

LEADING THE FIGHT

S.L.E. Lupus Foundation 2005 Annual Report

MISSION

Systemic lupus erythematosus (lupus) is a chronic autoimmune disease that can affect virtually any organ of the body. Nearly 1.5 million Americans have lupus. And the reality is that no new treatment has been approved for this devastating disease in more than 40 years.

Lupus seems to strike without warning. Symptoms come and go and can mimic those of other diseases. Rash, fatigue, and painful or swollen joints are common lupus symptoms, but no two people have the exact same complaints.

While 90 percent of people with lupus are women in the prime of their lives, children and men develop it as well. Lupus is a leading cause of kidney disease, stroke, and premature cardiovascular disease among young women. Women of color are especially at risk.

Having lupus can be devastating. Early detection and treatment often lessen the severe effects of active lupus, but the fact remains that many people have the disease long before it is diagnosed.

As yet, there is no known cause or cure.



LEADING THE FIGHT AGAINST LUPUS FOR 35 YEARS

RICHARD K. DESCHERER, PRESIDENT

MARGARET G. DOWD, EXECUTIVE DIRECTOR



Richard K. Descherer, President



Margaret G. Dowd, Executive Director

As the SLE Lupus Foundation marks 35 years of uninterrupted service to the lupus community, we renew our commitment to hasten the day when we truly know a life without lupus.

We are especially pleased that this report outlines a steady record of solid progress achieved through collaboration—with partnerships in New York and nationwide—that brings us all into the bright loop of light and hope. In common

purpose, we are making concrete headway every day in research, education, awareness, and community outreach.

A pioneer in private sector research in lupus since 1977, the S.L.E. Lupus Foundation in 2000 helped to create the Lupus Research Institute, now the nation's leading sponsor of novel research in lupus. Working together to fund the most promising science, our joint research investment now tops \$30 million—the largest lupus research initiative in America. And results are now streaming in, bringing breakthroughs and exciting findings on how lupus affects the heart, the brain, the kidneys, the skin—tangible answers and real promise for new treatments.

As in previous years, we convened legislators at city, state and federal levels to learn about the public health issues in lupus and recognize the need for more research in 2005 and beyond.

Lupus LA, the Foundation's west coast division headquartered in Los Angeles, dramatically broadened our base of patients, families, and friends as it launched the largest lupus patient education conference in that city's history.

The Lupus Cooperative of New York brought help and hope to thousands who suffer from lupus in our most disadvantaged neighborhoods in Manhattan and the Bronx. Plans for expansion to Brooklyn in 2006 are well underway.

The year 2005 was a landmark one that set records for research, awareness and fundraising. To all of you who "got into the loop" and reinforced the links we forged from borough to borough, coast to coast, and laboratory to laboratory, thank you for the remarkable impact you have helped us to achieve.

2005 MARKED THE 35th ANNIVERSARY OF THE S.L.E. LUPUS FOUNDATION



The S.L.E. Lupus Foundation was started by Susan Golick and her parents, Morrie Golick and Dorothy Newman, after Susan's lupus diagnosis in 1970.

Headquartered in New York City and Los Angeles, it is the leading lupus organization providing patient services, public awareness and funding for lupus research. For 35 years, the Foundation has served as the resource for people with lupus and their families in the New York region and beyond. A powerful and effective advocate, the Foundation works to shape lupus health policy on the local, state, and federal levels. And through its research partner, the Lupus Research Institute, the Foundation supports the innovative research so desperately needed to prevent, treat, and someday soon cure lupus.

35 YEARS LEADING THE FIGHT

Linking people with lupus to care, borough to borough.

The **Lupus Cooperative of New York** began in 1999 as a pilot program with a small outreach office in East Harlem. With planned expansion to all five boroughs, it stands today as a national demonstration model for helping underserved populations with lupus – often, inner-city minority women – bridge the gap in access to information and care.

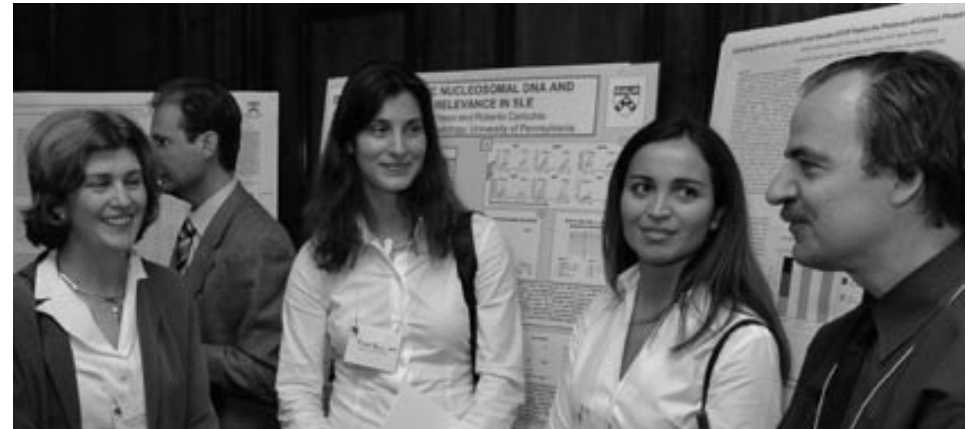
Linking people with lupus to care, coast -to- coast.

The Foundation's **national expansion** became a reality with the establishment of the West Coast division, **Lupus LA**, in 2000. Helping to raise funds for the Lupus Research Institute, this west coast location has the unique ability to harness the power of Hollywood to make the public more aware of lupus.

Linking people with lupus to the fight against lupus through awareness and advocacy.

“Get into the Loop”

In 1999, the Foundation created the orange loop that is now the recognized symbol for lupus. Thousands of people across the country “get into the loop” each year and build awareness of the fight against lupus by wearing the bright “Life Without Lupus” wristband. The Foundation distributed more than 25,000 wristbands in 2005 alone.



Linking people with lupus to research that makes hope tangible.

The S.L.E. Lupus Foundation initiated private sector funding of lupus research in 1977. So far the Foundation has awarded more than \$15 million in independent research grants, fellowships and career development support for new investigations in lupus.

In 2000, the Foundation together with lupus organizations across America created the **Lupus Research Institute (LRI)** to focus solely on the pursuit of novel scientific research. Collectively, the Foundation and the LRI have now funded more than \$30 million in lupus research – currently the largest private sector research initiative in America.

Linking thinkers in lupus.

The Foundation, among other key undertakings, developed and co-funded the country's first national scientific conference on lupus with the National Institutes of Health in 1997 and again in 2002. These pivotal, collaborative efforts brought together hundreds of leading research scientists from 19 countries, allowing them, for the first time, to focus solely on lupus research.

REACHING OUT THROUGH EDUCATION AND VITAL PATIENT SERVICES

“Get into the Loop” New York City Hospital Tour

In the fall of 2005, the S.L.E. Lupus Foundation, in partnership with six leading New York City hospitals, presented a series of free lupus education and awareness events in every borough. Commemorating 35 years of caring, this event brought up-to-date information and much-needed awareness of lupus to key communities.

At each stop in the tour, experts discussed a specific aspect of lupus, a disease that can attack virtually any organ or system in the body including the heart, brain, kidneys, joints and muscles. Patients and families heard the latest in diagnosis, research, new treatments and available support services.

Participating hospitals included: Hospital for Joint Diseases, Jacobi Medical Center, New York Hospital Medical Center of Queens, SUNY Downstate Medical Center, Staten Island University Medical Center, and the Hospital for Special Surgery. The program was sponsored in part by an unrestricted educational grant from Genentech/Biogen Idec as well as the U.S. Department of Health and Human Services' Office on Women's Health.

Reaching Out Coast-to-Coast

A “sold-out” patient education program at Montefiore Medical Center in the Bronx marked the Foundation's 35th year. Two hundred people attended the free event to hear experts discuss “The Latest on Lupus,” supported in part by unrestricted educational grants from Aspreva Pharmaceuticals and Pfizer Inc.

Lupus LA, the Foundation's west coast division, commemorated its fifth anniversary and the expansion of its patient services with a program at Cedars-Sinai Medical Center. This free educational event attracted more than 200 patients, family members and friends – the largest patient education conference about lupus in the city's history. The program was sponsored in part by an unrestricted educational grant from Genentech/Biogen Idec.



Helping Children and their Families

Through its Let Kids Be Kids Fund, the S.L.E. Lupus Foundation supports Camp Sunshine, a retreat in Maine for children with life-threatening illnesses and their families. In 2005, the Foundation set a new record by sponsoring the largest group yet—33 New York-area children with lupus and their families.

*“Raise awareness of this dreadful disease in any way you can.”
- New York State Assembly Member Naomi Rivera at the Bronx patient education program*

BUILDING PUBLIC AWARENESS

Public Service Campaign Points to Lupus Risks

In spring 2005 the S.L.E. Lupus Foundation in conjunction with the Lupus Research Institute's National Coalition of state and local patient organizations launched a hard-hitting public service campaign urging people to "Get Into the Loop" and learn about lupus. Featuring actor James Garner, the campaign was designed to alert women to the risks and dangers of lupus. Its 30-second TV ad was created pro bono by New York ad agency Saatchi & Saatchi.

The National Kidney Foundation and WomenHeart: the National Coalition for Women with Heart Disease joined with the Foundation's Coalition members to promote the "Get into the Loop" campaign.

Websites Provide Access to Latest Information

The Foundation's three websites—LupusNY.org, LupusLA.org, LupusResearchInstitute.org—are worldwide resources for the latest on lupus treatments, research findings, events, and information. The high-traffic sites are visited by people with the disease, their families, researchers and health-care professionals.



ACCELERATING THE PACE OF RESEARCH

The S.L.E. Lupus Foundation's research grant program develops and encourages new investigators ideas in lupus research. In partnership with the Lupus Research Institute, the Foundation advances breakthroughs in lupus science nationwide.

Supporting New Scientific Talent

Six additional New Investigator Grants were awarded in 2005, bringing the Foundation's current commitment to new investigator research support to almost \$2 million. It is now the largest program in America specifically supporting the development of new scientific talent in lupus research.

The following researchers were funded:

Fellowship Award Recipients

These three-year post-doctoral grants of up to \$150,000 support outstanding young investigators interested in pursuing careers in lupus research.

- Philip Kahn, MD, Columbia University
- Sun Jung Kim, PhD, Columbia University

Career Development Award Recipients (\$150,000 over three years)

- Giovanni Franchin, MD, PhD, Columbia University
- Meera Ramanujam, PhD, Columbia University

Research Grant Recipients (\$150,000 over three years)

- Elena Peeva, MD, MSc, Albert Einstein College of Medicine
- Ann Haberman, PhD, Yale University

In February 2005 the **Lupus Research Institute** raised its individual novel research grant awards to \$300,000 to enable scientists to pursue innovative and “outside the box” thinking that has the potential to make a significant impact.

To date, 91 percent of investigators who completed their LRI studies have secured large-scale federal funding to expand their research. In this way, the LRI’s investment of nearly \$2.5 million in grants has yielded a remarkable \$11.2 million in new funding.

In 2005, following an intensive scientific review of the largest number of grant applications ever received, Lupus Research Institute (LRI) awarded \$4.5 million in new \$300,000 grants to 15 scientists to investigate highly promising novel research approaches to lupus.

2005 Recipients, who received three-year grants, are:

- Pascale Alard, PhD, University of Louisville Research Foundation, Inc., KY
- Felipe Andrade, MD, PhD, Johns Hopkins University, Baltimore, MD
- Timothy W. Behrens, MD, University of Minnesota Medical School, Minneapolis, MN
- Janis Burkhardt, PhD, Children’s Hospital of Philadelphia, PA and the University of Pennsylvania, Philadelphia, PA
- Marcus R. Clark, MD, University of Chicago, IL
- Christine M. Grimaldi, PhD, Columbia University, New York, NY
- Roland G. Henry, PhD, University of California, San Francisco, CA
- Daniel H. Kaplan, MD, PhD, Yale University School of Medicine, New Haven, CT
- Greg E. Lemke, PhD, The Salk Institute for Biological Studies, La Jolla, CA
- Theresa T. Lu, MD, PhD, Hospital for Special Surgery, New York, NY
- Amy S. Major, PhD, Vanderbilt University School of Medicine, Nashville, TN
- Marko Z. Radic, PhD, University of Tennessee, Health Science Center, Memphis, TN
- Inez Rogatsky, PhD, Hospital for Special Surgery, New York, NY
- Martin Weigert, PhD, University of Chicago, IL
- Zhixin (Jason) Zhang, PhD, University of Alabama at Birmingham, AL

Lupus Research Institute funding has led to multiple research breakthroughs. Two were reported recently:

- Betty Diamond, M.D., and colleagues at Columbia University found that lupus antibodies (anti-DNA antibodies) can, under certain conditions (infection, high stress hormones), cross the normally well-sealed blood brain barrier and cause damage to parts of this precious organ responsible for cognition and emotions.
- Bevra H. Hahn, M.D. and her team at UCLA reported that a certain form of the normally “good” high density lipoprotein (HDL) cholesterol linked to cardiovascular health plays a counterproductive role in people with lupus and rheumatoid arthritis. This “pro-inflammatory” HDL can promote atherosclerosis and heart disease.



Betty Diamond, M.D.

“The Lupus Research Institute is willing to take a gamble on ideas that have the potential to really cut new ground.”
- William E. Paul, MD, Chief of the Laboratory of Immunology, NIAID-NIH

ADVOCATING FOR CHANGE

The S.L.E. Lupus Foundation is an active member of the LRI's National Coalition – a network of state, regional and local lupus organizations – united to advocate for increased lupus research and awareness across the country.

First-Ever Congressional Briefing on Lupus Research

In September, the National Coalition briefed members of the U.S. House of Representatives and Congressional staff on the magnitude and impact of lupus, and the urgent need to develop safe and effective treatments. Hosted by Congressman Sherwood Boehlert (R-NY), this briefing helped to underscore the need for continued government funding of essential research, and to highlight the promise of new initiatives.

Congressional Black Caucus Legislative Forum

The S.L.E. Lupus Foundation, now in partnership with the National Coalition, is a national leader in education and advocacy to alleviate racial disparities in lupus. To spotlight the prevalence of heart disease and lupus in women of color, the National Coalition partnered with the Association of Black Cardiologists at the September 2005 Congressional Black Caucus Legislative Conference to educate attendees about this grave health risk.

"It's high time that the national spotlight turn on this twin threat—lupus and heart disease—that cripples the lives of so many young women."

- Margaret G. Dowd, Executive Director, S.L.E. Lupus Foundation

PROVIDING CRITICAL SUPPORT

Gala 2005 Raises Record Funds

Over 750 guests helped to commemorate the 35th year of the S.L.E. Lupus Foundation on December 5th and to pay tribute to honorees Richard DeScherer, president of the Foundation's Board of Directors for more than a decade, his wife Jennie, who joined the Foundation shortly after she was diagnosed with lupus in 1975, and William E. Paul, MD, chairman of the Lupus Research Institute Scientific Advisory Board. In a tremendous show of support and generosity, the event raised a record \$2.5 million for lupus research, education and patient services.

With American television icon Charles Osgood as Master of Ceremonies, New York City Mayor Michael Bloomberg, the Honorary Gala Chair, addressed attendees. A special performance by the legendary Tony Bennett brought the house down.

*"Every new voice – every additional dollar – brings us closer to a breakthrough in treatment."
- Mayor Michael Bloomberg*



Jennie and Richard DeScherer

35TH ANNIVERSARY GALA



John Silverman, Susan Golick, and Alan Wasserman, DDS



Lenard Tessler, Andrew Zaro, Katja Goldman and Fern Tessler



Bonnie Englebardt Lautenberg and Carol Weisman



Chris Paradysz with daughters Dani, Allie and son Nico



Tony Bennett



Mayor Michael Bloomberg



Robert Ravitz, John Luke and William Paul, MD

In Hollywood...

Name dropping was impossible to avoid at the star-studded "Hollywood Bag Ladies Lupus Luncheon" held in November at the Beverly Hills Hotel. Created and sponsored by Lupus LA, this third annual event generated an impressive \$200,000 for lupus research. Honorees were Lisa Gregorisch-Dempsey, Senior Executive Producer of EXTRA, and Julia van Hees-Aidner, a noted fashion and lifestyle columnist.

Special thanks go to Sharon Stone, Katie Couric, Courteney Cox, Jennifer Aniston, Reese Witherspoon and a host of other celebrities who donated new, gently used and vintage handbags for the live auction and played such a key role in furthering lupus research.

Great Chefs for a Great Cause

This first-ever culinary fundraising event to benefit lupus research was a clear recipe for success. More than 100 people came to a special dinner at Ono in New York in late February. Chefs David Burke, Vandana Naik, Don Pintabona, Scott Ubert and Tom Valenti generously donated their time and talent to prepare an outstanding meal. Thanks to Herb Estrin and Norman Mais for creating this evening.

Young Professionals Invest in Futures

More than 150 of New York's best and brightest young men and women came out to raise awareness and support of the Foundation at the first annual Young Professionals party. Held in September at one of New York's hottest restaurants, the event brought in new friends and raised new funds to support of lupus research.



Lupus LA Luncheon



Lupus LA Luncheon



Lupus LA Luncheon



Great Chefs for a Great Cause



Great Chefs for a Great Cause



Young Professionals Event



Young Professionals Event

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