

LUPUS LA

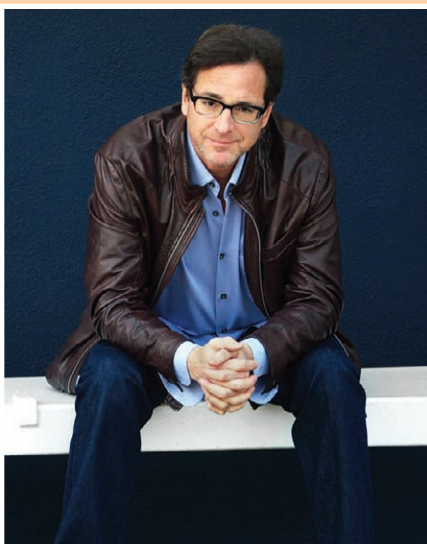
West Coast Division of the S.L.E. Lupus Foundation • Member of the Lupus Research Institute National Coalition • Spring/Summer 2013

Toni and Jason and Bob, oh my!

Singer Toni Braxton will serenade one of her doctors, “Seinfeld” star Jason Alexander will be honored for his work on behalf of Lupus LA and comedian Bob Saget will keep the laughs coming at the May 9 Orange Ball at the Beverly Wilshire hotel.

As a touring stand-up comedian and seasoned TV host, Saget is sure to bring some kick to the event, although this will not be Saget’s first time working with an autoimmune disease-focused charity. In 1994, his sister passed away from scleroderma, which has many similarities to lupus, and he has been an active

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Cindy Frey Partners with Donna Karan to Benefit Lupus LA

When Donna Karan thought of Cindy Frey, Cindy Frey thought of Lupus LA.

Cindy was an obvious choice when the internationally known fashion designer named her to be part of the Donna Karan Ambassador Program. Karan selects prominent customers from around the world who best represent the spirit of her philanthropic nature. These ambassadors host Donna Karan seasonal trunk shows and events in their markets, tied into charitable awareness and fund-raising. As a result of a Donna Karan luncheon and fashion show hosted by Cindy Frey at Saks Fifth Avenue Beverly Hills, Lupus LA received a check from Saks Fifth Avenue for \$10,115, and another \$5,000 check from Donna Karan.

Cindy, a mother of three and a lupus patient, is familiar with our organization through her physician and Lupus LA founder Dr. Daniel J. Wallace. “I am so grateful to Dan for helping me to navigate through this devastating illness,” Cindy said.

Cindy’s generosity did not start with Lupus LA, however. In 1992, Cindy became aware of an emerging charity based in Aspen, Colorado called “A Grassroots Aspen Experience.” The non-profit endeavor brought at-risk-youth from all over the United States to Aspen for empowerment exercises, mentoring and

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Dear Friends,

As we come into the spring season at Lupus LA we always look forward to our premier event, the Orange Ball. And while this year is no exception, we also have more exciting news: Lupus LA, in conjunction with Cedars-Sinai Medical Center (CSMC), will be launching the first Lupus LA/CSMC Fellowship.

This fellowship will support the training of a clinician/scientist over a two-year period. The training will involve research and clinical practice and will allow the fellow to focus on rheumatic diseases, particularly lupus. This is a significant step forward in filling a big gap in the availability of rheumatologists nationwide and will allow CSMC to deploy a new lupus doctor into the community. We hope to replicate this program at many of the area hospitals and possibly beyond as we obtain more funding.

Lupus LA has been raising significant funds, alongside the dollars we already raise for research and patient services, to specifically address the needs of the community and the lupus world as a whole. But we are not done yet and every dollar is critical toward making this program a success. Supporters of Lupus LA should be proud of how their contributions are being used, and I encourage all of you to consider this new program as you think about our upcoming events.

Now, back to the Orange Ball! It's a personal privilege to be honoring one of the top cardiologists in the country this year as we present Dr. Jay Schapira with the Dr. Daniel J. Wallace Founder's Award. I know firsthand how Dr. Schapira is making a difference for lupus patients, as I am one of his success stories. Alongside Dr. Wallace, Dr. Schapira has made groundbreaking discoveries in the treatment of lupus patients with cardiac involvement.

We will also be honoring Dr. Stanley Naides from Quest Diagnostics with the Medical Visionary Award. The work Dr. Naides has done at Quest, on behalf of lupus patients, is truly game changing and we can't wait to recognize him with this award.

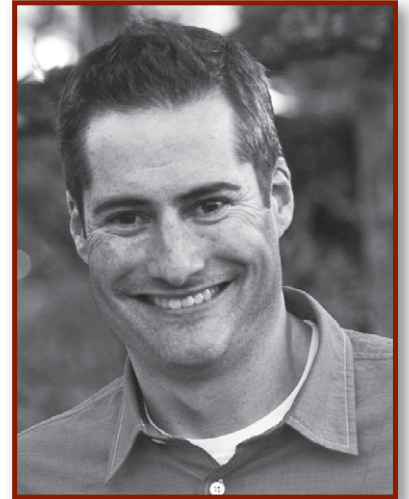
To round out lineup, we are honored to be presenting this year's Loop Award to a great friend of Lupus LA. Jason Alexander has lent his enormous talent (not to mention his poker playing skills) to many of our events and, in the process, has helped raise lupus awareness nationwide.

There are plenty more surprises in store for the Orange Ball and more exciting Lupus LA news to come. And I would be remiss not to give a huge shout out to all of our Marathon and 5K runners – Lupus LA is so appreciative of your support and dedication. Please enjoy this informative newsletter and don't forget to visit us on the web (www.lupusla.org), follow us on Twitter (@lupusla) and "like" us on Facebook.

Feel great,



Adam Selkowitz
Chairman



LUPUS LA AND CEDARS-SINAI MEDICAL CENTER TEAM UP FOR RHEUMATOLOGY FELLOWSHIP

Rheumatologists treat multiple-related disorders, including lupus, arthritis, gout, fibromyalgia, carpal tunnel syndrome, back and neck pain and other ailments. Rheumatology is a specialty whose number of practitioners is steadily declining, and whose number of patients is steadily increasing. The shortage of rheumatologists is likely to become a crisis within twenty years, more so than other specialties, unless something changes in the funding and availability of fellowships.

An American College of Rheumatology Workforce Study in 2006 estimated that about half of practicing rheumatologists would retire within eight years, and that by 2025, there will be a shortage of 2,600 rheumatologists in the U.S.

In Los Angeles County alone, there are over 60,000 lupus patients suffering from this sometimes fatal autoimmune disorder. Combine the shortage of rheumatologists, socio-economic barriers, and the fact that lupus is one of the nation's least recognized major diseases, and you can understand why many of these patients are particularly vulnerable to a lack of access to quality health care.

Many of these lupus patients, including many that Lupus LA serves, must use free/low-cost clinics or county-run

hospitals, and many of these clinics don't have specialists who can diagnose and treat this complex disease. There is currently a six-to-nine-month waiting list at Los Angeles county hospitals to see a rheumatologist.

For these reasons, as Lupus LA Chairman Adam Selkowitz mentioned in his letter, Lupus LA and Cedars-Sinai Medical Center (CSMC) have joined together to support a two-year Fellowship Program at CSMC. The specific training will involve mentoring and research projects that focus on lupus (systemic lupus erythematosus – SLE) diagnosis, treatment and disease prevention.



Dr. Michael H. Weisman, Director, Division of Rheumatology at CSMC, will educate our Fellow on the challenges of diagnosis and treatment in patients who are being followed on the clinical service. Because Dr. Weisman recognized the shortage of rheumatologists for lupus patients in Los Angeles, our Fellow will be providing consultation services to the physicians, and seeing

patients for free at other hospitals and clinics.

If you are interested in making a restricted donation to specifically support this fellowship, please contact Lupus LA Executive Director Patti Koltnow at 310.657.5667, or at pkoltnow@lupusla.org.



By the time you read this story, Lupus LA's Team Life Without Lupus will have completed the ASICS LA Marathon and 5K. As a premier charity of the ASICS LA Marathon, Lupus LA had over 100 runners and walkers. In exchange for training and support, participants raised money toward critical patient services in the Greater Los Angeles area, made new friends and reached their health and fitness goals. A big thank-you

goes out to our long-time sponsor, the Rotary Club of Beverly Hills. You can read more about Team Life Without Lupus, and see a complete list of sponsors and our top fundraisers on our website and in the next issue of our newsletter.

10TH BAG LADIES LUNCHEON WAS PURE GOLD

It was a lunch to remember, as 500 women filled the main ballroom of the Beverly Wilshire Hotel on November 1, 2012. Tenth anniversaries do not typically pass by without much fanfare, and the Lupus LA Hollywood Bag Ladies Luncheon was no exception. The support and generosity of the guests raised \$360,000 – the second highest luncheon revenue to date.

To commemorate this milestone, all of the previous recipients of the Woman of Achievement Award were honored on the same stage. As part of the award presentation, a short video was shown, giving an overview of the past ten years. Through the visible camaraderie among these women, it was clear that the Hollywood Bag Ladies Luncheon has grown to be more than just a tradition. 2007 honoree Nicole Paxson explained, “Lupus LA is more of a family than a charity.” Watch the Woman of Achievement film at www.lupusla.org.

The main event of the luncheon was a silent auction filled with the finest handbags in Beverly Hills. In addition to personal donations, bags were donated from the collections of Burberry, Jimmy Choo, Fendi, Michael Kors, Prada, and Tiffany & Co, to name a few.

Celebrities also got into the spirit of giving, and bidders took home bags that were previously owned by Natalie Portman, Jennifer Aniston, Zoe Saldana, Kelly Osbourne, and more.

The highlight of the luncheon was when Sharon Stone took

the stage. Dressed to the nines, Stone went above and beyond the role of auctioneer as she solicited donations from the audience for Lupus LA’s first rheumatology fellowship. Thanks to her passionate plea, Lupus LA raised \$53,000 of the \$160,000 needed to fund this fellowship.

The luncheon ended on a high note, as the fashions of international designer Kevan Hall took the stage. Beautiful gowns were showcased in this glamorous



2012 Honorees: (left to right) Carrie Brillstein, Marla Paxson, Nicole Paxson, Toni Braxton, Carolyn Folks, Janice Arouh, Julia Van Hees-Aidner, LaDoris McClaney and Christine Devine. Not pictured: Lisa Gregorisch-Dempsey, Melissa Joan Hart, Carol Weisman and Rachel Zoe.

fashion show, which received rave reviews from all of the guests. At the end of the show, Kevan Hall provided the audience with a special treat as he walked down the runway and thanked the crowd.

The 10th Anniversary Hollywood Bag Ladies Luncheon was a huge success, and it is all thanks to the hard work of

the committee members and generosity of the Lupus LA supporters. Join Lupus LA on Friday, November 15, 2013 to see what they have in store for the 11th anniversary of this stand-out event.

LATEST ON LUPUS PATIENT CONFERENCES

In September, Lupus LA held its 8th annual Los Angeles Patient Conference at Cedars-Sinai Medical Center. With over 200 participants, it was our largest audience to date. In October, we held our 2nd annual Orange County Patient Conference at UC Irvine with over 50 participants.

Our featured speakers at both conferences were some of the top rheumatologists in Southern California: Dr. Lisa Cook, Dr. Catherine Driver, Dr. Lindsay Forbess, Dr. Paul Hackmeyer, Dr. Noreen Hussaini, Dr. Wesley Mizutani and Dr. Daniel J. Wallace, founder of Lupus LA.



Lupus LA Board members at the Lupus LA Cedars-Sinai Conference. From left to right: Dr. Daniel J. Wallace, Roger Cowan, Debbi Cowan, Janice Wallace and Kate Kelly.



Three generations attend the Lupus LA Cedars-Sinai Conference. From left to right: Daughter, Eureka Norris; granddaughter, Taylor Norris; grandmother and lupus patient, Helen Washington.

A big thank-you goes to all of the doctors for presenting. They donated their personal time over the weekend to share their knowledge on a variety of topics, including: Managing Lupus, Lupus and Non-traditional Therapies, How a Rheumatologist Keeps Track of Disease Activity, Lupus and

Pregnancy, CNS Lupus and a Treatment Update. Following each presentation, the doctors took questions from very interested and appreciative audience members.

English/Spanish translation for Spanish-speaking participants was provided for all featured presentations, and as usual, our awesome volunteers helped with everything from signage to registration.

After a delicious buffet lunch, participants networked and joined their choice of Round Table Discussions with experts. Topics included: Ask a Rheumatologist, Lupus and the Workplace, Finding Resources, Support for Caregivers, Getting Involved with Lupus LA, Lupus and Young Adults, Managing Relationships with Lupus, SSI & SSD, and Learning More About Clinical Trials

As always, we are very grateful to our sponsors, GlaxoSmith-Kline, Pfizer Inc. and UCB Inc., who enabled us to host both conferences free of charge to patients and their families.

Cindy Frey, *continued from page 1*

counseling. Cindy and husband Glenn Frey (of the rock band The Eagles) raised awareness and monies for the charity through fundraisers, lectures and concerts. Cindy served on the board of Grassroots for five years.

Glenn Frey and fellow Eagle Joe Walsh performed at the 2007 Lupus LA Orange Ball, and Cindy has been instrumental in raising awareness and giving support to Lupus LA. "Lupus has been raging through our population of young women, cutting short the opportunity for them to reach their full potential. Often it targets the very driven woman who has so much to give. Lupus LA has been a front-runner in the fight to cure this disease by raising funds for research and supporting patients."

Karan's ambassador program is part of "Women Who Inspire," which Karan launched on her website donna-karan.com. Among the women named to the group were:

Demi Moore, Maria Shriver, Kerry Washington, Susan Sarandon and Nicole Kidman.

"I believe in the power of women," Karan explained when she formed the group. "As nurturers, we have a unique ability to care and share and make the world a better place. "Women Who Inspire" is women who are making a difference. This website gives their inspiring messages an interactive forum, encouraging women everywhere to take action and get involved."

"Lupus has been raging through our population of young women, cutting short the opportunity for them to reach their full potential. Often it targets the very driven woman who has so much to give."

Thank you, Cindy, for taking action.

LUPUS LA SUPPORT GROUPS

Being truly "supported" is a powerful feeling that many people with lupus long to have, and that can help enormously in riding out the emotional "rollercoaster" of life with this exhausting and unpredictable chronic illness. But there is support out there – Lupus LA's support groups are here to help you learn more about lupus and how to cope with all of the stress that comes along with it.

These groups are free and open to the public. For more information about the Lupus LA adult support groups listed below, and our pediatric support group at Children's Hospital of Los Angeles, please contact Lupus LA at (310) 657-5667 and/or info@lupusla.org.

Irvine Support Group

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

Spanish-Language Support Group

Primer jueves del mes de
7pm a 8:30pm
Los Angeles, CA

Howse Foundation & Lupus LA Support Group

Second Saturday of every month
10am – 11:30am
Ontario, CA

Loom 4 Lupus Support Group

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

Cedars-Sinai Support Group

Second Wednesday of every month
7pm – 9pm
Los Angeles, CA

Alhambra Support Group

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

Santa Clarita Support Group

Fourth Sunday of every month
2pm – 3:30pm
Santa Clarita, CA

San Fernando Valley Support Group

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

Long Beach Support Group

Fourth Tuesday of every month
10am – 11am
Long Beach, CA

Orange Ball, continued from page 1

board member for the Scleroderma Research Foundation ever since.

Alexander will be the recipient of the *Loop Award*, which recognizes a member of the entertainment industry who uses his or her voice to put a public and compassionate face on the mystery of autoimmune related diseases, like multiple sclerosis, rheumatoid arthritis, scleroderma and lupus.

In addition to the actor's ongoing connection to Lupus LA, which includes hosting the Orange Ball and participating in our poker tournament, Alexander has been a strong advocate by bringing awareness to autoimmune diseases, including scleroderma. Alexander's sister is a long-time sufferer of the disease.

Another honoree will be Dr. Jay Schapira, who will receive the *Daniel J. Wallace Founder's Award* in honor of his work with lupus patients. One of those patients – the dynamic Toni Braxton – will sing her big hit "Un-Break My Heart" to her physician.

Dr. Schapira's cardiology practice treats many lupus patients, and his research resulted in the discovery of microvascular angina, a type of heart disease found in lupus patients. "These patients continuously inspire me," Dr. Schapira said, "and that is why I have chosen to receive this award in the hope that my acceptance will bring greater awareness and much-needed fundraising to this important organization."

Dr. Stanley J. Naides will receive the *Medical Visionary Award* for his work on behalf of Quest Diagnostics.

As the director of immunology at the Quest Diagnostics Nichols Institute, Dr. Naides' leadership and work was instrumental in the recent improvement of laboratory testing

Two New Programs Will Launch in the Spring of 2013:

Ambassadors The Lupus LA Ambassador Program is a network of committed entertainment industry professionals who are passionate about promoting lupus awareness and Lupus LA. By creating an official celebrity ambassador program, Lupus LA is taking a vital step towards improving lupus awareness nationwide.

Medical Advisory Board The Medical Advisory Board of Lupus LA is comprised of medical and health-care professionals dedicated to supporting the important work of Lupus LA, including expanding patient services and funding novel research. The committee is charged with acting as a liaison to health care agencies and institutions, advising the Lupus LA Board on matters of clinical and public policy, assisting with professional education programs, and fostering Lupus LA's relationship within the medical and scientific communities.

for lupus patients. Lab testing is a critical part of getting a correct diagnosis for those with autoimmune diseases, and this advancement has made a huge impact, and will continue to make a difference in the lives of many.

The Orange Ball, which has been held at the Beverly Wilshire the last five years, is a Lupus LA tradition that continues to exceed expectations. Last year's Orange Ball raised more than \$575,000.

Guests should look forward to an unforgettable evening, filled with great food and top-level entertainment. Join Lupus LA on May 9, 2013 for its premier event of the year. Tickets can be purchased at www.lupusla.org or by calling 310.657.5667.



We are excited to have Emmanuel Urbano join the Lupus LA team as the new Administrative Assistant. Emmanuel majored in piano performance and minored in general business at Virginia Commonwealth University, where he graduated with a BA in Music. Prior to joining Lupus LA, Emmanuel was a Copyright Assistant in Intellectual Property at Twentieth Century Fox Film Corporation. His extensive experience volunteering in various non-profits, as well as managing volunteers, has given Emmanuel an understanding of the everyday challenges of working in a non-profit organization. In his free time, he enjoys playing the piano and staying active.



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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.

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SAVE THE DATES!



SAVE THE DATES!

