

LUPUS LA

Member of the Lupus Research Institute National Coalition • Fall/Winter 2014

Riding for Lupus

On May 18, 2014, Lupus LA raised \$6,800 at its first *Ride for Lupus* at SoulCycle West Hollywood. Guests donated money to support lupus research and received a spot in Lupus LA's private indoor spin class. There were 54 participants, including supporters, patients, and such notables as Eden Sassoon and actress Busy Phillips. Every rider received a custom "I Am Lupus LA" T-shirt. The instructor for the *Ride for Lupus* was Angela Manuel-Davis, one of the most popular SoulCycle instructors. Angela is currently on tour as part of Oprah's "The Life

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Jerome and Angela Davis



It's Bag Ladies Time!

Last year, Lupus LA hosted the most successful *Hollywood Bag Ladies Luncheon* in the event's history. After raising \$432,000, the momentum for the 2014 luncheon couldn't be better. The luncheon will be held at a new venue – the prestigious Beverly Hilton Hotel – on November 21 at 11:00 AM.

The *Woman of Achievement* honorees this year are two impressive women who are most deserving of recognition: Kathy Gallagher and Bruna Papandrea. Kathy has been involved with Lupus LA since 2007 and is a member of the Board of Directors. Her dedication to funding lupus research has made a real impact at Lupus LA. She headed up Team Lupus LA's involvement with the LA Marathon & 5K and participates on the planning committee for all of Lupus LA's fundraising events. Bruna is a noted film executive, who co-owns Pacific Standard with her producing partner, Reese Witherspoon. Bruna is a lupus patient, whose passion is improving lupus awareness. Her willingness to share



Roberto Cavalli's Budva Fashion Show

her story is what led Lupus LA Board Member, Nancy Utley, to introduce Bruna to Lupus LA. Two of last year's honorees – Kelly Stone Singer and Janice Wallace – will serve this year as the event's co-chairs.

Also this year, guests will be treated to an exclusive Roberto Cavalli fashion show. Over the years, the Roberto

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Dear Friends,

It's fall, and that means Lupus LA is in the midst of one of our busiest seasons. We've just had our most successful poker event ever, which raised more than \$125,000 for lupus research and Lupus LA programs. We're now about to welcome over 450 guests to The Beverly Hilton for the *Hollywood Bag Ladies Luncheon*, and we continue to serve thousands of lupus patients in Southern California through our patient services division.

But fall also means change (maybe not so much in LA, but you get my point), and change is something that can be both good and bad. That's very true for Lupus LA as we say goodbye to one of our most valued team members. Patti Koltnow joined Lupus LA in early 2011 as the Interim Executive Director. Patti was brought in to help Lupus LA grow and to help make us competitive in the ever growing world of non-profit fundraising. She really helped us, sometimes in ways we didn't even realize we needed help. Patti did two stints as our interim executive director, and during her second visit, we convinced her to drop the "interim" and to become our full-time Executive Director, a first for Patti. She's held that position for over two years and has been a major catalyst for our recent success. Patti has decided that it's time for her to cut back and slow down a bit, and although we are sad to see her go, we all know that her influence will be a constant presence at Lupus LA and that our doors are always open to her.

Please join me in welcoming our new Executive Director, Toby Berkow. We are extremely fortunate to have found someone like Toby to fill Patti's shoes. Toby is a driven, dynamic, smart, and enthusiastic professional who has already begun to make her own mark at Lupus LA. Look for her at the *Hollywood Bag Ladies Luncheon* and all of our future events and introduce yourself if you get the chance – I know she's eager to meet as many Lupus LA supporters as possible.

So, much like lupus itself, our world is always changing. But as you'll see from the contents of this newsletter, we're not slowing down one bit. In fact, we're growing. We're raising more money for research, helping more patients, and creating more lupus awareness every day, and we're thrilled that you're along for the ride.

Warm regards,



Adam Selkowitz
Chairman



Advocate Bridget Hood Joins Lupus LA Board

Lupus LA is very pleased to welcome Bridget Hood to the Lupus LA Board of Directors. Bridget, a real estate agent, was diagnosed with lupus at 17. She has had more than 20 surgeries and procedures, including a kidney transplant in 2006 (her brother, Nick, donated one of his kidneys). Nevertheless, she made a decision at the age of 19, when she was critically ill, that she was going to get better and someday share her story to help and inspire others who are suffering from this serious illness. And that is just what she has been doing for Lupus LA for the last five years – from speaking with legislators

in Orange County and Los Angeles to meeting with House Representatives in Washington, D.C. In addition to her advocacy work, Bridget is the co-facilitator of the Lupus LA Irvine support group.

On joining Lupus LA, Bridget said, “I am honored to have the opportunity to be on the Lupus LA Board of Directors. When I do anything that I’m passionate about, there is nothing and no one that can stop me or get in my way!”



Update on Lupus LA’s Community Awareness Program

As many of you know, lupus is a chronic and often disabling autoimmune disease that can affect virtually any organ of the body. While lupus is widespread, awareness and accurate knowledge about it are lacking. Research shows that although 1.5 million people in the U.S. have lupus, nearly two-thirds of the public knows little or nothing about it. In fact, more Americans have lupus than AIDS, cerebral palsy, multiple sclerosis, sickle-cell anemia and cystic fibrosis, making it one of this country’s most prevalent medical problems. That’s why raising awareness about lupus is a vital part of the Lupus LA mission, and why in 2013, Lupus LA launched the Community Awareness Program (CAP). Here’s what Lupus LA and our patient advocates have accomplished so far in 2014.

We received Lupus Awareness Month proclamations declaring the month of May Lupus Awareness Month from numerous local and state governments. These proclamations are important because they educate elected officials and the general public about lupus. Proclamations were received from the State of California, Orange County, Placer County and the following California cities: Baldwin Park, Beverly Hills, El Monte, Glendora, Irvine, Los Angeles, Mission Viejo, Moreno Valley, Ontario and Upland.

The health of many lupus patients is reliant upon their Part D medication coverage. In partnership with the Lupus Foundations of Northern and Southern California we sent a letter to members of Congress to educate them on pending legislation critical to holding down patient drug costs, and

to voice our opposition to any proposals that would erode the beneficial protections provided by Medicare Part D. We also sent letters to members of Congress educating them on the importance of including \$32 billion in the Labor-Health and Human Services-Education appropriations bill to support funding for biomedical research at the National Institutes of Health.



(Top photo) City of Beverly Hills Proclamation Ceremony: (left to right) Vice Mayor Julian Gold, Hon. Nancy Krasne, Lupus LA Board Members Debi Cowan and Alan and Michelle Kaye, Mayor Lili Bosse, Hon. Willie Brien, and Hon. John Mirisch; (bottom photo) Los Angeles City Councilmember Tom LaBonge, 4th from left, presents Lupus LA staff and board members with a proclamation declaring May as Lupus Awareness Month in the City of Los Angeles.

MORE MEMORABLE EVENTS

Orange Ball

Guests gathered in support of lupus research and awareness at the Beverly Wilshire Hotel on May 8, 2014 to attend the 14th annual *Orange Ball*. The event, which raised over \$450,000, honored four outstanding honorees for their contributions to improving the lives of those living with lupus. EMD Serono, Inc., a leader in the U.S. biopharmaceutical industry, received the *Medical Visionary Award* for improving medical treatments for lupus patients. Actor and director Phill Lewis received the *Loop Award* for his dedication to improving lupus awareness as a Lupus LA Ambassador. Lannette and Scott Turicchi received the *Daniel J. Wallace Founder's Award* for their generous contributions to Lupus LA and the Lupus Research Institute.

Emmy Award-winning actress Kristen Johnston hosted the evening. Kristen was diagnosed with lupus by Dr. Daniel J. Wallace in 2013. Now a Lupus LA Ambassador, she told the crowd how frustrated she was by the inability of countless doctors to diagnose her medical problems. Then she met Dr. Wallace, who immediately diagnosed her condition. She is so grateful for his help that she offered to host the event.

Guests helped raise important funding for the Carole & Barry Kaye Lupus LA Emergency Grant Program, which was launched in 2009. Grants up to \$500 are awarded to help cover emergency expenses related to lupus. Over \$45,000 was raised for the program on the night of the event. To view a video about the emergency grant program, please go to www.youtube.com/thelupusla.

The evening came to an end with everyone enjoying a performance by Judith Hill, a popular contestant on *The Voice* who also was featured in the Academy Award-winning documentary, *20 Feet from Stardom*.



Clockwise from top left: Judith Hill; host Kristen Johnston; Phill Lewis and Billy Gardell; honorees and board members; honorees and Lupus LA Board Members: (left to right) Scott Turicchi, Lannette Turicchi, Dr. Daniel, J. Wallace, Janice Wallace, Laurie Selkowitz, Adam Selkowitz.

Science at SoHo

On June 4, 2014, Lupus LA supporters Cathy and Henry Winterstern hosted a very special event at the exclusive SoHo House in West Hollywood. The 60 guests were treated to scrumptious appetizers, cocktails and desserts, but the real treat was being able to hear first-hand about the latest in lupus research from Lupus LA Medical Advisory Board Member Dr. Mariko Ishimora of Cedars-Sinai Medical Center. Dr. Ishimora was preceded by Lupus LA Board Member Bridget Hood, who told the audience about her personal battle with lupus and what being a part of Lupus LA has meant to her over the years. Hearing from a patient and a doctor, back to back, really gave the audience a unique perspective on lupus and the fight to treat and cure this disease. Thanks to the Wintersterns for such an incredible evening.

The Winterstern Family



Get Lucky for Lupus LA

The annual *Get Lucky for Lupus LA* poker tournament is always one of the coolest parties in town, but with the location moved this year to Hollywood's hippest nightclub, the Avalon Hollywood, the event transformed into the coolest party in any town.

More than 400 revelers descended on the club for the 5th annual fundraiser, and not only partied the night away but broke records in the process. Over \$125,000 was raised for lupus research and local patient programs.

Toni Braxton, six-time Grammy Award winner and Lupus LA board member, presented Nick Cannon, multi-faceted entertainer and TV and radio host, with the *Ace Award* for his work on behalf of Lupus LA. Describing himself as a "fellow Luppie," Nick told the crowd that he was thrilled to be with people who know exactly how he feels.

Mixed martial artist Tito Ortiz led an impressive parade of celebrities who competed with Lupus LA supporters and other poker players in hot pursuit of the top prize – a \$10,000 seat in the PokerStars Caribbean Adventure Main Event. Ortiz won the big pot after placing fifth in the competition last year. Before this year's event, the personable fighter announced proudly that he had trained all year for the tournament.

A big thank-you to our sponsors Fenix Cosmetics, PokerStars, 20th Century Fox, The Malone Neuhaus Group at Morgan Stanley Private Wealth Management and the Avalon Hollywood. Thank you to our bar sponsors, Tito's Handmade Vodka, Heineken, and Wente Vineyards. And thanks to the many gift bag sponsors, silent auction donors, committee members and volunteers who all contributed to the success of the event.



Clockwise from bottom: final table with tournament winner Tito Ortiz 3rd from left; Michael B. Jordan; guests playing poker and partying; Nick Cannon and Toni Braxton.

Latest on Lupus Patient Conferences

Our 4th annual *Latest on Lupus* Irvine patient conference was held on June 28, 2014, at the University of California, Irvine. The keynote presentations provided the most up-to-date information on lupus research and treatments by two members of the Lupus LA Medical Advisory Board, Dr. Sheetal Desai and Dr. Racheal Abuav. Dr. Desai is the Director of the Lupus Clinic at the UCI Medical Center and a board-certified rheumatologist. She presented the *Latest on Lupus Research*. Board-certified dermatologist Dr. Abuav, presented *Updates on Skin Manifestations of Systemic Lupus Erythematosus (SLE)*. In addition to general dermatology, Dr. Abuav cares for patients with complex dermatologic conditions and sees many lupus patients in her practice.

The conference closed with a presentation by patient advocates Deidre Gee Baptista and her twin sister Kirsten Gee Maeda, co-facilitator of the Lupus LA Irvine support group. They shared their personal journeys of advocacy work and how to obtain proclamations from local government for Lupus Awareness Month. Attendees reported that they left the conference motivated to engage in advocacy work, and with a better understanding of lupus and the latest on lupus research.

We would like to thank our long-time 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 will be held December 6, 2014, at the UCLA Medical Center. For more information, please contact Katherine McMahon, Program Manager, at kmcmahon@lupusla.org, or call our office at 310-657-5667.



Speakers Dr. Racheal Abuav and Dr. Sheetal Desai

BAG LADIES, continued from page 1

Cavalli fashion house has supported the luncheon with beautiful hand bag donations. "Last year, I was so impressed by the dedication and passion all the people involved in Lupus LA give for this cause," says Cristiano Mancini, Director of Marketing at Roberto Cavalli. He continues, "[The] Roberto Cavalli brand is about color, positive attitude and joy of life. We hope our contribution will bring more passion and strength to find a cure."

Lupus LA is still accepting new and gently used handbag donations for the silent auction, the main event of the luncheon. Tickets and tribute journal ads can be purchased at www.lupusla.org. Please contact Megan Hatch, Special Event Manager, at mhatch@lupusla.org if you would like to make a donation or have any questions.



Kathy Gallagher



Bruna Papandrea

RIDING, continued from page 1

You Want Weekend.” Angela’s involvement attracted participants who learned about lupus and Lupus LA through this event.

Nicole Fogel, who attended and was on the planning committee for the ride, says: “The partnership with SoulCycle helped get the healthy and able involved in raising awareness for those who might not be able to participate for themselves. It was the perfect synergy with Lupus Awareness Month.”

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Last but certainly not least we met with United States Senator Dianne Feinstein’s office to discuss three key areas which need more support in Congress: joining the Lupus Caucus in Washington D.C., approving more NIH funding for lupus research, and including lupus as one of the diseases listed for the next round of public meetings regarding the FDA Patient-focused Development Initiative program.

Lupus LA at Emmys Gifting Suite

Lupus LA was one of two charities represented at the elite DPA Gifting Suite for the Emmys last month run by Nathalie Dubois at the Luxe Hotel on Rodeo Drive. A big thank you goes out to Kelly Stone Singer for arranging this wonderful opportunity. We were on-site for four days creating more awareness for lupus and our many Lupus LA programs and services.



Angela Bassett proudly displays her Lupus LA orange leather bracelet while Michelle Kaye and Megan Hatch look on.

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 and learn more about lupus and how to live well with this chronic illness. For more information about the Lupus LA adult support groups and our pediatric support group at Children’s Hospital of Los Angeles, please contact Lupus LA at 310-657-5667 and/or kcmahon@lupusla.org.

Irvine Support Group

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

Spanish-Language Support Group

Primer Jueves del mes de
7 pm - 8:30 pm
Los Angeles, CA

UCLA Support Group

Second Wednesday of every month
6:30 pm – 8 pm
Los Angeles, CA

Howse Foundation & Lupus LA Support Group

Second Saturday of every month
10:30 am – 12 pm
Rancho Cucamonga, CA

Loom 4 Lupus Support Group

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

Alhambra Support Group

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

Sherman Oaks Support Group

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

Long Beach Support Group

Fourth Tuesday of every month
6:30 pm – 8 pm
Long Beach, CA



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Lupus LA promotes lupus research, awareness, and education, and serves the needs of people with lupus and their families in the Greater Los Angeles Area.

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Janice and Daniel J. Wallace, M.D.

Toby L. Berkow, *Executive Director*



asics LA MARATHON

Join Lupus LA in the 2015 ASICS LA Marathon & 5K
and help raise money for lupus research!

MARCH 14-15, 2015



Sign up at www.lupusla.org!