

# Lupus Research UPDATE

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LUPUS RESEARCH ALLIANCE

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## The ALR Becomes the Lupus Research Alliance

More than a change in name, the *Alliance for Lupus Research* (ALR) has taken a major step in ramping up its ability to defeat lupus by merging with two other giants in the field — the *Lupus Research Institute* (LRI) and the *SLE Lupus Foundation* (SLE).

As of July 1, 2016, our new organization is the **Lupus Research Alliance**.

The decision was years in the making — in fact, when the ALR was founded in 1999, we specifically chose the word “alliance” to be in our name. Among our many aims, we envisioned a scientific community that would be inspired and motivated by greater collaboration.

Today — through the newly created Lupus Research Alliance — the best and the brightest scientists, scholars, technicians, and administrators of three leading lupus organizations will work as one.

Our ambitious goal is to make even greater advances in treatment options for people who cope with the often-debilitating effects of the disease.

Kenneth M. Farber, Co-CEO and Co-President, Lupus Research Alliance, explains the reasoning behind the merger:

*“No non-governmental organization has done more to advance the science of lupus than the Alliance for Lupus Research — that left us in a predicament: Where does the world’s largest private funder of lupus research go from there and how do we become even better at making lupus a disease of the past?”*

The answer was clear. By merging with the LRI and the SLE Lupus Foundation, our bold new entity — the Lupus Research Alliance — is uniquely positioned to tackle the very complex intricacies of this very complicated disease with greater facility than its legacy organizations.

Larger and with greater resources, the Lupus Research Alliance promises to usher in a new era of unprecedented scientific progress for the entire lupus community — especially lupus patients.

*“It’s a thrilling moment in lupus research,”* said Mr. Farber. *“We’re excited by the merger and the vast potential it holds for our new organization.”*

## LUPUS RESEARCH ALLIANCE

FORMERLY



## A History of Collaboration

The ALR and the LRI first collaborated in 2012 in establishing the Lupus Insight Prize (along with the Lupus Foundation of America). Each year, the prize is awarded to an outstanding investigator with a solid record of achievement in lupus research and a strong probability of generating further advances in diagnosis and treatment of lupus.

Next, we worked together on a unique project in the arena of lupus research — to repurpose existing drugs already approved by the FDA. Under the leadership of Dr. Peter Lipsky — who served on the Scientific Advisory Boards of both organizations — we began to identify and test specific existing drugs that might be efficacious in treating lupus.

Because repurposing drugs can save years of research time — as well as millions of research dollars — the application of this initiative has the potential to radically change the landscape of lupus scientific inquiry.

As an outcome of this effort, the ALR and the LRI also collaborated on the creation of LuCIN — the Lupus Clinical Investigators Network — which is about to conduct its first clinical trial.

## Advantages Going Forward

**IN RESEARCH ...** More of the world's top-flight lupus research investigations will be funded through Lupus Research Alliance, bringing us closer and closer to new discoveries that have the potential to dramatically improve the lives of lupus patients.

**IN ADVOCACY ...** We will be redoubling our advocacy efforts to give voice to an urgent need — more governmental funding for lupus research. Plans are also underway to expand our Multicultural Outreach Program, which reaches out to the groups most vulnerable in the lupus community.

**IN INDUSTRY ...** Pharmaceutical companies are very excited about the merger and have actually given us more money for the new investigations we'll be pursuing under the auspices of the Lupus Research Alliance.

**IN FUNDRAISING ...** Fundraising will be bigger and better. We estimate that Lupus Research Alliance will increase its funding capacity by 100%.

**IN BRINGING PEOPLE TOGETHER ...** We will continue to raise awareness and critical funds through our grassroots fundraising effort, *Walk with Us to Cure Lupus*. Additionally, our first joint Gala raised \$3 million — the largest lupus fundraiser in the world.

**IN LAUNCHING A \$100 MILLION CAMPAIGN ...** The new organization will have greater expertise in bringing the various facets of our constituency together. Our aim is to raise \$100 million to bring greater understanding to lupus and ways to treat it.

**IN GARNERING GOODWILL AND TRUST ...** Lupus Research Alliance's newly expanded Board of Directors wishes to carry forward a unique policy. The Board has again pledged to pay for all fundraising and administrative costs so that 100% of each donor dollar will go directly toward lupus research programs.

In summing up the many pros of our merger, Mr. Farber said: *"Our newly formed Lupus Research Alliance is comprised of dedicated individuals who share the common aspiration of defeating lupus. This merger will further empower us to lead the way to a cure."*

**"It's a thrilling moment in lupus research.**

**We're excited by the merger and the vast potential it holds for our new organization."**

Kenneth M. Farber,  
Co-CEO and Co-President,  
Lupus Research Alliance

## Driving Discoveries that Make a Difference

The Lupus Research Alliance leads the quest to prevent, treat, and cure lupus through the power of science. We are driven by one central goal — to improve the lives of people living with the disease, today and in the long term. We believe scientific research is the most effective path to achieve this goal.

# Advancing Advocacy: Making Even Greater Strides

The Lupus Research Alliance is building on the groundbreaking advocacy efforts that the ALR, LRI, and SLE Lupus Foundation pioneered to heighten awareness about lupus and to help generate greater funding for lupus research at the federal level.

Moving forward, the emboldened new organization will be an even stronger voice in sounding the siren of need for stronger support of lupus research among members of Congress, health groups, the pharmaceutical industry, and the public.

We're off to a great start. Last year alone, we set into motion initiatives that will greatly amplify the voices of patients with lupus by:

**MAKING SCIENCE ACCESSIBLE TO NON-SCIENTISTS** – Over 100 patients, family members, and friends gathered for the 3rd annual *Advancing Lupus Care Through Research and Advocacy* conference. Four scientists and two advocates presented the promise and progress of cutting-edge research to improve the lives of people with lupus.

**EDUCATING HEALTHCARE PROVIDERS** – We were awarded a \$500,000 grant from the Federal Office of Minority Health for Provider Education for our *Lupus Education Advancement Project (LEAP)*. The aim of this project is to help healthcare providers better understand the unique health issues and racial disparities experienced by minorities with lupus.

**CARRYING OUR MESSAGE TO THE HILL** – Over 70 advocates and staff representing 15 states carried a message to Washington, DC: Strengthen biomedical research at the National Institutes of Health (NIH) and establish a new Lupus Research Program in the Congressionally Directed Department of Defense Medical Research Program. This action contributed to a \$2 billion increase in NIH budget and \$5 million in new lupus research approved by the House Defense Appropriations Subcommittee at the Department of Defense.

**HOSTING A CONGRESSIONAL BRIEFING** – With the Lupus Caucus, we orchestrated a briefing to reveal the new NIH *Action Plan for Lupus Research*, which provides a new roadmap building on decades of NIH research.

**GIVING PATIENTS A STRONGER VOICE** – Together with the Lupus and Allied Diseases Association and the Lupus Foundation of America, we are working on a groundbreaking *Lupus Patient-Focused Drug Development Initiative* to bring the perspectives of people with lupus to the attention of the Food and Drug Administration (FDA) to help guide decisions about lupus drug development and review processes. We will keep you updated on the progress of this initiative.

**THE TIME TO BECOME INVOLVED IS NOW!** – Everyone can become an effective advocate for lupus research ... improved treatment options ... and the path to a cure. Every individual can make a difference by becoming an advocate for lasting change.

## Meet Kathleen Arntsen: Advocate Extraordinaire



**Kathleen Arntsen**

If one thing is certain, Kathleen Arntsen is a survivor. After coping with the ups and downs — and frustrations — of lupus for several years, Kathleen had had enough. She became a “lupus warrior” — an advocate for herself ... and others with the disease.

As with so many people newly diagnosed with this highly unpredictable disease, Kathleen soon discovered that having lupus changes everything.

*“I was in college when I was diagnosed. And in no time I went from being a social butterfly — a young woman in the prime of my life — to suddenly wondering if I’d be alive in five years,”* Kathleen shared with open candor.

But rather than sit back and view herself as a victim, Kathleen actively took charge of her life.

*“I had to take a step back to figure out what I needed to do,”* said Kathleen. *“I realized I had to become better educated and empowered. I knew I would need to learn as much as I could about treatments. And I knew I would not only have to find the best physicians — I’d have to work with them to move forward.”*

Of course, Kathleen hopes for a cure in her lifetime — but she is pragmatic about what it will take to make that day a reality. She understands that research is the key to discovery but also that everyone — not just scientists — can help make a difference.

Kathleen is committed to doing her part: Her voice echoes loudly in Albany and on Capitol Hill each year.

She has helped to lead the charge in New York State to pass a Lupus Education and Outreach Bill and on efforts to protect patients, such as preserving access to Medicaid drugs, stopping Tier IV drug formularies, and reforming step therapy policies. And in Washington, DC, Kathleen has taken up the tough battle of safeguarding Medicare and bringing to light the fact that health insurance companies have the authority to switch a patient’s treatment even if it is not in their best interest.

*“It’s appalling to me that cost savings are the priority, not a patient’s health outcome,”* said Kathleen. *“I can’t say it more loudly: I want no bureaucrats on my treatment team!”*

And she doesn’t want them on any other patient’s treatment team either. This is why Kathleen has made advocacy her life’s work. She talks with newly diagnosed patients and their families almost daily — *“I counsel patients and their loved ones to become as educated and as empowered as possible. I tell them about the importance of advocacy ... that they must first self-advocate,”* shared Kathleen.

But Kathleen’s vision is comprehensive and she also asks the lupus community to become involved for the sake of every person struggling with the disease ... to contact legislators and urge them to take action on important research and access issues.

Strong and persuasive, Kathleen leads by example. Even her license plate carries the message dearest to her heart: “NO LUPUS.”

### Drive ... Determination ... Compassion

President/CEO of the Lupus and Allied Diseases Association, Inc., Kathleen Arntsen is a dynamic grassroots activist who possesses unique qualities that motivate others to support advocacy and research initiatives. She has openly provided public witness testimony before the FDA, US Senate & House, NYS Senate & Assembly, and various federal and state agencies.

Kathleen was appointed to a 2nd 5-year term as the Lupus Patient Representative for the Office of Health & Constituent Affairs with the FDA in 2015 and is serving a 4-year term as the Patient Advocacy Representative for the IUIS/WHO/AF/CDC Committee for the Standardization of Autoantibodies in Rheumatic & Related Diseases.

Robust in putting a face to autoimmune disease, Kathleen is a strong catalyst of inclusion of the patient perspective in biomedical research. She believes that medical research advancements are best achieved through innovative, collaborative efforts uniting all stakeholders.

To learn more about Kathleen Arntsen’s work, please visit [www.nolupus.org](http://www.nolupus.org). If you would like to contact Kathleen Arntsen directly, you can send an email to her at [Lupusinnovators@aol.com](mailto:Lupusinnovators@aol.com).