognized Cara Dellaverson, Executive Vice

President of Drama Development at NBCUniversal, and Emily V. Gordon, writer and producer of the breakout hit film *The Big Sick*, each with the Woman of Achievement Award. Hosted by Lupus LA Ambassador Paula Abdul, the Beverly Hills mainstay raised over \$320,000 for Lupus LA.



SAVE THE DATE
Hollywood Bag
Ladies Luncheon 2018
Friday, November 16
The Beverly Hilton

Clockwise from top left: Host and Lupus LA Ambassador Paula Abdul leads the event in style; Bag Ladies committee member Kathy Gallagher, board members Alan and Michelle Kaye, and committee member Deena Blum; a stunning fashion show by Roberto Cavalli; Woman of Achievement honoree Cara Dellaverson with her parents, John and Vicki Dellaverson; Comedian Kumail Nanjiani and honoree Emily V. Gordon.

Current Research Tackles Lupus from All Angles

Lupus research falls into three main categories: basic science research, translational research, and clinical research. Here's an outline of what's currently underway in each of these areas.

Basic science research is the “benchwork” where laboratory testing is a priority. Examples of current, ongoing basic science research are:

- Environment and lupus: What role do chemical exposure, pollution, drugs and smoking have on lupus patients?
- T and B cell, complement, and mechanisms of inflammation: What types of white cells, proteins and cellular factors promote inflammatory activity?

Translational research involves taking basic science insights and applying them to patients. Currently there are “bench to bedside” studies underway where ideas generated from test tubes are tested on lupus patients.

Clinical research reflects studies on lupus patients. Examples of ongoing clinical research include:

- Organ systems: Heart, lung, kidney, liver, brain, bone marrow, joints and skin are being studied in observational, biomarker, genetic and quality-of-life studies.
- Clinical aspects: Can we improve sleep, fatigue, exercise, mindfulness and diet in patients with lupus without using any medication?
- Medications: Nearly 50 drugs are now being studied as part of clinical trials.

Stay tuned for more updates and results in our future newsletters.

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 or (310) 657-5667.

Alhambra Support Group

3rd Tues. of the month

6:30 PM - 8:00 PM

Alhambra Civic Center Library
2nd Floor Conference Room
101 S. First Street
Alhambra, CA 91801

Crenshaw Support Group

2nd Tues. of the month

7:00 PM - 8:30 PM

West Angeles Church
Multipurpose Bldg., Room 9
3045 Crenshaw Boulevard
Los Angeles, CA 90016

Howse Foundation & Lupus

LA Support Group

2nd Sat. of the month

11:30 AM - 1:00 PM

Olive Branch Diagnostic Imaging
Women's Health Center
10722 Arrow Route, Suite 520
Rancho Cucamonga, CA 91730

Irvine Support Group

1st Mon. of the month

7:00 PM - 9:00 PM

University United
Methodist Church
18422 Culver Drive
Irvine, CA 92612

Long Beach Support Group

4th Tues. of the month

6:30 PM - 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

2nd Sat. of the month

9:30 AM - 11:30 AM

Kaiser Permanente,
Educational Outreach Program
4141 Maine Avenue
Baldwin Park, CA 91706

Sherman Oaks Support Group

2nd Tues. of the month

6:30 PM - 8:00 PM

Circle of Care Conf. Room
Sherman Oaks Hospital
4929 Van Nuys Boulevard
Sherman Oaks, CA 91403

Spanish-Language Support Group

Primer Jueves del mes

7:00 PM - 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

Lupus Patient Advisory Council (LPAC)

Lupus LA launched a new group in January to engage patient leaders in the activities of Lupus LA and the greater lupus community. The Lupus Patient Advisory Council's (LPAC) mission is to bridge the gap between lupus patients and the larger community by acting as liaisons for our patient programs and other events. Together the group hopes to maximize Lupus LA's efforts and resources by ensuring all programs and services are targeted towards patients' needs, while promoting initiatives, and fundraising for events and research. If you would like to find out more about the council, please reach out to us at info@lupusla.org.

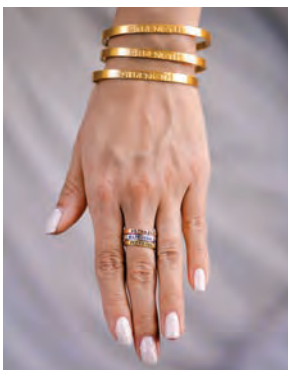


Patient Quote: Kimberly Burnett

"When I first got diagnosed, lupus meant a death sentence. It meant that I was less-than. It meant that none of my dreams would come true. It meant something that was going to plague my life, weaken me and cause me to give up. But over the past 10 years, after numerous medications, surgeries, seizures and a stroke, lupus has begun to mean something else to me. It means strength. It means resilience and perseverance. It means being able to defy the odds and graduate college and do papers while hooked up to a chemotherapy IV. It means being able to have a miracle baby despite being high risk. It means marrying the man of my dreams and him not flinching once when I told him I had lupus. Now it means that though my dreams may take longer to accomplish, it doesn't mean they won't happen. Lupus has taught me a strength I never knew I had. Lupus to me means I am an overcomer!"



—Kimberly Burnett, one of six local lupus patients who won a pair of tickets to our Orange Ball



Wear Your "Strength"

Strength means finding the courage to keep going despite steep challenges. Lupus LA has partnered with NicoleHD Jewelry to create a line of jewelry celebrating the strength and resilience that lupus patients channel every day. The collection includes bangle bracelets, necklaces, stackable rings and a keychain. A portion of every sale funds Lupus LA's patient services, medical research and advocacy. To learn more, visit lupusla.org/about-lupus-la/advocacy-and-awareness/strength-jewelry-collection. Show your strength!

Lupus LA Events

MBJAM: A Slam Dunk for Lupus

Last year, Lupus LA Ambassador Michael B. Jordan teamed up with Lupus LA to bring a new event to our calendar, MBJAM! Held at The Ritz-Carlton, Marina del Rey on September 16, 2017, MBJAM sought to bring together celebrities and guests for an afternoon of fun for adults and kids alike.

Co-hosted by Blake Griffin and featuring Terrence J as

guest MC, MBJAM also featured celebrity friends such as Emmanuelle Chriqui, Sofia Boutella, Miles Brown, director Ryan Coogler, James Worthy, and Lupus LA Ambassadors Niles Fitch and Krista Marie Yu. The courtside carnival event raised over \$240,000 to fund our work. We're currently gearing up for MBJAM 2018 on Saturday, July 28 (see back page for more details). You won't want to miss it!



Clockwise from top left: Lupus LA Ambassador Michael B. Jordan with his father Michael A., mother Donna (a lupus patient, to whom the event was dedicated), sister Jamila, and brother Khalid; Jr. NBA kids on the basketball court; guests help paint an interactive art wall; Actor Caleb McLaughlin ready to play ball; Actor Miles Brown with Emmanuelle Chriqui.

Lupus Awareness Night with the Los Angeles Clippers

Lupus LA was featured as the Charity of the Night at Staples Center on Saturday, March 10 for Lupus Awareness Night with the Clippers. Over 200 Lupus LA guests spread public awareness at the game by wearing orange Lupus LA shirts, and a 30-second PSA featuring Lupus LA Ambassador Niles Fitch aired during pre-game warmups. The event not only raised awareness for lupus, but also nearly \$50,000 for Lupus LA's vital programs. Special thanks to event sponsor GlaxoSmithKline (GSK) for their support.



Lupus advocates Juana Mata and K. Elle Jones, Board Chairman Adam Selkowitz, and GSK's Kimberly Williams on the court.

GO Team Fundraisers Benefit Lupus LA

Lupus LA's GO Team program continues to be very successful this fiscal year. With events such as Riding Route 66, Underground Fitness LA's spinning fundraiser, the Newport Beach Clam Jam, Comedy Night, Riding for a Cure – the Leadville 100, and others, Lupus LA community partners have helped to raise over \$40,000 for our vital patient programs and research.

Part of that support also comes from fundraisers created through Facebook, which have helped raise over \$12,000 for Lupus LA. It's easy! Just go to facebook.com/fundraisers and click the "Raise Money for a Nonprofit Organization" button. From there, Facebook will walk you through the steps to donate your birthday or other occasion and help support Lupus LA!



Comedian Zoe Rogers performs at Comedy Night at M.i.'s Westside Comedy Theater, which she organized to benefit Lupus LA.

Shining a Spotlight on Lupus Awareness Month



The LAX pylons were aglow in Lupus LA's orange hue to raise lupus awareness in the L.A. area.

Did you catch the orange lights at LAX this past May? As part of our public awareness campaign for Lupus Awareness Month, Lupus LA partnered with Los Angeles World Airports to turn the iconic pylons at LAX orange from May 18-21 to represent our cause. Thanks to Lupus LA Ambassadors Sharon Stone, Kellie Martin and Krista Marie Yu for promoting this awesome moment and raising lupus awareness!

Also in May, Lupus LA Program Manager Katherine McMahon secured official Lupus Awareness Month proclamations from two major SoCal municipalities – Los Angeles and Beverly Hills. We appreciate the city officials who took the time to recognize this important designation.

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.





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www.LupusLA.org

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MICHAEL B. JORDAN PRESENTS
MBJAM18

Saturday, July 28 • Hollywood

TICKETS ON SALE

www.lupusla.org/event/mbjam18