

The Loop

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

FALL 2005

Gala 2005 to Honor Jennie L. DeScherer and Richard K. DeScherer A Couple with a Deep Commitment to Each Other—and To a Cause



Jennie L. DeScherer and
Richard K. DeScherer

In its 35th Anniversary year, the S.L.E. Lupus Foundation is proud to honor Jennie and Richard DeScherer, a couple that has made such a difference in the lives of so many, and to recognize immunologist William E. Paul, MD, a scientist of remarkable contributions to the field of lupus research.

Television anchor Charles Osgood will serve as Master of Ceremonies at the December 5th Gala at the New York Marriott Marquis, and the legendary Tony Bennett will provide entertainment.

The DeScherers' remarkable journey began when Jennie developed signs and symptoms of illness as a teenager in Charleston, South Carolina. It took nearly a decade to get a formal diagnosis: systemic lupus erythematosus. Jennie recalls reaching out for support to what was a fledgling organization at the time: The S.L.E. Lupus Foundation. "It was a lifeline for me," she says. "I couldn't wait to call and talk to someone who was facing the same illness and was doing something constructive about it."

Thirty-five years later, that lifeline is still there for thousands of others, from communities in New York City and Los Angeles to countless visitors to the Foundation's website. Caring for the lupus community is just one part of the Foundation's dynamic growth that can be attributed in large measure to the determination and dedication of the DeScherers.

Under Dick's firm and focused guidance as Board president, the Foundation has become a bicoastal organization gaining crucial insights into the cause and cure of lupus. "We are extremely proud of what the Foundation has accomplished—cutting edge research, our social service programs, which include two model lupus cooperatives in New York, a vibrant office in Los Angeles and award-winning public awareness programs, including our website," he explains.

But of all that has been accomplished, the DeScherers are proudest of the research advances. The Foundation lays claim to supporting the nation's largest nonprofit, non-government lupus research program, as in 2000 it emerged as a major force in creating the Lupus Research Institute (LRI), of which Dick and Jennie are both founding members.

"We're encouraging brilliant minds and eager researchers to work in lupus," Jennie says. "But we still need to do more."

In addition to Board activities, Jennie oversees the distribution of emergency access grants to people with lupus in underserved communities. She also continues her lifelong involvement in the arts

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through various board memberships and associations. Dick, Co-Chairman of Willkie Farr & Gallagher, is an active member of numerous distinguished boards in addition to the Foundation and the LRI. The couple has two grown children.

The DeScherers' unyielding commitment to scientific breakthroughs in lupus and the care of patients is an achievement of exceptional proportions, and we are deeply grateful to them for it.

Scientific Honoree: William E. Paul, MD The Nation's Preeminent Voice in Immunology

In selecting William E. Paul, MD as the 2005 Scientific Honoree, the Foundation recognizes his service and dedication to the lupus community as Chairman of the LRI Board of Scientific Advisors. Since the LRI's inception, Dr. Paul has constantly pushed the Institute to seek new frontiers in biomedical research in lupus. He has held the position of Chief of the Laboratory of Immunology at the NIH's National Institute of Allergy and Infectious Diseases since 1970.



William E. Paul, MD

Dr. Paul has pioneered many research programs. As Director of the NIH's Office of AIDS Research in the mid-1990s, he oversaw a 50% increase in NIH-funded AIDS research grants.

"The LRI, a bold and courageous organization willing to take risks, has been the catalyst for major progress," notes Dr. Paul. "Now, these initial successes must strengthen our resolve to push the frontiers of new science in lupus even further."

Charles Osgood: Master of Ceremonies

The celebrated television anchor and radio journalist has been an invaluable and committed friend in the Foundation's work. Osgood's daughter, Emily, was diagnosed with the disease two years ago, and his good friend and television colleague, Charles Kuralt, passed away from lupus complications in 1997.

Osgood is best known for his position as anchor of CBS News Sunday Morning and as anchor and writer of "The Osgood File," his daily news commentary that broadcasts on the CBS Radio Network. Kuralt called him "one of the last great broadcast writers." Osgood narrated the S.L.E. Lupus Foundation's 2002 Gala videotape, and plays an important role in advancing lupus awareness and research.

Please join us on December 5th for this very special evening to honor the DeScherers and Dr. Paul and to enjoy dinner, dancing and entertainment. For Gala information or reservations, call Anita Cruso at 212-685-4118 or email her at acruso@LupusNY.org.

35 Years of Caring for the Lupus Community: 1970-2005

2005 is an anniversary year for the S.L.E. Lupus Foundation, and we've found several ways to mark it, from our five-borough hospital tour this fall to the start of our new initiative, **35 Stories of Lupus**, a published compendium of diverse personal journeys.



Through rigorous work—and tremendous accomplishments—the Foundation has evolved from a small group meeting in co-founder Susan Golick's apartment to New York's comprehensive resource for all people with lupus.

Thanks to the Foundation, people in the New York metropolitan area have a place to turn to learn more about lupus, get counseling and referrals to doctors, find the support and comfort of peers, and secure funding for everything from emergency assistance grants to children's programs. These and other practical services have enabled millions with lupus, and their families, to lead healthier and more fulfilling lives.

As a result of the Foundation's awareness programs and extensive, one-of-a-kind community outreach efforts in every borough, countless more people of diverse ethnicity and income level know about lupus and the dangers it poses. That awareness saves lives.

Finally, what scientists and physicians actually know about lupus in 2005—how and why it develops, tools to stop it from flaring, solid prospects for a cure—differs radically from what they knew in 1970. The Foundation is proud to have taken the leading role in generating this shift, and in nurturing and funding not only key research projects but the careers of so many new lupus investigators.

Now with West Coast headquarters in Los Angeles, the Foundation has become a truly bicoastal organization. Lupus LA was founded by renowned physician and author, Daniel J. Wallace, MD, and is committed to promoting lupus research and awareness, as well as serving the needs of people with the disease and their families, in Los Angeles County.

In 2005 and beyond, the Foundation will continue what it started 35 years ago: the critical task of improving lives while seeking a cure.

Six Additional New Investigator Grants Awarded To N.Y. Scientists

The recent addition of six New Investigator Program grants brings the S.L.E. Lupus Foundation's total research commitment for New York's area scientists to \$2 million, making it the largest program in America designed specifically to support the expansion of new talent in lupus research.

Researchers funded are from seven New York area medical centers across the metropolitan region. "With these grants, 13 exceptional scientists will have the chance to make a real difference in the science of lupus, and in the lives of people with this autoimmune disease," said Foundation Executive Director, Margaret G. Dowd. "The New Investigators Program brings vitally needed fresh talent to the field by supporting researchers early in their careers, when many scientists produce their most creative and innovative work."

Three types of grants were awarded in the latest round. For the Extended Fellowship and Career Development Awards, the promise of the applicant and the richness of the training environment were particularly vital.

Recipients of the **Extended Fellowship Awards** are:

- **Philip Kahn**, MD, Columbia University. Dr. Kahn will use the 3-year \$150,000 award to investigate a mouse model of anti-phospholipid syndrome (APS), which affects about a third of people with lupus.
- **Sun Jung Kim**, PhD, Columbia University. Working with established lupus investigator and mentor, Betty Diamond, MD, this postdoctoral fellow will use the 3-year \$135,000 grant to

investigate the interaction between B cells and a type of receptor on dendritic cells (FcRγ) possibly responsible for generating S.L.E.'s sustained autoantibody response.

Recipients of the **Research Grants** (\$150,000 over 3 years) are:



Grant recipient
Elena Peeva, MD

- **Elena Peeva**, MD, MSc, Albert Einstein College of Medicine. Dr. Peeva will examine the mechanisms by which the hormone prolactin may promote the development of lupus.
- **Ann Haberman**, PhD, Yale University. Dr. Haberman was awarded the grant to examine the mechanisms at play in so-called germinal centers that form to produce high affinity B cells when the immune system gets alerted to pathogens.

Recipients of the **Career Development Awards** (\$150,000 over 3 years) are:

- **Giovanni Franchin**, MD, PhD, Columbia University. Dr. Franchin will explore the potential of new agents to inhibit a specific interaction likely used as a communication gateway between immune cells in lupus, CD40-CD40L.
- **Meera Ramanujam**, PhD, Columbia University. Dr. Ramanujam will examine the biology of two soluble B cell survival signals in mice with lupus. Antagonists to these B cell survival signals already are being examined in clinical trials.

35th Anniversary Event to Educate Patients throughout the Five Boroughs

"Get Into the Loop" New York City Hospital Tour Features the Speaker Series: "Unlocking the Mysteries of Lupus"

Get into the loop.

As a disease, lupus is nearly as diverse as the communities affected by it. Organs body-wide are vulnerable—as are people from every race and ethnicity. Our New York City Hospital Tour will recognize this heterogeneity by looping through the city's distinct five boroughs with a message for everyone: by staying aware and alert to lupus, damage can be minimized.

Manhattan: Hospital for Joint Diseases
September 17 (Saturday) 9:30 AM – Noon
Presentation by Jill Buyon, MD and Michael Belmont, MD
The Latest in Lupus Research, Treatment & Pregnancy

Bronx: Jacobi Medical Center
September 29 (Thursday) 6 PM – 8:30 PM
Presentation by Meggan Mackay, MD
Thinking, Memory and Behavior: How Lupus Affects the Brain

Queens: New York Hospital Medical Center of Queens
October 8 (Saturday) 9:30 AM – Noon
Presentation by Gary Zagon, MD
Diagnosing, Treating & Living with Lupus

Brooklyn: SUNY - Downstate Medical Center
October 27 (Thursday) 4:30 PM – 7 PM
Presentation by Ellen Ginzler, MD
What You Need to Know about Lupus Kidney Disease

Staten Island: Staten Island University Hospital
October 29 (Saturday) 9:30 AM – Noon
Presentation by Mark Jarrett, MD
Easing Aching Joints & Muscle Pain in Lupus

Manhattan: Hospital for Special Surgery
November 3 (Thursday) 6 PM – 8:30 PM
Presentation by Michael Lockshin, MD
Lupus & the Heart

The program will include giveaways, refreshments and information on support services. For location details, visit www.LupusNY.org or call us at 212-685-4118. Tour sponsored in part by an unrestricted education grant from Genentech/Biogen Idec.

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. Interviews featured explore these topics through the personal stories of New York-area people with lupus.



Maggie Gonzales (L) and her sister, Gloria Brinn (R)

Maggie Gonzales has lived with lupus for most of her 46 years, but wasn't diagnosed until her 20s, after the disease had damaged her liver and kidneys. Today, this New Jersey mother of three struggles with her illness while working to spread awareness of lupus among Hispanics.

Three years ago she helped to establish the S.L.E. Lupus Foundation's Lupus Cooperative of New York, Bronx Division. In this interview, Maggie shares some of her struggles to raise a family while coping with lupus, and her hopes for promoting awareness of the disease among people in the Hispanic community.

How has lupus affected your life?

So many ways...most painfully, I suffered a flare up in the ninth month of pregnancy with my youngest son, and as a result he was born hearing-impaired. Lupus has also burdened our family financially—from the hospital stays to medication costs.

Recently, I developed severe photosensitivity. My nine-year-old son, Justin Ryan, wants to go out to play baseball and swim, but I can't be in the sun or I'll break out in a rash or even get so sick that I need to be hospitalized.

What prompted you to get involved in helping to start up the Lupus Cooperative of New York's Bronx Division?

I grew up in the South Bronx. This community was so underserved. There was no place for people with lupus to get advice, education, or support. Because I personally felt a need within that community, I joined with the Foundation and we were able to expand services of the Cooperative's Northern Manhattan Division to the Bronx. Both are a division of the Cooperative of New York, a network of health and supportive services designed to improve the quality of life for people with lupus and their families.

What gets you through the day?

I cope with lupus by writing, singing, journaling, and educating people about lupus. On any given day, I know I need to wake up the next to see my children grow. I have to take my youngest to school and make his life as normal as possible. I need to be alive.

What would you say to other Hispanic women about lupus?

Hispanics need to be more aware of lupus because they (and people in the African American community) are at greater risk for it. Early diagnosis and prompt treatment are the best prevention against lasting damage. I know this first-hand. Twenty years ago, when I was in the hospital and unable to move, with swollen joints, fever—all the symptoms—lupus wasn't even mentioned. My father and sister had lupus, but I didn't know enough about it—I didn't realize I was at risk.

When I was finally diagnosed, the doctor said to me, "You must have had lupus for a long time for it to be this bad, to be so out of control." That's how misunderstood and unrecognized lupus is. (The Foundation is releasing a Spanish-language TV public service campaign this fall that will reach out to the Hispanic community, alerting them to the warning signs of lupus.)

What is the greatest challenge you face, living with lupus?

I struggle with getting friends and family and people in general to understand this awful and complex disease. People always tell me, "You don't look sick." I wish I could get people to understand why I feel so tired.

I tell myself that I am not dying with lupus, I am *living* with lupus! I want to see my child play baseball, to go out with my husband. Everyday I pray for a cure, if not in my lifetime, then in my children's lifetime.

Lupus LA Convenes Largest Patient Education Conference in City's History



Lupus LA founder Daniel Wallace, MD, and S.L.E. Lupus Foundation Executive Director Margaret G. Dowd, at the patient education conference.

Things are heating up for Los Angeles' lupus community. Lupus LA, the west coast division of the S.L.E. Lupus Foundation, has launched a new program to expand patient services, commemorating its fifth anniversary with a free educational event.

More than 200 patients, family members, and friends attended "The Latest on Lupus" seminar on June 18th at Cedars-Sinai Medical Center.

Leading California-based lupus experts, including Lupus LA founder Daniel Wallace, MD, Bevra Hahn, MD, Michael Weisman, MD, Arash Horizon, MD, and Boris

Ratiner, MD, presented on topics ranging from detection and diagnosis to prevention and treatment. The turnout was huge and audience feedback overwhelmingly positive.

"For five years, Lupus LA's fundraising efforts have brought significant awareness to the disease and support for the Lupus Research Institute," said Dr. Wallace. "Now we are expanding our efforts and increasing our outreach to the thousands of people affected by lupus in Los Angeles County."

Lupus LA's newly redesigned online home, www.LupusLA.org, is one component of the outreach effort, highlighting events in Los Angeles as well as medical and research news.

Dr. Wallace is an eminent clinician who has treated more than 2,000 lupus patients—the largest such practice in America. He will oversee Lupus LA's patient-focused programs. For more information, visit the website (www.LupusLA.org), call 310-657-LOOP (5667) or email info@LupusLA.org.

Brenda Elaine Pillors, 1952–2005

The Foundation mourns the sudden passing of this great friend and champion of the lupus cause. Brenda Pillors, Ph.D., was an enthusiastic and highly respected public servant who served as Chief of Staff for U.S. Congressman Ed Towns of New York (D-Brooklyn). Prior to joining Rep. Towns' staff in 1982, Dr. Pillors was the Legislative Director for former U.S. Congresswoman Shirley Chisholm (D-Brooklyn). In her eulogy on June 17th, friends and colleagues noted her dedication and leadership on health legislation and policy. Her work in support of the Lupus Cooperative of New York City was invaluable, bringing critical attention to the disorder in underserved communities. Ms. Pillors will be greatly missed.

Kate Anastasia Joins Foundation



Kate Anastasia

In August we welcomed our new Director of Programs, Kate Anastasia. For nine years, Kate worked at the Health and Welfare Council of Long Island, most recently as Senior Vice President for Programs. While at the Council she coordinated the September 11th Fund's On-going Recovery Program for L.I., staffed the L.I. Children's Program, and directed the facilitated enrollment program for L.I. families applying to New York State's free and low-cost public health insurance programs. She also worked on the agency's outreach to L.I.'s most culturally diverse and isolated communities. Kate has a Masters Degree in Public Administration and graduated from Columbia University's Institute for Non-Profit Management.

Tai Chi Workshops Offered in East Harlem

The Foundation's Lupus Cooperative of New York is always on the lookout for creative ways that people with lupus can cope with the physical and mental challenges of living with the disease. Tai-Chi workshops are one example. In June, the Cooperative's Northern Manhattan Division offered such workshops during the bi-monthly, bilingual support groups. Guest instructor Edgar Medina introduced basic concepts of the peaceful Chinese martial art that focuses on balancing one's

mental and physical being. With an emphasis on deep breathing and relaxation, the slow motion routine is meant to stimulate circulation, thereby releasing stress, relieving pain, boosting energy, and encouraging a positive attitude. For more on upcoming activities at the Lupus Cooperative of New York, call 212-289-9811 in Manhattan, 718-620-2555 in the Bronx, or visit our website at www.LupusNY.org.

The American College of Rheumatology and a consortium of clinics worldwide—the Systemic Lupus International Collaborating Clinics (SLICC)—are revising the criteria for classifying a person with systemic lupus erythematosus. The following essay by Louisa Ziglar, a medical student in her last few months at SUNY-Downstate Medical Center in Brooklyn, describes the thrill she experienced in gathering the patient information to help shape the new criteria—and her mounting excitement about pursuing research.

Research—the Last Hurrah of a Medical Student

I was finalizing my elective schedule for the completion of my journey as a medical student and wanted to end with something that I believe in deeply: research. I had done some biochemical research during college and early medical school. With each experience I had a sense of contributing to the advancement of science.

My university's chief of rheumatology, Ellen M. Ginzler, MD, offered me a position as "site coordinator" for a multi-center, international study on the reclassification of lupus. The position was ideal, since it allowed me to meet with patients with many of the rheumatologic diseases while performing research.

I found myself to be green—yet excited. The finesse involved in clinical research is very different from the finesse involved in coaxing purified proteins from Chinese hamster ovary cells!

At my site we needed patients from several doctors—and all offered personal time to help. But of all the people I came into contact with, I was most impressed by the patients. Since there was no reimbursement for the time and blood that each gave, I initially thought I would have to plead and beg to get the 22 patients I needed to complete the study.

But to my delight, when asked, the vast majority offered to volunteer. Each had their own reasons for participating, but the unifying motivational factor was, "It will help other people." Some said they volunteered so that in the future, diagnoses can be made earlier, thus preventing or slowing further disease damage. Others mentioned the sacrifice that patients in trials before them had made. One woman with badly sclerosed veins was stuck five times to get a blood sample. Each time her vein was missed, she courageously said, "Keep going."

Some of these volunteers became my friends. We had potluck lunches, made plans to go on the New York Arthritis walk, and shared our lives. Each bore scars and stories from different forms of rheumatologic disease: family members afflicted, jobs lost, and fortunately for some, strength and abilities replenished as years of treatment brought them remission.

Yesterday, I sent out the last of the blood samples and patient forms to the central research site. This week marks the last of my medical school career, and I am grateful that it was with the generous spirit of these patients as well as devoted research mentors that I close this chapter in my life.

Every Penny Counts!

In a lesson that philanthropy can start at any age, the elementary school students of Staten Island's P.S. 22 have dedicated a portion of the pennies they collected last fall—\$275 worth—to the S.L.E. Lupus Foundation. As part of New York's Common Cents Penny Harvest Program, the students spent a month of afternoons and weekends fanning out across their neighborhoods to collect the unwanted pennies. With funds in hand, they then began a comprehensive process of distributing them to organizations that fill crucial needs in their community. In June, P.S. 22's Peace and Wishmakers Roundtable gave the Foundation its grant at the school's Celebration of Community ceremony for local organizations that "strive to make peace and wishes come true." The Foundation extends its heartfelt appreciation to P.S. 22 for recognizing its efforts to serve New York's lupus community.

LRI Receives Record Grant Applications

The Lupus Research Institute (LRI), the Foundation's research partner, received an unprecedented response to its 2005 request for grant proposals to examine the cause, test new treatments, and find a cure for lupus. In all, 81 scientists from 24 states submitted proposals by the deadline of June 30th. The LRI will announce the 2005 recipients this fall, following a rigorous peer-review process.

To date, the 5-year-old LRI has funded 42 basic and clinical studies. It's recognized nationwide as an organization with a unique and powerful model for generating groundbreaking research. The current grant request attracted the interest of many investigators who had not previously worked in lupus, including scientists from such diverse specialties as cardiology, nephrology, dermatology, and neurology—all organ systems vulnerable to damage from lupus.

"Cutbacks in NIH research budgets that will lead to lower rates of funding for critical research make vigorous private-sector initiatives essential if we are to drive development of new ideas and achieve scientific breakthroughs," notes Mark Shlomchik, MD, PhD, the professor of laboratory medicine and immunobiology at Yale University School of Medicine and co-chairman of the LRI Novel Research Task Force. This unprecedented response from the scientific community, he adds, speaks to the growing awareness of the LRI's leading presence in novel research, and the dearth of federal funding for new scientific projects.

The Foundation's research partner has a new website: www.LupusResearchInstitute.org



Gift Planning Means Changing with the Times

Whether you realize it or not, your estate plans may have changed. Shifts in your charitable priorities, family, state or federal estate tax law, or the performance of the economy can make it necessary to revise even the most well-considered plans. Routine reviews of your estate plans with your attorney and other advisors are the best way to make sure your arrangements keep up with the times and your current wishes are known.

If advancing lupus research and helping people cope while living with this devastating disease is important to you, be certain that the S.L.E. Lupus Foundation is

included in your plans. To hear more about gift planning options, please contact Andrea O'Neill at the Foundation (212-685-4118, ext. 243).

Do These Apply?

- ▶ Family changes
- ▶ A move to another state
- ▶ Tax-law changes since last review
- ▶ A change in wealth

CLINICAL TRIAL UPDATE

CLINICAL TRIAL ON RITUXIMAB

Genentech and Biogen Idec are currently enrolling patients in a Phase II/III study of the drug rituximab (Rituxan) for the treatment of moderate to severe systemic lupus erythematosus (SLE). Preliminary studies suggest that rituximab, currently approved by the FDA for the treatment of B cell non-Hodgkin's lymphoma, may benefit people with lupus. The 52-week trial will enroll 250 participants at more than 50 sites around the U.S. People aged 16 to 75 with lupus (as defined by American College of Rheumatology criteria) may be eligible for participation in the trial. Participants must have an active disease flare at screening and stable use of one immunosuppressive drug to qualify. For more information, call the Genentech Trial Information Support Line at 888-662-6728.

PHASE III STUDY OF EPRATUZUMAB

Immunomedics, Inc., is conducting two Phase III trials to evaluate the safety and effectiveness of epratuzumab, an anti-B cell antibody, for active disease or acute SLE flare. The drug is FDA-approved for patients with non-Hodgkin's lymphoma. A Phase I trial in SLE indicated improvements in clinical symptoms. This current study will examine how the body processes epratuzumab and its effects when given once weekly for four weeks in a row at one of two dosage levels. Participants must be 18 years old and have been diagnosed at least six months previously, and be free of active or severe central nervous system or renal (kidney) disease. Five medical institutions in Manhattan and Long Island areas are participating. For more information, contact Sally Klemm at Immunomedics, Inc. at 973-605-8022.

STUDY: MYCOPHENOLATE MOFETIL FOR LUPUS NEPHRITIS

The Aspreva Lupus Management Study (ALMS) is a 3-year, Phase III study to assess the efficacy and safety of the drug Mycophenolate Mofetil, or MMF (CellCept), in inducing and maintaining remission in people with lupus nephritis, a serious type of kidney involvement. The trial's first six months involves a randomized, open label comparison of MMF with the current standard of care—cyclophosphamide—followed by a double blind comparison of MMF to azathioprine for up to three years. The study will enroll 358 patients in over 100 centers worldwide, and is one of the largest lupus nephritis studies ever undertaken. For more information, please contact medinfo@aspreva.com.

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35th Anniversary Patient Education Program



- ▶ "Get Into the Loop"
New York City Hospital Tour
- ▶ A Five-Borough Series
of Lupus Talks and Events
*For people with lupus and those
who think they're at risk*
- ▶ Manhattan – Bronx – Queens –
Brooklyn – Staten Island
- ▶ See inside (page 3) for details on
participating hospitals, dates,
and times through Fall 2005.