

# LUPUS LA

West Coast Division of the S.L.E. Lupus Foundation · Member of the Lupus Research Institute National Coalition · Fall 2008

## SUCCESS OF LA RESEARCHERS SPURS MILLIONS IN ADDITIONAL \$\$ TO EXPAND LUPUS WORK

*LA helps Lupus Research Institute secure over \$50 million from NIH and others*

In confirmation of the power of the Lupus Research Institute (LRI) model to find answers to lupus, three area researchers are among the many who have proven their innovative hypotheses and secured over \$50 million from the National Institutes of Health (NIH) and others to continue their exciting work, a recent analysis reveals.

In all, 65 percent of the scientists done with their 3-year "Novel Research" grants from the LRI have won ongoing funding.

"The scope, speed, and consistent pace of this scientific discovery are unprecedented in private-sector lupus research," said LRI President Margaret Dowd. "We began convinced that the path to a cure lay in freeing investigators to think creatively and imaginatively, so we asked for outside-of-the-box thinking. LRI investigators have turned that box inside-out and upside-down."

"The LRI strategy of funding novel scientific ideas in lupus has more than demonstrated its power," adds William E. Paul, MD, chief of the Laboratory of Immunology at NIAID-NIH, and chair of the LRI's Scientific Advisory Board. "The model strengthens the lupus research landscape by moving novel concepts forward to secure large-scale federal funding."

The LRI invests \$300,000 each in grants for innovative work at academic medical centers nationwide. It's the only organization pioneering lupus discovery through this bold, high-risk model.

**At first, no one would fund exploration of Dr. Greg Lemke's novel idea** that a curious family of immune system

*Clockwise: Bevra Hahn, MD, Maureen McMahon, MD, and Greg E. Lemke, PhD.*



receptors called "TAM" receptors might function as a core 'control switch' over the immune system's inflammatory response. But he was right. **Now the Salk Institute for Biologic Studies researcher has grants of**



**\$1.4 million from the NIH and other organizations** to explore exciting new approaches to mastering this switch—shutting down the uncontrolled inflammation of lupus and other autoimmune illnesses by restoring immune system regulation. "Without the LRI...this fundamental discovery in immunology would not have happened," Dr. Lemke said.

**At first, no other funding group except the LRI would support exploration of Drs. Bevra Hahn and Maureen McMahon's novel idea** that a certain form of the normally "good" HDL cholesterol linked to heart health might play a counterproductive role in lupus and actually promote atherosclerosis. **Now the University of California at Los Angeles researchers have various new grants totaling over \$869,000** to find ways to detect, prevent and treat lupus-related atherosclerosis.



**Lupus  
Research  
Institute**

Gregory Barton, PhD  
University of California, Berkeley

Roland G. Henry, PhD  
University of California, San Francisco

### FORUM FOR DISCOVERY

The Lupus Research Institute (LRI) hosts its annual scientific conference in New York City on October 6 & 7. Now in its 8th year, the forum is the country's foremost scientific conference on lupus—a scientific showcase of new ideas. **With Lupus LA's support, these California researchers will be there:**

Greg E. Lemke, PhD  
Salk Institute for Biological Studies, La Jolla

Betty Tsao, PhD  
University of California, Los Angeles

Mathias Wabl, PhD  
University of California, San Francisco

# New Lupus LA Executive Council to Help Expand, Strategize, Think Nationally

It is with great pleasure that I announce the formation of Lupus LA's first Executive Council. These individuals, all touched by lupus, are now committing their time, experience and expertise in industries ranging from health care to entertainment to ensure that Lupus LA continues to expand and have a large impact in southern California and nationwide.

Growth at the organization has been particularly vigorous since the appointment of Linda David as our full time executive director 15 months ago—and with this growth comes the need for particularly careful and inspired strategic planning and intelligent governance.

Please join me in welcoming our first Lupus LA Leadership Council members:

**Debbi and Roger Cowan, Dorothy Ellis,  
Kathy and Tim Gallagher, Michelle and Alan Kaye, and  
Janice and Dan Wallace, MD**

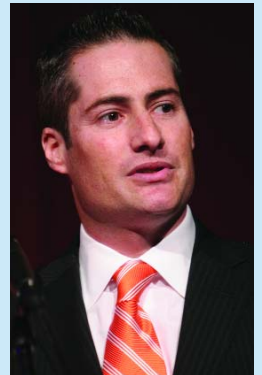
Be sure to look for profiles on these leaders in coming newsletters, so that you can get to better know the decision makers helping to move Lupus LA forward!

I have never been more proud to serve with a group of people.

Sincerely,  
Adam Selkowitz,  
Chairman, Lupus LA

## Getting to Know the Executive

Adam Selkowitz is the CEO and principal of Waterfall Films, a production company that specializes in multi-generational, family friendly feature films and television shows. Waterfall recently released the feature film *Greener Mountains* on DVD. The film, with Adam as producer, won the 2005 Boston International Film Festival Jury Award and can currently be seen on the Starz Network.



A graduate of Ithaca College, Adam has an extensive background in event planning and fundraising, and has worked with many major charitable organizations and corporations. Diagnosed with lupus 21 years ago, he has been involved in Lupus LA for nearly a decade and has held a leadership role in the organization from the start.

Adam, along with his parents Arty and Betsey and brother Jed, will be honored at the "Life Without Lupus Gala" on November 20 in New York. Learn more at the S.L.E. Lupus Foundation's website, [LupusNY.org](http://LupusNY.org)

## Lupus LA Gives Angelenos An Opportunity to Learn from the Experts on Lupus



The June 28th patient education conference drew over 100 people to Cedars-Sinai Medical Center to hear about the latest research in lupus and the rising prospects for better treatments. At the podium were some of the city's finest lupus physicians and investigators, including Lupus LA founder Daniel J. Wallace, MD. Participants, who came from across the region, had a chance to listen in, question the experts, and gather information and resources to better handle the disease.

*At left:* Mariko L. Ishimori, MD, a staff physician with Cedars-Sinai Medical Center's Division of Rheumatology and an assistant clinical professor of medicine at the Geffen School of Medicine at UCLA, fielded questions from attendees.

**Are there topics that you'd like to see covered at next year's conference?**  
Let us know! Email us at [lupus@lupusla.org](mailto:lupus@lupusla.org).

## Expanding Our Reach

### An Update on the Emergency Grant and Outreach Program

Planning is underway to broaden Lupus LA's outreach through a new program expected to launch in early 2009. In the underserved communities of L.A. County, traditional awareness and health education efforts fail to adequately reach people most at risk for lupus. We are currently conducting a survey of needs, which will be used to design culturally appropriate programs, channels to lupus screening, diagnosis and treatment, and services to provide support in periods of hardship.

## Join Lupus LA's Online Community

**Search "Lupus LA" on Facebook and become a fan or send us a friend request at [MySpace.com/LupusLA](http://MySpace.com/LupusLA)**

Connect with others affected by lupus and get updates on the latest Foundation news and events.

## Support Groups in LA

*“If I can help someone else cope, it’s a good day.”*

by Alexis Markowitz

*“The last thing I wanted to do last night was attend the support group.*

*Working up the will to go is so hard...I always need to talk myself into it. In the mornings it’s a huge challenge to even get out of bed.*

*Everything is sore and achy: my back, my neck, my shoulders, my hands. I am so tired and move at a snail’s pace. Every day, the same thing; I feel like I am going in circles. Have to schedule 10 hours a night now just for sleeping. So frustrated. And nauseous every day from my meds. Sometimes it’s all too much.*

*But...I push myself to go to the support group...and miraculously I feel better afterwards, mostly because I always meet a new patient who has just been diagnosed and needs a shoulder to lean on. Being in the dark about the diagnosis is so scary—I know I was terrified three years ago when I got the news,*

*and being able to share my frustrations and fears with those who also go through this experience brought and continues to bring me solace. I just hope I can offer that same comfort to someone else.*

*And then last night, ‘Beauty Night’ actually ended up being very fun....a nice break from*

*same old, same old. It gave us the chance to be silly and girly. It felt uplifting to do something positive, something lighthearted. **Something that reminded us of how lupus doesn’t have to be a death sentence.**”*

The Lupus LA support group meets the second Wednesday of every month at 7 p.m. at Cedars-Sinai Medical Center’s Thalians Auditorium. Come to learn coping strategies, get advice, and talk with other people affected by lupus. [Note: There will be no support group in October. Please join us for our next meeting on Wednesday, November 12.]

Cedars-Sinai Medical Center  
8730 Alden Drive, Plaza Level  
Los Angeles, CA 90048

Complimentary parking: Lot 2 (Spielberg lot) on the corner of George Burns & Alden. Enter on George Burns.



Above: a support group member gets a make-over at ‘Beauty Night.’

## In a Lupus Clinical Trial

There is no known cause of lupus, few medicines, and no cure. But in recent years, more and more pharmaceutical and biotech companies have developed lupus treatments and are conducting clinical trials to meet FDA approval.

There are 11 lupus trials now recruiting in the Los Angeles area.

Here, Stacey, who is 48 and from Los Angeles, weighs the pros and cons of the process, and shares why she volunteered for a clinical trial.

*Stacey:*

*“My doctor approached me about getting involved in a clinical trial. He knew I was struggling with the illness, and financially.*

*It may seem strange but I didn’t really have any major concerns—just questions about the logistics and the process. I take so much medication for lupus and fibromyalgia that receiving “test” infusions just seemed like the next logical step...and having more access to my doctor was a huge incentive.*

*Since enrolling in the trial I not only get more “face” time with my doctor, but it’s also opened me up to being a better “patient”—if there is such a thing. Because I go to the study office frequently, I don’t have a tremendously long list of items to go over. And I’ve found that I’m calmer about what I’m enduring.*

*The trial technician, Inga, is extremely helpful when I’m experiencing new symptoms. For example I’ve had some fainting episodes lately and she took time to go over the issue. I’ve already mentioned to her that I would love to do another trial after this one*

*Participating in a clinical trial affords me the gift of feeling more in control over the illness with every visit I make. If I’m helping someone else in the process. It’s the icing on the cake!”*

► Visit [LupusTrials.org](http://LupusTrials.org) to get the facts on clinical trials, read more volunteer stories, and learn how you can get involved.

► Find out more about trials in southern California at [LupusLA.org](http://LupusLA.org)

# A cure for lupus is...*in the bag!*

Join us for two days this autumn to advance the fight against lupus in southern California.

Monday, October 13 at 10am



Enjoy breakfast at Fendi, a talk on fall bag trends by Nathan Cooper, (editor of *C Magazine*), and receive your "passport" for a day of shopping on Rodeo Drive, where participating boutiques will donate 10% of sales to Lupus LA.

To register, call Lupus LA at 310-657-5667 or sign up at [LupusLA.org](http://LupusLA.org)

Friday, November 7 at 11am at the Beverly Wilshire Hotel



Tickets are now on sale for Lupus LA's most popular annual event. Hobnob with a bevy of celebrity "Bag Ladies" and bid on hundreds of fabulous designer bags in a silent auction. This year's luncheon honors prominent Los Angeles philanthropist, La-Doris McClaney.

Honorary Chairs: Carrie Brillstein and Toni Braxton  
Luncheon Chairs: Kelly Stone and Dorothy Ellis

Individual tickets from \$200. Purchase online at [LupusLA.org](http://LupusLA.org) or call 310-657-5667.



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