

The Loop

The Newsletter of the S.L.E. Lupus Foundation

Leading the Fight Against Lupus

WINTER 2006

Gala 2005 Raises Record \$2.4 Million For Lupus Research, Education & Patient Services



Mayor Michael Bloomberg proclaims December 5, 2005
"S.L.E. Lupus Foundation Day"

The S.L.E. Lupus Foundation's 35th Anniversary gala, held on December 5, 2005, generated \$2.4 million – the largest amount ever raised in a single event for lupus research, education and patient services. Nearly 750 Foundation supporters attended the gala at the New York Marriott Marquis, which featured remarks by New York City Mayor Michael R. Bloomberg and tributes to the evening's honorees: Foundation President Richard K. DeScherer, Board Member Jennie L. DeScherer and Chairman of the Lupus Research Institute (LRI) Scientific Advisory Board, William E. Paul, M.D. The LRI, established by the S.L.E. Lupus Foundation in 2000, is the nation's preeminent sponsor of innovative, novel research into lupus.

"Every new voice—every additional dollar—brings us closer to a breakthrough in treatment," said Mayor Bloomberg. "A cure for lupus will be found some day, and all our hopes will be fulfilled. With the S.L.E. Lupus Foundation leading the way, I have no doubt that will happen." He then presented a proclamation to Susan Golick, Foundation Vice President and Founder, that designated December 5, 2005 as "S.L.E. Lupus Foundation Day."

Gala Honors Richard K. and Jennie L. DeScherer, and William E. Paul, M.D.

In introducing Richard DeScherer and his wife, Jennie, Mayor Bloomberg praised the couple's commitment to the S.L.E. Lupus Foundation, noting, "Dick and Jennie have truly poured their hearts into finding a cure for lupus." Richard DeScherer has served as President of the Foundation's Board of Directors for 10 years, a period of great achievement for the organization, including the establishment of the Lupus Research Institute, sponsor of the largest number and widest range of novel lupus research investigations nationwide, and Lupus LA, the Foundation's West Coast division. Mr. DeScherer is co-chairman of Willkie Farr & Gallagher LLP.



Gala Honorees Jennie and Richard DeScherer

Jennie DeScherer, who was diagnosed with lupus 34 years ago, is an active Board member who oversees the S.L.E. Lupus Foundation's distribution of emergency grants, which assist individuals with lupus during particularly trying times. Mayor Bloomberg said, "As a lupus patient herself, Jennie is a shining example of someone who won't let this disease get in the way of living her life to the fullest."



The legendary Tony Bennett
at the 35th Anniversary gala

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The recipient of the Foundation's 2005 Scientific Leadership Award was William E. Paul, M.D., Chief of the Laboratory of Immunology at the National Institute of Allergy and Infectious Diseases of the National Institutes of Health since 1970. He also serves as Chairman of the Lupus Research Institute Scientific Advisory Board. The evening's master of ceremonies, Charles Osgood, host of "CBS Sunday Morning" and "The Osgood File," introduced Dr. Paul. He noted, "Dr. Paul has urged the LRI to defy safe and conventional thinking in the pursuit of new insights into lupus. 'Take risks,' he said. 'Look for fresh thinking, the novel and even surprising ideas. Support the investigators willing to pursue them. Do this and we will change the face of lupus research.' And that's exactly what's happening."

The evening's entertainment was provided by the legendary Tony Bennett. Distinguished guests at the gala included Senator Frank Lautenberg (D-NJ), former New York Governor Mario Cuomo, New York City Deputy Mayor Patricia Harris, and Queens District Attorney Richard Brown.

"We truly appreciate the strong show of support for our work from generous individuals, foundations and corporations," said Foundation Executive Director Margaret Dowd. "Their ongoing encouragement and support will enable the S.L.E. Lupus Foundation to continue leading the fight against lupus."



Pictured: 1. John Silverman, Foundation Vice President Susan Golick and Alan Wasserman, DDS; 2. Bonnie Englehardt Lautenberg and Carol Weisman; 3. LRI Co-chair Robert Ravitz and Treasurer John Luke with Gala Scientific Honoree William Paul, MD; 4. Master of Ceremonies Charles Osgood with his wife, Jean; 5. Jerome A. Chazen and Jennifer Dwork; 6. Erica Sternin and Adam Selkowitz with Betsey and Arthur Selkowitz; 7. Morrie Golick and Paula Kupferberg; 8. Chris Paradysz with daughters Dani and Allie and son Nico; 9. Lenard Tessler, Andrew Zaro, Katja Goldman and Fern Tessler; 10. Former New York Governor Mario Cuomo with his wife Matilda.

Perspectives On the Headlines: Oral Contraceptives in Lupus

Two studies in the December 15, 2005 edition of *The New England Journal of Medicine (NEJM)* indicate that women whose lupus is inactive or mild, and who meet certain other health criteria, can take the birth control “pill” without risking a severe flare. These findings are notable given that for more than two decades, doctors have advised women with lupus to avoid taking the pill for fear of triggering or worsening the disease.

Warning signs of this link include the high prevalence of lupus in women—9 out of 10 people with the disease are female—and the tendency to develop it during the childbearing years, when estrogen exposure peaks. What the new studies mean regarding estrogen in lupus, said one lupus expert, is that “we need to continue to be cautious, but perhaps not as scared as we used to be.”

In the multi-center Oral Contraceptives-SELENA Trial, a severe flare was just as likely to occur in the 91 women randomized to receive an oral contraceptive over the course of 12 months as in the 92 women who got a placebo (dummy drug). Seven women in each group had a severe flare. About the same number of people in the “pill” group as in the placebo group experienced a mild to moderate flare. All the participants were of childbearing age and had inactive or stable lupus when they enrolled.

Interestingly, six months earlier, the associated Hormone Replacement-SELENA Trial in 351 menopausal women with lupus indicated that 12 months of estrogen-containing hormone replacement therapy did not significantly increase the risk for severe flare either. However, it did raise the likelihood of mild to moderate flares.

Caution Advised

“While these are encouraging results,” said one scientist, “they require careful interpretation – the findings can’t be extrapolated to all patients.”

According to Mary Anne Dooley, MD, MPH, one of the OC-SELENA study authors, “Women who are newly diagnosed with lupus should avoid oral contraceptives, since these women are at the highest risk of developing more lupus complications.” Each patient needs to be looked at individually, stressed Dr. Dooley, who is an Associate Professor of Medicine at the University of North Carolina at Chapel Hill.

The approximately one-quarter to one-third of women with lupus and antiphospholipid antibodies (aPL) in their blood should also proceed with caution, advises Robert A.S. Roubey, MD, an Associate Professor of Medicine at the University of North Carolina at Chapel Hill. “Most experts agree the potential benefits of oral contraceptives are not worth the additive risk of blood clots in patients with aPL.”

For additional perspective on these studies, **Visit** www.LupusNY.org

NOTE: No two cases of lupus are alike, so consult your physician for advice on the potential benefits and hazards that oral contraceptives pose for you.

Two Thousand Chances to Win! Spring Raffle Features \$10,000 Top Prize

It’s a “win-win” situation.

When you buy one—OR MORE!—tickets for the S.L.E. Lupus Foundation’s 2006 Cash Raffle, you will help raise much-needed funds for lupus research, *and* have a chance to win the grand prize of \$10,000, or one of three, second prizes of \$1,000 each. Tickets are only \$25 each—and there is even an “early bird special”: buy four tickets by April 30 and receive a fifth ticket free!

Only 2,000 tickets will be sold and special prizes will be awarded to the top three ticket sellers, including two tickets to the Foundation’s Gala 2006. The drawing will be held on Friday, June 9, 2006. You may purchase tickets online at www.LupusNY.org, by mail or by calling the Foundation at 212-685-4118 no later than June 5, 2006. But please don’t wait—**BUY YOUR TICKETS TODAY!**

Note: *You need not be present to win. Total prize money awarded will be reduced proportionately if fewer than 2,000 tickets are sold. Winners are responsible for any applicable federal, state, or local taxes. Prize money will not be distributed at the drawing – winners will be contacted afterward.*

Save the Date

Spring 2006 Wine Tasting
To Benefit the S.L.E. Lupus Foundation
May 4, 2006 / 6:30 p.m. – 8:30 p.m.

at
Table XII

The Lombardy Hotel
109 East 56th Street
New York City

Details to follow

For information, call 212-685-4118

or **Visit** www.LupusNY.org

Living with Lupus

Lupus is unpredictable with symptoms coming and going, mimicking other illnesses and threatening major organs. This unpredictability brings with it a host of emotional, psychosocial and lifestyle issues. "Living with Lupus" explores these topics through the personal stories of New York-area residents with lupus.



Annette Rodriguez

Bronx native Annette Rodriguez was diagnosed with lupus seven years ago, at age 11. After a difficult, initial bout with the disease, Annette has been free of flare-ups for the past four years. Today, she's a pre-med freshman at New York University, and there's no indication that lupus (or anything else!) will prevent her from reaching her goals.

What led to your diagnosis?

In 1998, after an intense summer studying at an academic enhancement program, I went to Puerto Rico to relax before starting the new school year. I began to feel very weak while I was there. I lost my appetite. I had a mild fever all the time.

One day, while at the beach, my cheeks became a really shiny tomato red. My mother knew that something was wrong. When we returned to New York, we went to three different hospitals. I was misdiagnosed a few times, until finally I was told I had lupus.

What's it like to get sick with lupus when you're a kid?

I was relieved to finally find out what I had, but it was also frightening because no one in my family had any idea what lupus was. My family was very supportive, but, at school, life became difficult. I had the butterfly rash on my cheeks, I didn't eat and I had migraines almost daily. As my condition progressed, other children began to pass on nasty rumors about my health.

The Foundation sponsored you and your family at Camp Sunshine. Did being at camp help you cope with your disease?

Camp Sunshine was awesome. The first time I went was also the first time I was in a place with other people who had lupus. Up until then, I was in denial about having lupus, since it was difficult to accept I would never be normal again. But going to camp and meeting so many people with lupus from my area helped me feel like I wasn't so different after all—and that I was not alone.

"Once I acknowledged the fact I had lupus, my life became much easier. I am determined not to let it be the deciding factor in how my life story is written because I am so much more than lupus. There are so many interests I want to pursue and so many skills I want to develop. I will never let lupus take over and hinder me from accomplishing my goals."

—Annette Rodriguez

How do your friends relate to your lupus?

No one can really know what I'm going through, not even a doctor. But it has been a blessing to have friends who really try to understand my condition and support me through it all.

What are your plans for the future?

Last fall I started my undergraduate studies at New York University, where I plan on a double major in Journalism and Anthropology, with a minor in History—while maintaining a pre-med concentration so I can attend medical school. Ultimately, I want to become a Pediatric Rheumatologist so I can help others going through health situations similar to mine.

Let the Sun Shine In!



Does your child have lupus? If so, and if you live in the New York Metropolitan area, why not consider participating in the S.L.E. Lupus Foundation's weeklong summer camp experience at Camp Sunshine on scenic Lake Sebago in Maine? Camp Sunshine is a camp for families with children living with serious illness. It provides these children with the opportunity to play just like other kids in the summer—with all costs covered by the Foundation. For an application and information about the August 20-25, 2006 session, please contact Anita Cruso at 212-685-4118 or acruso@LupusNY.org.

Bag Ladies Take Over Hollywood!

...And Raise \$200,000 For Lupus Research

Last autumn, nearly 500 of Hollywood's most fashionable and chic gathered at the exclusive Beverly Hills Hotel for one of the year's most anticipated events—no, not that other party held the “Night Before” the Oscars, but the hugely successful Third Annual “Hollywood Bag Ladies Lupus Luncheon.” Created and sponsored by Lupus LA, the Foundation's West Coast division, the November 16 event raised more than \$200,000 for lupus research.

The charity luncheon and auction honored two special individuals for their strong support of Lupus LA: Lisa Gregorisch-Dempsey, Senior Executive Producer of the syndicated entertainment news-magazine, *EXTRA*, and Julia van Hees-Aidner, a noted fashion and lifestyle columnist.

When it was time for the auction to begin, a surprise guest auctioneer stepped forward in her pink Versace crocodile shoes—actress Sharon Stone! Equally dramatic and hilarious, she even auctioned the shoes right off her feet!

Guests bid on more than 200 new, gently used and vintage handbags donated by celebrities such as Ms. Stone, Katie Couric, Courteney Cox, Jessica Simpson, Jennifer Aniston, and Reese Witherspoon. They also bid on designer bags from Jimmy Choo, Fendi, Jamah, Valentino, and Escada. The luncheon featured a fashion show by Donald J Pliner, with special surprise runway model, Paula Abdul (*American Idol*).

The “Hollywood Bag Ladies Lupus Luncheon” attracted such celebrities as Melissa Joan Hart (*Sabrina, The Teenage Witch*); Rachael Blanchard (*7th Heaven*); Sara Rue (*Less Than Perfect*); Leeza Gibbons (*Leeza Live*); Sherri Shepherd (*Everybody Loves Raymond*);



Kelly Stone, Auctioneer Sharon Stone and Honoree Julia van Hees-Aidner

Morgan Fairchild (*Friends*); Linda Dano (*One Life To Live*); Julie Benz (*Angel*); Danica McKellar (*West Wing*); Kathy Hilton (mom of Paris and Nicky); and Marla Maples Trump.

The event was co-chaired by Noah Alexander, Peri Ellen Berne, Carrie Brillstein, Marla Paxson and Janice Wallace, and produced by Adam Selkowitz, Lupus LA president, and Pamela Sharp, head of Lupus LA media relations. Event sponsors included *The Hollywood Reporter* and PacifiCare.



Honoree *EXTRA*'s Lisa Gregorisch-Dempsey with Lupus LA President Adam Selkowitz and Vice President Carrie Brillstein

Save the Date

**An Evening of Love, Light & Laughter
May 11, 2006
To Benefit the Lupus Research Institute**

Lupus LA's annual spring gala—which has raised hundreds of thousands of dollars for the Lupus Research Institute—will be held on Thursday, May 11 at the famed Beverly Hills Hotel. Actor Jason Alexander (“George Costanza” on *Seinfeld*) will serve as the evening's emcee, which will feature a special performance by Glenn Frey of The Eagles. For more information and tickets, please contact Mina Sung of Sharp Associates at 310-652-7770 or visit www.LupusLA.org.

Is Part D for Me?

Medicare's New Prescription Drug Coverage

For people with lupus, there can be an exhausting array of medications to take: immunosuppressants, corticosteroids, antimalarials, anti-inflammatories and more. Managing the various prescriptions and doses can be a difficult task for almost anyone and paying for them can be even more challenging. But now, with the launch of Medicare's new prescription drug coverage, called Medicare Part D, millions of Medicare-eligible people can obtain insurance coverage, if they wish, that will help cover the cost of prescription drugs.

While Medicare Part D is still a government program, prescription coverage is now provided by many private health insurers offering many different plans. The choices can be overwhelming, but the S.L.E. Lupus Foundation and the Lupus Cooperative of New York are here to help. In December and January, the Foundation presented bilingual Medicare Part D forums at Jacobi Medical Center in the Bronx and Mount Sinai Hospital in Northern Manhattan, sponsored in part by an unrestricted educational grant from Pfizer. During these presentations, experts offered the following tips:

- As a first step, make a list of all the drugs you take, how frequently you take them, and how much they cost (both for brand name and generic).
- Remember, participation is voluntary (unless you have Medicare and Medicaid, which enrolled you automatically on January 1, 2006).
- If you have a prescription drug plan through a current or former employer or union, compare your plan with some of the Medicare Part D plans. If your current plan is better, you can keep it.
- If you choose to participate, select a Medicare Part D plan that: has a covered drug list (“formulary”) that includes all or most of the drugs you need; sells them at a reasonable price; allows you to purchase them at a nearby pharmacy; and, if possible, features a prescription mail-order service, which can save you additional money. You can learn which plans cover your prescription drugs online at www.medicare.gov, or by calling 1-800-633-4227.
- If you have limited income, you may be eligible for extra assistance through the Social Security Administration. Further information is available at www.ssa.gov or by calling 1-800-772-1213.
- Keep all letters and other communication you receive from Medicare, Medicaid and health insurers.

NOTE: This information is accurate only as of publication date.

Call for Research Grant Applications

For more than 35 years, a core mission of the S.L.E. Lupus Foundation has been to identify and foster the work of promising new lupus investigators in the New York Regional area, chiefly through the awarding of training and research grants. Currently, the Foundation is accepting applications for a new round of grants in the following categories: Clinician-Scientist and Basic Science Fellowship Awards; Career Development Awards; and Research Grants for junior faculty. Grants total between \$135,000 to \$150,000 over a three-year period, with funding commencing in July 2006. All applicants must hold advanced degrees and be affiliated with institutions of higher learning located in the New York Regional area. The deadline for applications is April 28, 2006. For further information and applications, contact the Foundation's Grants Administrator Laura Hack at lhack@LupusNY.org or 212-685-4118, or

Visit www.LupusNY.org

NIH Budget Cuts May Slow Pace of Research

From 1998 to 2003, the National Institutes of Health experienced a doubling of its budget, resulting in a record number of research grants. This trend came to a decisive halt in December 2005, when legislation was passed that effectively cut the NIH budget for the first time since 1970.

The fiscal year 2006 NIH budget totals \$28.6 billion, a one-tenth percent decrease in funding from the previous year.

Science magazine writer, Jeffrey Mervis, notes that the fiscal year 2006 NIH budget “will result in fewer new grants and a continued decline in success rates. A few years ago, NIH funded more than 30 percent of proposals submitted; this year it will fund 20 percent or less.”

What does this all mean for biomedical research, in general, and lupus research, in particular? For in-depth perspective, garnered from four leading lupus scientists,

Visit www.LupusNY.org

Lupus Forum

Throughout the year, the S.L.E. Lupus Foundation receives thousands of phone and email inquiries from people with lupus, their families and others concerning various aspects of the disease—including the relationship between lupus and fibromyalgia. The following are some of the most common questions and answers on this topic.

The Link between Lupus and Fibromyalgia

Is it Lupus or Fibromyalgia—or both?

Like lupus, the disorder called fibromyalgia, or FM, often involves muscle pain, joint pain and fatigue, and occurs mostly in young women of childbearing age. It is sometimes mistaken for lupus, but as many as one in four people with lupus also at some point have symptoms of FM.

What are the symptoms of FM?

FM is generally linked with long-term sleep loss. People with FM may also have muscle pain and tenderness, stomach aches, headaches, and feelings of numbness and tingling in the hands and feet. Constant pain for more than three months and tenderness in many areas of the body—such as the neck, spine, shoulders and hips—usually lead to a diagnosis of FM.

How is FM different from lupus?

Unlike lupus, FM does not cause inflammation, arthritis, skin rashes, or damage to tissues, organs and bones. In terms of

treatment, medications commonly used to treat lupus have little or no effect on the symptoms of FM.

Why do I need to know about FM?

People with lupus often suffer from the symptoms of FM or may be initially diagnosed as having FM. If you have FM, it is important to know that it is not rare—three to six million Americans are affected—it is never life-threatening, and it is manageable.

How is FM treated?

The best treatment for FM is exercise. Exercise in the morning and afternoon will give you energy for the day and help you sleep better at night. Swimming, walking and cycling can strengthen muscles and reduce pain. Doctors may recommend a combination of physical therapy, exercise, relaxation, and medication to treat FM.

Have a question for the **Lupus Forum**?

Please email it to the Foundation's Director of Social Services, Enid Engelhard, CSW at engelhard@LupusNY.org.

LRI Awards \$4.5 Million to Advance New Science in Lupus

The S.L.E. Lupus Foundation's research partner, the Lupus Research Institute (LRI), recently announced that it would fund 15 scientists to investigate highly promising, novel research approaches to lupus. To date, \$14.5 million has been awarded to fund 56 studies.

Recipients culled from the pool of 81 applications from around the country will receive three-year, \$300,000 grants to pursue the type of research the LRI defines as core to its mission: innovative and creative work, representing "outside the box" thinking that has the potential to make a significant impact on the field of lupus research. A remarkable number—nearly half—of the 2005 grant recipients are bringing their scientific talents to the study of lupus for the first time.

While often high-risk—nine of the new grants qualify as such—many of the projects have already demonstrated the potential for "high-reward," surging ahead in breakthroughs in understanding the cause, prevention and treatment of the disease.

Exploring All Possibilities

The recipients, who will pursue such diverse aspects of lupus as what makes the immune system go awry and how the disease attacks the renal, neurological and cardiovascular systems, include:

- Felipe Andrade, M.D., Ph.D., of Johns Hopkins University, who will explore the mechanisms involved in lupus remission
- Roland G. Henry, Ph.D., of the University of California in San Francisco, who will examine whether neuropsychiatric symptoms can be linked to visible changes in brain images of people with lupus
- Christine M. Grimaldi, Ph.D., of Columbia University, who will investigate the genetic basis for estrogen-exacerbated lupus

By appealing to scientists in many areas of research such as these, the LRI spurs novel approaches and collaborations not previously applied to lupus, according to Mark Shlomchik, MD, PhD. Dr. Shlomchik, a Professor of Laboratory Medicine and Immunobiology at Yale University School of Medicine, is co-chairman of the LRI Novel Research Task Force.

To date, more than 91 percent of the LRI investigators who have completed their projects have gone on to secure large-scale federal funding. With the awarding of these 15, new grants, the LRI now funds the largest number and widest range of privately-supported, novel lupus research investigations nationwide.

Learn more about the novel research supported by the LRI at www.LupusResearchInstitute.org.



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The Loop is published by the S.L.E. Lupus Foundation and is distributed to all members.

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Think Orange!
The Story Behind the Orange Loop

Lupus is serious and widespread. Yet, prior to 1999, lupus awareness was low, due in part to the lack of an “identity”—an easily-recognizable symbol that, when you saw it, would immediately remind you of lupus.

Like the red ribbon for AIDS or the pink ribbon for breast cancer.

That all changed in 1999, when the S.L.E. Lupus Foundation created the orange loop as the symbol for the disease. It was quickly adopted by the lupus community across the country and around the world. The orange loop, now the defining, global symbol of lupus, urges everyone to “Get into the Loop” and work for a time when lupus is prevented, treated and cured—in essence, “Life Without Lupus.”

Now, you can join the fight against lupus—and make a fashion statement at the same time! By purchasing and wearing a bright orange, “Life Without Lupus” wristband, you will increase awareness of the disease and help fund lupus research. Wristbands are available in quantities of 10 for only \$10 (plus shipping and handling). You can place your order by calling the Foundation at 212-685-4118 (800-74-LUPUS) or

Thank you for your support.

Visit www.LupusNY.org

