

THE LOOP

Gala 2008 to Honor Families Committed to the Fight Against Lupus A Tribute to the Paradysz and Selkowitz Families

When 22-year-old Susan Golick and her parents gathered a handful of people with lupus in a small New York apartment nearly 40 years ago to talk about lupus, they gave birth to an organization destined to thrive because of the families in their midst willing to stand up, reach out, and be a part of something bigger than themselves.

“From the beginning, we knew that families would be our strength—that those with lupus surrounded by loved ones, working together, would change the outlook for this disease,” Golick said recently.

She (and her family!) was right. The Foundation has forever changed the landscape for people with lupus thanks in large measure to the energy and ideas of its committed families.

The Selkowitz and Paradysz families—unique in style yet similar in their leadership response to the adversities of lupus—have been integral to the Foundation’s ability to challenge the status quo,

care for people with lupus, and pioneer paths to better treatments and a cure through innovative medical research.

This November we pay special tribute to families and the remarkable empathy, strength, and service that they embody.

Continued on page 2

Life Without Lupus Gala 2008

Thursday, November 20th | 6 PM

Marriott Marquis in Times Square

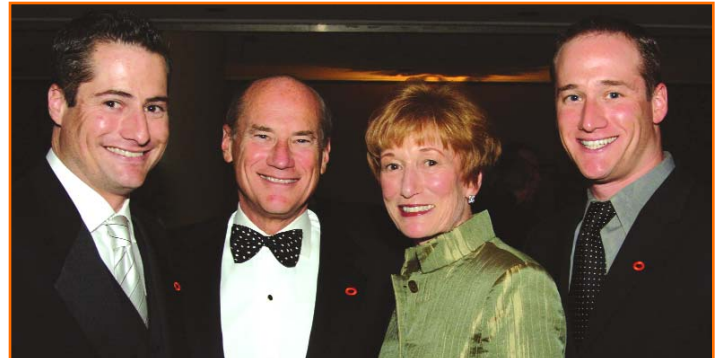
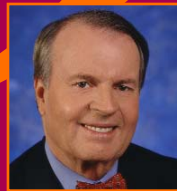
Corporate Leadership Award:

Genentech
 IN BUSINESS FOR LIFE

For more than 30 years, this leading biotechnology company has worked to discover, develop, manufacture and commercialize medicines to treat patients with significant unmet medical needs—such as systemic lupus and other autoimmune illnesses.

Master of Ceremonies:

Charles Osgood, CBS Broadcaster and Foundation Board Member



Two Extraordinary Families Answer the Call

Above: Betsey and Arty Selkowitz with sons Jed (right) and Adam (left), who has lupus and serves as chairman of Lupus LA. Below: Chris Paradysz with wife Angie (center), daughter Allie (top), who has lupus, Nico (left), and Dani (right).

LupusTrials.org: Help Science Find Answers to Lupus

Sign up for a Clinical Trial Today

Did You Know? Of the some 50,000 clinical trials taking place in New York and across the nation today, 8 in 10 are delayed by at least a month because too few people have enrolled?

LUPUS Together FOR CLINICAL TRIALS TODAY

A MEMBER OF THE LUPUS RESEARCH INSTITUTE National Coalition The National Voice for Lupus Research

About Us | What is a Clinical Trial? | Why Participate? | Find a Trial | Next Steps

ABOUT LUPUS
 More than 1.5 million Americans have

There is no known cause of lupus, few medicines, and no cure. This time for people with lupus, doctors, drug makers, scientists

The Selkowitz Family

Thirty-seven-year-old Adam Selkowitz says a lot has changed in the two decades that he has lived with lupus. “I think the most important part is that now, people have heard about lupus,” explains the Los Angeles film and TV producer and chairman of the Foundation’s eight-year-old west coast division, Lupus LA.

“Through the power of Hollywood, for example, we’ve gotten out the word about lupus in places it didn’t normally get—on to shows like “House” and “ER.”

But as was true for most Americans in the late 1980s, when the Connecticut teen was diagnosed, “lupus” was not just a frightening, but an unfamiliar diagnosis. “We knew nothing about lupus, and we didn’t know anybody who had it,” recalls Adam’s father, Arthur (Arty), retired chairman and CEO of the worldwide advertising agency, D’Arcy Masius Benton & Bowles, Inc. “And as a male with lupus manifested in his lungs, Adam’s case was so rare that the doctor said ‘I’m going to have to experiment.’

As Adam was being treated, Arty and his wife, Betsey, hunted for more information, and tried to keep life as normal as possible for him and their younger son, Jed.

Community Service an Expectation

“At some point, our doctor recommended calling the S.L.E. Lupus Foundation,” Arty recalls. Within a few months, Betsey—savvy, quick, and always ready with a question or comment—was on the Foundation board. She has served ever since.

Arty volunteered his advertising expertise and led a team that developed the popular “Get into the loop®” lupus branding and public service campaign. And in 2000, when the Foundation launched the Lupus Research Institute to shake up the field of lupus science, Arty took an active position on the board.

This bent for community service and philanthropic giving was passed along from Arty’s and Betsey’s parents, who had always been very involved in civic and community activities, and clearly infused the next generation with similar leanings.

“In my family, service isn’t requested, it’s expected,” Adam said. “You make sure to reach out and help those around you, and open up doors that others can’t open themselves. This idea has just been part of our lives. It’s how we grew up.”

Add Arty and Betsey: “We’re very proud of our sons’ community-mindedness. It’s a genetic thing, but children learn by example too. They’ve been this way since they were young.”

On Both Coasts

Adam’s association with the Foundation started in New York when he organized a fundraiser at “Caroline’s Comedy Club.” Upon moving to Los Angeles in 1999, he helped to spearhead the sister organization, Lupus LA. Working with founder Dr. Daniel J.

Life Without Lupus Gala 2008 Entertainment:



Kelli O’Hara, Broadway ingénue and star in the Tony Award-winning revival of *South Pacific* at Lincoln Center.

In the past year alone, the Oklahoma native completed her first album, performed her Carnegie Hall solo debut, and won critical acclaim as Eliza Doolittle in the NY Philharmonic production of *My Fair Lady*.

Wallace, Adam took part in steering the organization to fundraising success through such signature events as the Hollywood Bag Ladies® Luncheon and the Orange Ball. Lupus LA now raises over \$1 million annually for lupus research.

Today, Adam oversees his production company, Waterfall Films, and essentially is in good health. Meanwhile, Jed, a senior marketing manager of entertainment for the Coca-Cola Company in Atlanta, has been instrumental in revitalizing the Lupus Foundation of America’s Georgia Chapter, serving on its board, and garnering significant media attention for the cause.

“Lupus actually has brought us closer together as a family and the Foundation has been a strong support all along the way,” Arty and Betsey say. “Their combination of service and information, plus supporting the Lupus Research Institute’s focus on novel research, provides the best means of not only helping current sufferers but also providing hope that we can make lupus a disease of the past.”

The Paradysz Family

“When something in life happens, the only choice is to stand up and do,” says Angela (Angie) Paradysz. “And that is what Chris and I did the day in January 2002 when we learned that our 11-year-old, Allie, had lupus—we chose to learn more about it and to help find a cure.”

From initial feelings of “helplessness,” says Chris, to the vision of a cure in under a decade, the Paradysz family has taken bold steps to change the outlook for their spirited daughter. “Our actions are purely selfish: to help our child get well,” they say. “And we know what will lead us there: research, research, research!”

A Very, Very Sick Child

In early 2002, the unknowns for the Paradysz family were great and the fear immense. The 7th grader was at home in Mill Neck, NY with her parents and younger sister, Dani and brother Nico, when she first got sick.

It was Christmas break and school was out. Allie seemed to have some sort of viral infection, perhaps the flu. She was listless and had a fever. Her glands were swollen. The pediatrician tested for strep throat, mono, and other illnesses.

North Shore’s Schneider’s Children’s Hospital admitted her for closer observation—and she ended up staying for two months. “No one knew what was wrong,” Angie recounts. “Every department saw her. There were questions, lots of tests. They did heart scans. Blood transfusions. Her fever was so high—104°—that she was put in ice beds. But the treatments didn’t change anything.”

When they moved Allie to the ICU, pediatric rheumatologist Dr. Norman T. Ilowite, diagnosed and started treatment for lupus. Within 24 hours, the fever that had lasted 28 days was gone.

Hunting for Answers, Finding the Foundation

“As I sat in the hospital room caring for Allie,” Angie recounts, “Chris was on the phone outside finding out as much as he could about lupus.” He was so very hungry for information, recalls Foundation founder Susan Golick. “He’d call me in the morning and on his train ride home.”

“We found Susan and the Foundation at one of our most desperate moments in life—a sick child,” Angie says. “They educated and guided us to the right specialists and the best care.” Allie was additionally diagnosed with thyroid disease and juvenile diabetes.

Hollywood Shines Bright & Bold at Lupus LA's Orange Ball

Dedicated to supporting innovative science in lupus, the Foundation's west coast division uses the power of Hollywood and the strength of its leadership to fulfill the mission of the organization. The 2008 Orange Ball fundraising event proved a huge success and raised over \$800,000.

Musician Seal was presented with a research grant in his name from the Lupus Research Institute. The \$300,000 grant was one of many to be given for exciting novel research this year. Paula Abdul presented Lupus LA's prestigious "Founder's Award" to her physician, Daniel J. Wallace, M.D. And starlet Dakota Fanning presented Lauren Shuler Donner with the 2008 "Loop Award." Donner has had lupus for 20 years and worked with some of the industry's biggest names on some of the world's most recognizable films.

Among other key funds raised at the Gala were donations to Lupus LA's inaugural Emergency Grant and Community Outreach Program to reach out and help LA families with lupus in times of crisis.



Above: Seal accepts the Lupus Research Institute honor from Lupus LA Executive Director Linda David and Chairman Adam Selkowitz.



Left: Loop Award honoree Daniel J. Wallace, M.D., with Paula Abdul.

More photos at LupusLA.org

August LUPUS WEEK at Camp Sunshine

Thanks to You...Kids and families with lupus across the metro region packed up their swimsuits and sunblock for a week in Maine (August 17th - 22nd)



It's the Foundation's eighth summer and its first as Lupus Week's solo sponsor. Forty families—more than 100 kids and teens—were there.

"I was drained physically and emotionally, juggling work, doctor appointments, and three kids. Coming to Camp Sunshine has given our family hope, a sense of belonging—and a week full of fun and relaxation." - Camp Sunshine Parent

Will you send a family to Camp Sunshine next summer?

\$1,500, or a portion thereof, can make it happen. Contact Camp Coordinator Anita Cruso at acruso@lupusny.org.

The Paradysz Family, continued from page 2

The Only Choice: To Stand Up and Do

That difficult spring for the Paradysz family, the Foundation was organizing a "Jazz Night" fundraiser. Chris, a jazz enthusiast and guitarist, jumped at the chance to help, saying "This is my thing!"

The dedication of Paradysz talent, funds, and energy to the lupus cause had only just begun. Chris applied the inquisitiveness and determination that spelled such success for him in co-founding ParadyszMatera, a marketing service organization specializing in customer acquisition, to finding solutions to lupus.

In 2003, he joined the Foundation board. And in 2006, the family hatched a plan with fellow board member Teri Wood to leverage contacts in the Palm Beach equestrian world with the creation of a "Shady Ladies®" fundraiser. The annual luncheon auction of celebrity sunglasses, together with contributions and the kids' collection of prize money from junior riders, has raised over \$235,000.

This November, on the night of the Gala, Chris plans to push off

on his bicycle Ride to a LifeWithoutLupus.org, a venture kick-started in August when NASCAR driver Brad Coleman sported a "Life Without Lupus" panel on his racecar. "I have to do something," Chris says. "That's why I'm going to ride my bike and rabble-rouse my way through the back roads of the eastern United States to the home of the Daytona 500—to raise money and make some noise for lupus."

A Family Living On

Today, lupus primarily affects Allie, a Drew University sophomore, with flares signaled by sore muscles, weakness, and fatigue. But for the most part, her lupus is quiet. She's home on weekends to ride horses and be with the lively Nico and her 'best friend,' Dani.

"Following every board meeting, I get a call from my daughter to ask how it went," says Chris. "And for the first time since she developed lupus, I am able to tell her that there is progress. Real progress. The fact that new drugs finally are being trialed is a huge breakthrough. But we also have a distance to go."

SAVE THE DATES!



Presented by the Foundation's Young Leadership Committee:

**4th Annual "Night for the Fight" at TOUCH | 240 West 52nd St, NYC
Thursday, September 25 | 7pm-10pm**

Dance the night away with friends and coworkers to raise funds for the fight against lupus. Featuring hors d'oeuvres, open bar, live auction, luxury item raffle, complimentary gift bag and more! For tickets, see LupusNY.org or call 212-685-4118.

Get into the Loop! New York City Hospital Tour - Autumn 2008

Learn about lupus from the experts in each borough this fall as they touch on concerns and strategies for neurological complications, kidney problems, skin health, new treatments, navigating the healthcare system, and more. **9/30 at Lincoln Hospital** in the Bronx, **10/2 at Staten Island University Hospital**, **10/14 at NYU Medical Center** in Manhattan, **10/30 at Interfaith Medical Center** in Brooklyn, and date TBD at **Elmhurst Hospital** in Queens. All programs run from 6pm - 8pm and feature complimentary dinner. Visit LupusNY.org to register. *Sponsored in part by an unrestricted educational grant from Genentech/Biogen Idec.*

October 25th, visit our Pumpkin Patch at the Central Park Pumpkin Festival

Sponsor a pumpkin for just \$10 and help turn the park orange for lupus awareness! 7,500 pumpkins distributed in 2007!

October is officially Lupus Research Awareness Month. Check your inbox for weekly lupus "discovery" eblasts from the Lupus Research Institute—and be sure to send us your email if we don't have it. Send to lupus@lupusny.org.

Caring for Yourself

Avoiding sunlight is one of the most important things you can do if you have lupus. New York dermatologist Andrew G. Franks, Jr., M.D., FACP, gives tips and ideas on protecting and caring for the skin in the latest Foundation brochure, "Lupus and Your Skin." Here's just one suggestion from the brochure for protecting yourself against a sun-induced flare:

- **To minimize exposure to UVA rays**, place plastic over window glass and encase halogen lights and fluorescent bulbs in plastic casings. Use a polarizing guard over your computer screen. Don't worry about flat screens, such as on laptops.

There are now 11 Spanish/English brochures in this popular series! Should your doctor have copies of our brochure in their office so that others can learn about lupus?

Order at 212-685-4118.

Monthly Giving Society

Lupus never stops. Join a special group of loyal Foundation supporters who, through monthly gifts, stay on just as unwavering a path in the fight for insight, information, and relief from this disease.

We offer two easy ways to give monthly:

Credit card: Your gift is automatically charged every month.

Checking account transfer: Your gift is automatically and electronically transferred from your account every month.

Questions?

Please email Development Director Andrea O'Neill at aoneill@lupusny.org

Get Started!

Go ahead and select "Monthly Giving" through the DONATE button on LupusNY.org



330 Seventh Avenue, Suite 1701
New York, NY 10001

212-685-4118

www.LupusNY.org