

THE SEMI-ANNUAL PUBLICATION OF LUPUS LA

**FALL/WINTER 2016** 

## **Planning Ahead**

## A Personal Story of a Legacy

By Toby L. Berkow, Executive Director

I am always thinking of the future. The future of me, my family and loved ones and of course, the future of Lupus LA. Our lupus community often reads a lot of what I write for Lupus LA, but this article is different – it's personal.

A few months ago my mother passed away. It was pretty sudden and although she had been quite ill for some time, we were unprepared. I wasn't aware of all of her wishes and I was left guessing as I put her estate in order. Some things she had shared with me, but there was an awful lot she hadn't. The truth is, my mom didn't plan ahead.

We all live and eventually die. It is important for us to think about what kind of legacy we want to leave upon our passing – even if we are completely healthy and plan to live a very long time. Have you thought about how you want your memory, life's work, and ideals to live on past you? It is important to have these conversations with your loved ones and to choose the continuation of your path.



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Going back to my mom's story, she was very involved with one charity in particular – not as a donor, but as a client. She didn't have a lot of money or resources, but upon her passing, we are creating a fund in her name to help others, as this charity had helped her. That's the funny thing about planned gifts, anyone, regardless of how much money or assets someone has, can make a difference and plan ahead.

As you may know, Lupus LA launched a new website about a year ago. This past month we launched a new section on *Ways To Give* with a dedicated section to planned



# We all want a cure for lupus.

Clinical trials are critical in the search of finding new and safer options for treating, preventing and curing lupus. Your participation in clinical research is the way to make this a reality. To learn more about clinical trials and to see if you are a possible candidate, check out www.lupustrials.org.

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Katherine McMahon Program Manager Ext. 303

Megan Stubbs Special Events Manger Ext. 304

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## **Lupus LA**

8383 Wilshire Blvd. Suite 232 Beverly Hills, CA 90211 310-657-5667

www.lupusla.org

# Letter from the Chairman



Dear Friends,

Sustainability. I want to talk to you about what that means to Lupus LA and what we're doing at the organization to achieve that goal. While we all hope that one day we will find a cure for lupus and that Lupus LA will no longer be needed, we are realistic in our thinking and, until that day comes, strive to stay vibrant and vital. That being said, the team at Lupus LA has been busy preparing for our future.

Sustainability comes in many forms. At Lupus LA we are focused on maintaining a strong board of directors, cultivating relationships with donors and patients, and building a solid infrastructure both in the office and online. One of the most exciting developments is the new planned giving section of our website. Planned giving is just that—it's a donor's plan to provide for Lupus LA, either during their life or after their passing. We have programs for both and they contain a variety of giving options to help tailor a gift to a donor's needs and requests.

Recently, after welcoming a new baby, my wife and I had to give renewed thought to our affairs. We spent time thinking about what would be important to us when we were no longer here and Lupus LA was a key component of that plan. This is an organization that is critical to so many people who suffer from this disease and we could not think of a more valuable way to show our commitment to the organization than placing a gift in our wills. While I certainly hope this gift isn't realized for many decades to come, I am comforted by the idea that we can continue to do good for the lupus community far into the future.

I want to encourage you, our most dedicated supporters, to visit the website and take a long look at the planned giving section that we've added. The office will be more than happy to answer any questions or walk you through the different available options.

I hope to see you at the Bag Ladies Luncheon on November 18<sup>th</sup> and wish you a wonderful fall season.

Best wishes,

Adam Selkowitz, Chairman

## A Personal Story (Continued from pg. 1)

giving. The planned giving section talks about gifts anyone can make - and I mean anyone. I ask that you take some time to think about your life story and your legacy over the next few months. How do you want to be remembered? What good can you leave behind that can help others? Please read through our website and if you would like to discuss how your legacy can help fulfill the future of Lupus LA and make a difference in the lupus landscape, please contact me at either tberkow@lupusla.org or 310-657-5667. No one likes to talk about death, but having a plan and a roadmap for your loved ones to follow is a gift unto itself.

## **Lupus LA Teams Up to** Take a Giant LEAP for **Lupus Education**

Lupus LA partnered with the Lupus Research Institute (now the LRA) and UC Irvine Medical Center for an important grant opportunity called the Lupus Education Advancement Project (LEAP). The LEAP grant was funded through the Office of Minority Health to help improve communication among the lupus community and their healthcare providers.

Through the grant, Lupus LA hosted four "Ask an Expert" Live Facebook chats on March 11th, April 15th, May 20th, and June 7th. Dr. Sheetal Desai, UC Irvine Rheumatologist and Lupus LA Medical Advisory Board member, participated in the live Facebook chats along with several of her rheumatology fellows and Jessica Rowshandel, a local clinical social worker. With the goal of increasing the number of providers with knowledge and expertise in lupus, ten provider training sessions were led by Dr. Desai and her fellows. The trainings were conducted with family medicine providers, internal medicine providers, dermatology providers, emergency medicine providers, nephrology providers and rheumatologists in the greater Irvine area. Provider trainings help increase provider expertise in lupus and will help reduce the amount of time it takes for a patient to get a lupus diagnosis. The live Facebook chats and provider trainings have allowed us to take a giant step forward in advancing lupus education and helping the lupus community.

## 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.



# **National Lupus Orgs** Merge for Research

In July of 2016, three major lupus research organizations (ALR, LRI, and the SLE Lupus Fdn.) joined forces to create the Lupus Research Alliance (LRA). The new merger represents the largest private sector organization dedicated to advancing lupus research in hopes to free the world of this autoimmune disease through power the scientific research.

Collectively, the three legacy organizations have devoted more than 75 years to the cause and are responsible for funding over \$200 million to support lupus research programs. newly formed organization serves as the primary catalyst setting the agenda vield new scientific discoveries into prevention, treatment and cure of the disease.

Lupus LA has been a longtime supporter scientific research through the LRI. We will continue to partner and work with the LRA as they begin their new quest together to finding the causes of and a cure for lupus.

rock

# **BRIGHT LIGHTS! BIG CITY!**

Celebrating Lupus LA on the New York Street at Fox Studios

On May 7, 2016, Lupus LA held our annual Orange Ball: A Night of Superheroes on the famous New York Street set on the Fox lot in Century City. Over 400 people attended the event to celebrate and honor our Lupus LA heroes for their work and dedication to supporting the lupus community. Lupus LA Medical Advisory Board member Paul Hackmeyer, MD, was honored for his tireless efforts on behalf of lupus patients. Hackmeyer was joined by philanthropist and longtime Lupus LA supporter Meredith Davidow Pegula who received the Daniel J. Wallace Founder's Award. Lupus LA Ambassador Kristen Johnston received the Loop Award and shared the inspirational story of her journey with lupus and Lupus LA. The night concluded with performances by pop sensations Howie Day and Ryan Cabrera.

Guests were treated to savory food up and down the street and were able to step into the pop-up SusieCakes shop for a sweet treat. Thank you to our evening sponsors including La Croix Sparkling Water, WE tv, Tito's Handmade Vodka, Essentia Water, Fenix Cosmetics, Carlsberg Beer, SusieCakes, and Twentieth Century Fox Studios for their support. Overall, the outdoor street party was a huge success, raising over \$400,000 for the cause and providing Lupus LA supporters

with a fun and exciting evening.

Bright Lights (top L to bottom R): Honoree and Lupus LA Ambassador Kristen Johnston and presenter Joseph Gordon Levitt; Honoree Dr. Paul Hackmeyer received his award from Dr. C. Andrew Schroeder; Honoree Meredith Davidow Pegula with husband, Chris Pegula; Event host Terrance Jenkins with Lupus

LA Ambassador Michael B. Jordan; Event performers Howie Day and Ryan Cabrera; Attendees enjoy the "New York" night; Gallery artist Marco Lorenzetto with Lupus LA Ambassador Taylor Spreitler and boyfriend, Max Ehrich; 3rd Rock Reunion at the Orange Ball: Kristen Johnston, Lupus LA Board Chairman Adam Selkowitz, Joseph Gordon Levitt, Wayne Knight.





# ALL IN for Get Lucky for Lupus LA

It was another great year for the 8<sup>th</sup> Annual Get Lucky for Lupus LA - Celebrity Poker Tournament and Party held on September 21<sup>st</sup> at the Avalon Hollywood. Over 300 guests were in attendance to play for a good cause and party for Lupus LA. Hosted by Lupus LA Ambassador

Kellie Martin, guests were treated to an amazing silent auction, fantastic food, and great poker. DJ Jake Gould was on hand to set the mood and tempo for this electric night.

The Band From TV (BFTV) was honored with our Ace Award for their commitment and work on behalf of Lupus LA. BFTV has been a longtime supporter of Lupus LA through Scott Grimes, a Lupus LA Ambassador, who donates the proceeds from his participation in the band to the organization. BFTV is a band full of TV

actors who get together to perform and raise money for charity. Joining Scott at the event were fellow band members, Bob Guiney (also a Lupus LA Ambassador), Adrian Pasdar, and Amanda Righetti.

The last nine members of the final table in the tournament were all treated to rockin' headphones from our friends at TRUE RELIGION. But the big winner of the night was

ACTOR AMAURY NOLASCO, who took it down by winning a poker themed weekend in Las Vegas hosted by Tiffany Michelle and Maria Ho.

A big thank-you to our friends at the Avalon Hollywood who graciously sponsored our event this year. Thanks also goes out to our bar sponsors, Tito's Handmade Vodka, Peroni, Biddle Ranch Vineyards, and the Ferini Family. Lastly, thank you to the many silent auction donors, committee members and volunteers who all contributed to the success of the event. Together we raised tens of thousands of dollars to support Lupus LA patient programs and medical research.



**ALL IN (top L to bottom R):** Awards presentation to the BFTV; Host and LLA Ambassador Kellie Martin; Professional poker player Tiffany Michelle with actor and *Get Lucky* tournament winner Amaury Nolasco; LLA board members Dorothy Ellis and Kathy Gallagher with longtime supporter Betsy Selkowitz; Sponsored poker table; Lupus LA Ambassadors and BFTV members Bob Guiney and Scott Grimes with LLA Board Chair Adam Selkowitz (middle).

## **VOLUNTEER SPOTLIGHT: RAYMOND PARRA**

Diagnosed with lupus in 2010, Raymond Parra found himself in his hometown just outside of Phoenix, Arizona, without many options for support and information. Raymond, a longtime fan of Lupus LA Ambassador and Board Member Toni Braxton, heard about Lupus LA though her TV show, *Braxton Family Values* and decided to find Lupus LA on the web. Raymond fou-



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# Advocacy Corner:

# **Step Therapy**

**Definition:** Step Therapy is a type of prior-authorization. It is the practice of beginning drug therapy for a medical condition with the most cost-effective and time-tested drug and then progressing to another more costly or innovated therapy, only if necessary (i.e., you must try drug "A" before you can get drug "B"). The goal is to control costs and minimize risks and is governed by your insurance company.

Lupus LA Executive Director Toby Berkow recently spoke at a California Partnership for Access to Treat (CPAT) Conference on Step Therapy from the patient advocate perspective. The message of the conference was loud and clear: Patients must be their own advocates. Through working with your team of caregivers and doctors, you can fight your insurance company's access to treatment decisions through writing letters, making phone

calls and making your voice heard. Some doctors are apprehensive to try and help because appealing these decisions can be time-consuming and sometimes not effective. However, in some instances, you can reverse the step therapy rule and get the medication that you and your doctor want you to have before going through a lengthy and sometimes counterproductive drug-trial process.

## Volunteer Spotlight (Continued from pg. 5)

-nd important information about his lupus along with volunteer opportunities to get more involved with Lupus LA. For the past two years, Raymond traveled six hours by car each way to attend and volunteer for the Orange Ball and plans to keep volunteering for years to come. When asked what advice he would give others, he said, "If you have the time to come out and help, Lupus LA is a good organization to work for. When I first volunteered for Lupus LA, I wasn't sure what I had signed up for. But I always feel loved, welcomed and cared for." Thank you, Raymond, for your tireless efforts!

# LATEST CALENDAR! ON LUPUS PATIENT CONFERENCE

UCLA | SATURDAY, OCTOBER 15 | REGISTER AT WWW.LUPUSLA.ORG

# Find a Group

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 310-657-5667 or via email at kmcmahon@lupusla.org.

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

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

Group
Primer Jueves del mes
De 7:00 PM a 8:30 PM
Clinica Oscar Romero, Sala 35
2032 Marengo Street
Los Angeles, CA 90033
(En frente del hospital general de USC)

Spanish-Language Support

# Support Near You

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

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

Howse Foundation & Lupus LA Support Group Second Saturday of the month From 10:30 AM to 12:00 PM

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

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

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

#### **HIGHLIGHTED GROUP THIS ISSUE:**

Looms 4 Lupus Support Group Second Saturday of the month From 9:30 AM to 11:30 AM

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

# Latest on Lupus:

## **The Orange County Patient Conference**

Our annual Latest on Lupus Orange County patient conference was held on June 25, 2016 at the University of California, Irvine. Lupus patients, along

with their loved ones, attended the conference from all across Southern California. Conference attendees applauded the event sharing that they were appreciative to attend an educational event where they could learn more about lupus and hear in-depth information about the latest developments in treatment and care.

The Director of the Lupus Clinic at the UCI Medical Center, Dr. Sheetal Desai, presented Women's Health & Lupus. Dr. Desai, a board-certified rheumatologist and member of the Lupus



Dr. Desai delivers keynote address.

LA Medical Advisory Board, focuses her research on lupus and Antiphospholipid Antibody Syndrome. Dr. Desai's presentation included a valuable question-and-answer session. Many conference attendees stated that they look forward to having the opportunity to ask questions to an expert rheumatologist, like Dr. Desai, and they felt empowered by the information.

Dr. Steve Aziz, rheumatologist, Dr. Summer Engler, rheumatologist, and Dr.



Orange County Conference Participants

Irene Yang, rheumatologist, participated in an informative Rheumatology Panel that also included a helpful question-and-answer session with the audience. Dr. Aziz presented Diet & Lupus, Dr. Engler presented Living Well with Lupus-Beyond Medications, and Dr. Yang presented The Role of Anti-Malarials in Lupus Treatment.

After lunch, Elizabeth A. Prescott, M.D.H. Certified Breathing Coordination Practitioner and Vocal Consultant, presented M.D.H. Breathing Coordination: Maximum Efficiency, Minimum Effort. Conference attendees learned important posture and breathing techniques.

Lupus LA would like to thank our sponsors Mallinckrodt and PhRMA, who enabled us to host the informative conference for patients and their families. We are looking forward to our next *Latest on Lupus* patient conference which will be held on October 15 at the UCLA Medical Center. For more information, please call us at (310)657-5667 or email bus at kmcmahon@lupusla.org.



Breathing Specialist Elizabeth A. Prescott explains techniques.



8383 Wilshire Blvd., Suite 232 Beverly Hills, CA 90211

P: 310-657-LOOP (5667) E: info@lupusla.org

www.LupusLA.org

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Lupus LA is dedicated to finding the causes of and a cure for lupus, while offering support to people with lupus throughout Greater Los Angeles.

