

# LUPUS LA

West Coast Division of the S.L.E. Lupus Foundation · Member of the Lupus Research Institute National Coalition · Summer 2012

## Hollywood Gets Behind Fight Against Lupus



Six-time Grammy winner Natasha Bedingfield performs at Orange Ball

The stars were all in alignment in support of the 12th Annual Lupus LA Orange Ball. Singers **Paula Abdul** and **Toni Braxton**, **Kellie Martin** (*Smooch*), **Carolyn Hennesy** (*Cougar Town*), **Verdine White** (*Earth, Wind & Fire*), **Nicholas Guest** (*Mad Men*), **Karina Smirnoff** (*Dancing with the Stars*), **Sophie Monk** (*Entourage*, *Click*) and many other stars hit the Beverly Wilshire hotel for the celebrated annual event. Guests enjoyed a musical performance by multi-platinum artist and six-time Grammy winner **Natasha Bedingfield**.

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### Lupus Awareness Month Recognized



Pictured from left: Lupus LA Patient Services Director Elyse Reyes, Los Angeles City Councilman Eric Garcetti, Lupus LA Executive Director Patti Koltnow, Senior Policy Advisor, Sarah Dusseault, Lupus LA Executive Council member Dorothy Ellis, Lupus LA Outreach Coordinator Gabby Trejo

Our Executive Council members and staff were honored to receive proclamations from the cities of Beverly Hills and Los Angeles, declaring May 2012 Lupus Awareness Month to coincide with National Lupus Awareness Month.

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## LUPUS LA'S SCIENCE AT SOHO, JUNE 21



Pictured from left: Dr. Maureen McMahon, Kelly Stone, Henry Winterstern, Cathy Winterstern

We thank Cathy and Henry Winterstern for generously hosting an elegant cocktail reception at West Hollywood's Soho House for 36 guests to learn about the latest in lupus research. Executive Director Patti Koltnow acted as Mistress of Ceremonies throughout the evening.

Kelly Stone, a lupus patient and long-time Lupus LA supporter, delivered a moving speech, ending with her inspiring declaration: "I have decided that I have lupus, but lupus does not have me."

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## LETTER FROM THE CHAIRMAN

Dear Friends,

Lupus LA turned Beverly Hills orange on May 24th, literally! The Beverly Wilshire hotel turned all of their exterior lights orange in honor of our 2012 Orange Ball, and that was just the beginning. Natasha Bedingfield gave an intimate and dynamic performance to over 500 guests as we honored Dr. Soram Khalsa and Pfizer Inc., all while being surrounded by edible centerpieces from Sherry Yard. What a great way to start our summer!

We continued to ride the wave of the success of the Orange Ball with a very moving evening of science, hosted by Cathy and Henry Winterstern. I can't thank the Wintersterns enough for their unwavering commitment to Lupus LA.

As you dive deeper into this newsletter you'll see many of the exciting things our patient services division has accomplished. They are doing a sensational job of reaching out into our communities and helping to serve the over 60,000 people living with lupus in Southern California. It's a daunting task for a team of two, but they rise to the challenge every day.

You'll also see inside this issue the introduction of our newest team member Megan Hatch as our Special Events Coordinator. Megan brings great new energy and enthusiasm to her role guiding all of our signature Lupus LA events. She has already made her mark on our upcoming schedule.

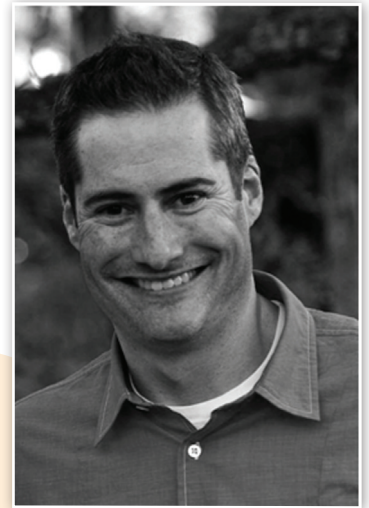
Speaking of our upcoming events, we have two great ones lined up. On September 13, we will once again take over the rooftop of the Petersen Automotive Museum for Get Lucky for Lupus LA, our party and poker tournament. We'll be honoring a terrific Lupus LA supporter Dennis DeSantis for all he's done for our organization. The poker event will be followed by the 10th anniversary of the Hollywood Bag Ladies Luncheon. We're honoring all of our past honorees this year — that's 13 spectacular women. This event will sell out, so be sure to get your tickets early.

On behalf of the Executive Council, I want to wish you all a terrific summer, and hope you enjoy this Lupus LA update. We are so appreciative of the support we receive from the Southern California community, and we hope to see you soon.

Warmly,



Adam Selkowitz  
Chairman



## UPCOMING EVENTS

### Get Lucky for Lupus LA



On Thursday, September 13, 2012, all eyes will be on the rooftop of the Petersen Automotive Museum as event-goers try to "Get Lucky for Lupus LA!" This celebrity poker tournament and party brings together young stars of Hollywood film, television, sports and music to increase community awareness of lupus. Money raised will benefit lupus research and patient services programs.

The Fourth Annual "Get Lucky for Lupus LA" event will honor **Dennis DeSantis**, an avid supporter of Lupus LA and owner of Dr. Tea's on Melrose in West Hollywood. The evening will also feature several live auctions by **Dave Hester**, the notorious "YUUUP!" man from "Storage Wars."



Put your cards on the table and be part of this great event: Bid in our exciting silent auction, enjoy delicious food and go all in at the poker tournament. This is an evening that promises to be unforgettable — it's a sure bet!

Tickets: \$100 to party; \$250 to play and party  
For more information or to become a sponsor, call 310-657-5667. To buy tickets, go to [www.lupusla.org](http://www.lupusla.org).



### It's in the Bag!

Who knew that 10 years ago, when Marla Paxson came up with the idea, that the Hollywood Bag Ladies Luncheon would become a "must-do" annual event? Lupus LA will mark a major milestone when the Hollywood Bag Ladies Luncheon celebrates its **10th anniversary on November 1, 2012** at the Beverly Wilshire hotel. Along with a fashion show, guests will enjoy an exciting silent auction showcasing bags from top boutiques including Prada, Fendi, Gucci, Burberry and Judith Leiber. Guests can also bid on handbags owned by such celebrities as **Natalie Portman, Sharon Stone, Julia Roberts** and **Jennifer Aniston**.



This year's event chairs, **Dorothy Ellis, Kathy Gallagher, Michelle Kaye** and **Janice Wallace**, are determined to make this the biggest and best luncheon yet. And what better way to start than by bringing back ALL of our previous honorees? Meet past recipients of the Hall of Fame "Woman of Achievement" award: **Janice Arouh, Toni Braxton, Carrie Brillstein, Christine Devine, Carolyn Folks, Lisa Gregorisch-Dempsey, Melissa Joan Hart, LaDoris McClaney, Marla Paxson, Nicole Paxson, Julia Van Hees-Aidner, Carol Weisman** and **Rachel Zoe**. It is because of the efforts of these great women that the Hollywood Bag Ladies Luncheon has become a signature Lupus LA event that has raised so much money for lupus research and patient services.

Don't forget to **save the date**. We look forward to toasting our 10th with you and all our extraordinary women of achievement as we raise funding to find better treatments and a cure.

For more information, to buy tickets, or to become a sponsor, call 310-657-5667.



### Star Light, Stars Bright at Lupus LA Orange Ball *(continued from cover)*



Pictured from left: Dr. Sudhakar Sridharan of Pfizer Inc. and Lupus LA founder Dr. Daniel J. Wallace

During the Orange Ball formal program Paula Abdul introduced Dr. Daniel J. Wallace of the David Geffen School of Medicine at UCLA and founder of Lupus LA. “Dr. Wallace is among a handful of doctors who’ve turned my life around. He’s a truly remarkable man, and I’m a big supporter of Lupus LA.”

Having helped mold alternative therapies with mainstream Western medicine, Dr. Soram Khalsa, Associate Physician, Division of Internal Medicine, Cedars-Sinai Medical Center received the Daniel J. Wallace Founders Award for his long-standing contributions to lupus care in LA. Dr. Sudhakar Sridharan accepted the Medical Visionary Award on behalf of Pfizer Inc. Our own Patient Services Director, Elyse Reyes, brought the challenges of lupus to life, describing working at Lupus LA as an opportunity to both give and receive support from others with lupus.

The event also raised national awareness for lupus. Media coverage included such outlets as TV’s *Extra*, US magazine, TVGuide.com, People.com, LATimes.com, and Examiner.com.

Some of the most popular photos, taken courtesy of our sponsor Dyson, featured our celebs vacuuming with style. A celebrity-signed vacuum was a coveted giveaway to the highest auction bidder. Guests left with Susie Cakes and pieces of the amazing edible centerpieces created by Sherry Yard, the Executive Pastry Chef for Wolfgang Puck.

### Lupus LA’s Science in Soho

*(continued from cover)*



Dr. Maureen McMahon, Assistant Professor of Medicine/Rheumatology at the UCLA School of Medicine and an active investigator in multiple clinical trials of novel therapies for lupus, shared exciting developments in lupus research. Dr. McMahon’s talent for making complex science understandable to general audiences sparked a lively Q&A.

Executive Council Chairman Adam Selkowitz closed the program and thanked everyone for coming. Guests lingered over dessert, enjoying the comfortable atmosphere and conversation.

### More on Lupus Awareness Month

*(continued from cover)*

Lupus LA also turned National Lupus Awareness Month into an opportunity to bring attention to lupus in our area. We hosted an evening workshop on how to make a difference in the lupus community. Topics included how local bills will impact lupus patients and how you can advocate on behalf of people with lupus in California and throughout the country. In addition, at each of our 10 support groups, we provided tips on how to become a lupus advocate.

### Lupus LA: A National Role Model

Our Patient Services Director **Elyse Reyes** will be presenting jointly with **Sandra Watcher**, Pediatric Rheumatology Nurse, Children's Hospital Los Angeles, and **Jennifer Ziegler**, Program Director, Arthritis Foundation Pacific Region at the upcoming American College of Rheumatology (ACR) Annual Scientific Meeting in Washington. ACR is the world's largest association of health professionals devoted to conditions such as lupus that affect the joints and bones.



Elyse will speak about **Lupus LA's pediatric support group model**, the first of its kind in the lupus community, first launched in 2009. Utilizing a special curriculum developed specifically for this program, the team teaches parents and kids new coping skills to help manage an often confusing and isolating disease. Childcare is provided for siblings. The pediatric program is held six times a year at Children's Hospital Los Angeles.

For more information, please call or email Elyse at 310-657-5667 or [ereyes@lupusla.org](mailto:ereyes@lupusla.org).

### Ask Jessica: Real Men Get Lupus



Jessica Rowshandel, MSW

Lupus is often called a "women's health issue" because about 90% of people with lupus are women; however, men get lupus too, and face challenges women do not:

**Even More Trouble Getting a Diagnosis** — Diagnosis is always tough. But so many men are told they can't have lupus because it's a woman's disease. Not true!

**Stigma of a "Woman's Disease"** — Because hormones may play a role in lupus, some men wonder if they are less manly (No!). Others who identify with being physically strong or family providers can have a hard time coping with physical weakness and fatigue particularly if it affects their ability to work.

**Lack of Social Support** — Emotional support is important but can be difficult for anyone. But it's even tougher for men. Lupus LA Support Groups are "co-ed" and men are welcome and encouraged to attend. Please share your experience as a man with lupus on our Facebook page at [www.facebook.com/lupusla](http://www.facebook.com/lupusla).

Jessica is the S.L.E. Lupus Foundation's Director of Social Services. Feel free to contact her at [jrowshandel@lupusny.org](mailto:jrowshandel@lupusny.org) or 212-685-4118.

## IN THE COMMUNITY

### Lupus LA Runs in Honda LA Marathon

Lupus LA is proud to announce that “**Team Life Without Lupus**” will be participating for the **fourth year** in the Honda LA Marathon and 5K. Members of our Team have an opportunity to make new friends and reach their health and fitness goals while helping others in the lupus community.

Our training program for the 2013 Marathon focuses on charity runners who may have never run a



race as well as seasoned runners. In exchange for training and support, you will help raise money for critical patient services in the Greater Los Angeles area, including educational conferences, emergency grants, one-on-one peer support and much more.

To find out more about “Team Life Without Lupus,” and to register for the 5K or full marathon, please contact Elyse Reyes at [ereyes@lupusla.org](mailto:ereyes@lupusla.org).

### Walk, Don't Run, with Lupus LA's New “Walk with Ease Program”

Have you ever felt like you wanted to get into an exercise program but didn't know how to start? Lupus LA can help!

We are happy to launch our new physical fitness program, “Walk with Ease,” in conjunction with the Arthritis Foundation. Led by certified instructors **Gabby Trejo** and **Elyse Reyes**, the “**Walk with Ease**” exercise program is designed to reduce joint pain and improve overall health. Starting in the fall, these hour classes meet three times per week for six weeks. Each session will include health-related discussion topics and self-paced group walks.

To learn more about Lupus LA's new “Walk with Ease” program, please contact Elyse Reyes at [ereyes@lupusla.org](mailto:ereyes@lupusla.org). To sign up, please ask your healthcare provider to provide you with a note giving approval for your participation.

## Highlights of the Lupus LA Fall/Winter Patient Services Calendar

### Latest on Lupus Patient Conference

Saturday, September 22, 2012, 9:00 AM – 1:00 PM

Cedars-Sinai Medical Center, Harvey Morse Auditorium

Hear from the city's finest lupus physicians and investigators. Participants will have the chance to question the experts and gather information and resources to better handle the disease.

### 2nd Annual Orange County Patient Conference

Sunday, October 14, 2012, 10:00 AM – 1:00 PM

UC Irvine Student Center

Learn from top lupus physicians and investigators at our second conference for residents of Orange County and the surrounding areas. Meet the facilitators of the Irvine support group, and learn about a local monthly resource.

### Arthritis in PrimeTime Conference:

#### Relationships, Arthritis and Related Condition in the Prime of Life

Saturday, October 20, 2012, 8:00 AM – 5:00 PM

PrimeTime includes sessions with expert advocates & health professionals on every aspect of relationships — how to make them, keep them and grow them.



To learn more about our programs, or to set up an appointment with our patient services staff, please call us at 310-657- 5667, or email [ereyes@lupusla.org](mailto:ereyes@lupusla.org) or [gtrejo@lupusla.org](mailto:gtrejo@lupusla.org).

## LUPUS LA ANNOUNCEMENTS

### You're Not Alone!

Lupus LA understands that life with lupus is challenging. We know it can be an isolating and devastating disease, as too often people don't understand what you are going through. But you are not alone. Throughout the year, Lupus LA hosts programs to give you an opportunity to meet people in similar situations. Many events are educational, providing important but easy-to-understand information to share with your family members and help you better interact with your doctors. This year's programs include:

- Three annual patient conferences to educate patients on the newest findings in lupus research and care
- Quarterly special topic workshops
- Ten monthly adult support groups (two held in Spanish)
- A children's support group in conjunction with Children's Hospital Los Angeles
- One-on-one peer support meetings for learning and sharing
- Lupus Emergency Grant program, which provides up to \$500 for lupus-related bills
- Patient Navigation Program to help negotiate through the healthcare and social service systems
- Wellness Day Conference focusing on complementary therapies

### New Resource with Opening of Lupus LA's Marengo Office

Lupus LA is thrilled to announce the opening of our new satellite office at the Clínica Msr. Oscar A. Romero Community Health Center in Boyle Heights. This amazing clinic features primary health care, a dentist, an optometrist, Medical Enrollment office, and assistance with WIC Enrollment, as well as health education programs.

The Marengo office was created so clients in this area can access our services nearby. Clients can meet with our Outreach Coordinator Gabby Trejo for one-on-one peer support, resource referrals and assistance applying to our emergency grant program and patient advocacy. Make an appointment to meet with Gabby at any of our offices by calling 310-657-5667 ext. 307 or emailing her at [gtrejo@lupusla.org](mailto:gtrejo@lupusla.org).

With our community outreach approach, Lupus LA provides local services to help a broad and diverse patient population made up of 42% Hispanic/Latino/Spanish, 24% White/Caucasian, 10% Black/African American, 8% Asian Pacific Islander and 16% other.

Clínica Msr. Oscar A. Romero Community Health Center,  
2032 Marengo Street, Los Angeles, CA 90033.

### Welcome Megan!



We are excited to have Megan Hatch join the Lupus LA team as the new Special Events Coordinator.

A Southern California native, Megan grew up in Redlands, California. She graduated from Brigham Young University in 2007 with a degree in Recreation Management. Megan's passion is event planning, and she comes to us with lots of experience. A few of her past events include working with "American Idol," coordinating the Utah AIDS Foundation Oscar Night America Gala and planning a county fair for 45,000 people.

Outside of work, Megan and her husband love going to Disneyland and taking their dog to the beach. Megan looks forward to using her event coordination skills to help improve the lives of those living with lupus.





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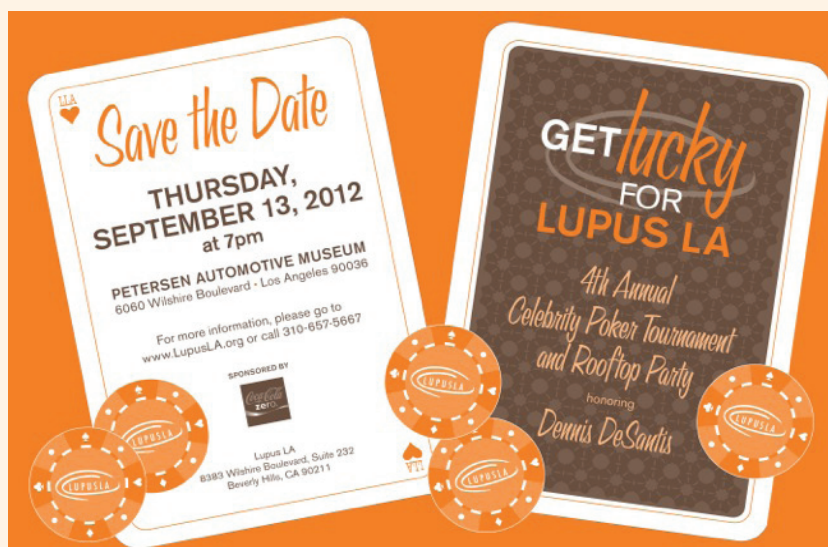
Lupus LA, the West Coast division of the S.L.E. Lupus Foundation, promotes lupus research, awareness, and education, and serves the needs of people with lupus and their families in Los Angeles County.

**LUPUS LA EXECUTIVE COUNCIL**

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