

Moving Forward with Incredible Success

Taking a Closer Look at 2019

In the course of the year, the Lupus Research Alliance (LRA) took daring chances, pursued bold initiatives, and made important strides in the conquest of lupus.

With support from great friends, we:

INVESTED IN TRAILBLAZING RESEARCH

PUSHED THE LIMITS OF SCIENTIFIC DISCOVERY

SOUGHT INNOVATIVE AVENUES OF INQUIRY

The LRA wishes to thank our Board of Directors, our corporate and foundation donors, and all of our loyal friends who want to make a difference, for their unwavering generosity.

It was through these efforts that the LRA was able to examine the many complicated characteristics of this very complex disease through the eyes of the most brilliant scientists in the world today.



Lupus News Corner

BIG ... BOLD ... IDEAS ARE TRANSFORMING LUPUS RESEARCH—thanks to people like you!

Thanks to our remarkable supporters, the Lupus Research Alliance awarded nearly \$7.5 million through the following grant mechanisms in 2019:

2019 Novel Research Grants (\$1,798,602)

Carla Cuda, PhD
The Role of Microglial Subsets in Driving Neuropsychiatric Symptoms of SLE
Northwestern University - Chicago Campus

Anne Davidson, MBBS
Circadian Dysregulation of Immune Function in SLE
Feinstein Institute for Medical Research

Neelakshi Jog, PhD
Contribution of Dysregulated Granulopoiesis to SLE Pathogenesis
Oklahoma Medical Research Foundation

Michelle J. Kahlenberg, MD, PhD
Shining a Light on the Drivers of Photosensitivity in Systemic Lupus
University of Michigan

Benjamin Kile, PhD
Establishing the Role of Apoptosis and MtDNA in the Pathobiology of Lupus
Monash University

Yee Ling Wu, PhD
New Mechanisms for Thrombosis and Atherosclerosis in SLE and APS
Loyola University Chicago

2019 Distinguished Innovator Awards (\$2,000,000)

Fabienne Mackay, PhD
Novel Therapeutic Approaches for SLE
The University of Melbourne

Jeffery Rathmell, PhD
Metabolic Networks and Unbiased Genetic Screens to Identify Targets for SLE
Vanderbilt University Medical Center

2019 Target Investigation in Lupus Grants (\$3,598,919)

Montserrat Anguera, PhD
Targeting the Inactive X for Correcting Dosage Imbalances in Lupus
University of Pennsylvania

Paolo Casali, MD
Intrinsic B Cell Epigenetic Mediators as Therapeutic Targets in Lupus
University of Texas at San Antonio

Hongbo Chi, PhD
Targeting Follicular Helper T cell Metabolism in Lupus
St. Jude Children's Research Hospital, Inc.

Hui-Chen Hsu, PhD
Cytokine Immunoregulatory Strategy to Target SLE Autoreactive B Cells
University of Alabama at Birmingham

Vicki Kelley, PhD
Ptprz: A Therapeutic Target for Lupus Nephritis
Brigham and Women's Hospital, Inc.

Jason Knight, MD, PhD
Relieving ER stress in Lupus Neutrophils
University of Michigan

Visit lupusresearch.org to make a donation, learn more about lupus and our funded lupus research, or find out about our *Walk with Us to Cure Lupus* program.



walk WITH US
TO CURE LUPUS

100% of all donations goes to support lupus research programs because the Lupus Research Alliance Board of Directors funds all administrative and fundraising costs.

For the latest, up-to-date information about lupus you can join our online community on:

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pinterest.com/lupusresearch

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lupusresearch.org/community



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LUPUS
research
UPDATE

2019 Lupus Insight Prize Awarded to Ignacio Sanz, MD

"Thinking outside the box" is jargon that often rings hollow—but not so when it's used to describe the ideas generated by **Ignacio Sanz, MD**, world-renowned expert on autoimmunity.

Dr. Sanz recently discovered that certain little-understood immune system cells are a major source of the harmful proteins that promote lupus symptoms. This breakthrough has the potential to alter the course of lupus research forever.

In recognition of his groundbreaking work, the Lupus Research Alliance awarded Dr. Sanz the 2019 **Lupus Insight Prize**.

The prize of \$100,000 was designed to acknowledge a major, novel insight and/or discovery—such as Dr. Sanz's—which has the promise of shifting the lupus paradigm. It is also the hope of the LRA that the award will generate further advances in the diagnosis and treatment of the disease.

"Dr. Sanz has already made invaluable contributions," said **Kenneth M. Farber**, President and CEO, Lupus Research Alliance. "We look forward to his next advances afforded by our *Lupus Insight Prize*." The LRA believes Dr. Sanz's study could spark new treatments for the disease and help doctors determine the best course of action for their patients.

Specifics on the Investigation

Researchers have known for some time that some B cells must mature in specialized parts of the lymph nodes or spleen before they can make these destructive antibodies.

But Dr. Sanz has shown that many damaging B cells follow a different route. And, he identified the molecular mechanisms that underpin this B cell activation pathway.

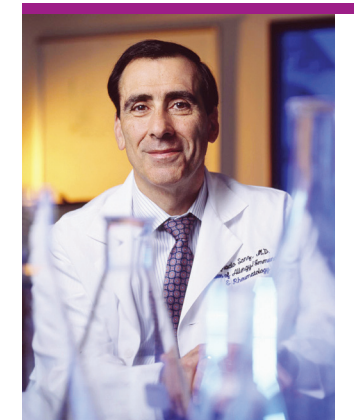
He and his team were the first to apply a comprehensive characterization of these cells using cutting-edge techniques such as multidimensional flow cytometry analysis of DNA in lupus patients. They found that this group of B cells was prevalent in patients who were undergoing lupus flares, particularly African Americans.

Dr. Sanz and his colleagues also found that, in contrast to healthy subjects, the lupus B cells were ready to transform into cells that produce harmful antibodies, even in patients without active disease.

Looking forward, researchers may be able to build on Dr. Sanz's discoveries to identify new therapeutic targets and to develop treatment tailored to each person.

In accepting the prize, Dr. Sanz gratefully acknowledged the LRA: "I am deeply humbled and honored by this award. I thank the LRA for recognizing my work, and I am eager to pursue further research with the potential for improving patient treatment."

The LRA congratulates Dr. Sanz on his discovery and wishes him further success. We look forward to his future breakthroughs in reducing patients' risks and severity of disease flares. Dr. Sanz is truly able to think outside the box—and every lupus patient stands to benefit from it.



Dr. Ignacio Sanz

Dr. Sanz is the Mason I. Lowance Professor of Medicine and Pediatrics and Chief of the Division of Rheumatology at Emory University School of Medicine in Atlanta, Georgia.

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Relentlessly Pursuing Answers Allows the **Lupus Research Alliance** to Make Unprecedented Gains

2019: A YEAR OF TREMENDOUS GROWTH

The **Lupus Research Alliance (LRA)** boldly pursued breakthroughs on the many fronts of lupus research in 2019—allowing the organization to fast-track avenues for new treatment options, including those orchestrated through our own clinical trials network. Throughout the year, the many brilliant scientists who received LRA funding brought new ideas to the table, ushering in discovery after discovery. These minds—the world’s best and brightest—helped the LRA achieve breakthroughs in directions that once were considered insurmountable. In the process, the LRA empowered compassionate individuals by giving them a platform to stand up to lupus ... to become involved ... and to fund some of the world’s most pioneering lupus research initiatives.

The results of 2019—combined with those of previous years—are staggering. As the world’s largest private funder of lupus research, we have granted nearly \$7.5 million to lupus research programs and delivered breakthroughs that are speeding up the development of new treatments.

Leading with Extraordinary Clarity and Grace



Dr. Mary (Peggy) Crow

The LRA is enormously grateful to **Mary K. (Peggy) Crow, MD** for her more than 10 years of devoted service and leadership as the organization’s Co-Chair of our Scientific Advisory Board. Dr. Crow’s tenure concludes on December 31st.

“It’s well known that Dr. Crow has brought vision ... leadership ... expertise to the LRA—but she also inspired all of us by her uncompromising determination to find answers for those who suffer from this debilitating disease,” said LRA President and CEO **Kenneth M. Farber**. *“Although she is stepping down as Co-Chair, we are fortunate that Dr. Crow will continue to work with the LRA in several other capacities.”*

Dr. Crow is Physician-in-Chief and Chair of the Department of Medicine at Hospital for Special Surgery and is Chief of the Division of Rheumatology at HSS and NewYork-Presbyterian/Weill Cornell Medical Center.

Collaborating and Sharing Ideas

Throughout its history, the LRA has played a pivotal role in bringing together the key players in the fight against lupus and 2019 is no exception.

More than 100 of the world’s top scientists in lupus research and treatment gathered on October 20-22 for the LRA’s 2019 annual three-day **Forum for Discovery** scientific conference.

Researchers shared their promising discoveries funded by the LRA, sparking dynamic discussion and exchange of ideas that may well lead to the next breakthrough.

At the conclusion of his presentation on metabolic networks and unbiased genetic screens to identify targets for lupus, **Jeffrey Rathmell, PhD**, stressed the inestimable value of the Forum for Discovery gathering.

“The diversity and promise of the science discussed at this meeting are impressive,” said Dr. Rathmell. *“As*



Dr. Jeffrey Rathmell

investigators, we tend to focus on our own work. But this forum allows us to see the big picture and the field at a higher level ... to learn what our colleagues are working on ... and to look to ways to collaborate together to tackle this very complex disease. It’s very impressive!”

And on September 19, the LRA hosted a collaborative meeting entitled **Microbiome in Lupus**. Thanks to the support and leadership of Board Member, **Bill Wolfe**—the LRA gathered world experts from a cross-section of varied disciplines to discuss how the burgeoning field could benefit people with lupus.

What’s the significance of gut bacteria or microbiome? For one, there are more microbiome cells than human cells in the body. Secondly, microbiome are capable of communicating with the immune system to fight infection.

Evidence already shows that bacterial imbalances are linked to immune-related diseases and even some cancers. More than ever, we’re finding out just how important these microbes are. This is why the LRA is open to the possibility of devoting funds for microbiome research in the near future, building on the organization’s past work in this fascinating field.



Forum for Discovery

Accelerating Drug Development

Recognizing the need to address the way clinical trials are conducted—and to speed drug development—the LRA formed an affiliation with **Lupus Therapeutics** in 2017.

Much progress has been made since then. *“Lupus Therapeutics serves as the organization that oversees the **Lupus Clinical Investigators Network (LuCIN)***

we created with the LRA,” said **Al Roy**, Executive Director of Lupus Therapeutics. *“We’re on a mission to accelerate drug discovery for all patients living with lupus.”* When the program started, about 30% of our sites participated in LuCIN trials. Today, all 57 sites participate—and many are simultaneously conducting more than one trial.

Partnering with Pharmaceuticals

Since our inception in 1999, the LRA has advanced scientific lupus research with the help of pharmaceutical companies, and in 2019, we formed a major alliance.

In August of this year, we formed a unique new partnership with the **Celgene Corporation**—which will be

providing \$3 million for bold cutting-edge research projects. The thrust of the research will focus on understanding the underlying mechanisms of disease, addressing heterogeneity (how much the disease varies from person to person), and identifying novel biomarkers.

Breaking Through the Fog

Lupus has an impact on the brain in a large number of patients. A staggering 95% of people with the disease experience neuropsychiatric lupus (NPSLE), a wide range of brain-involved symptoms like not thinking clearly, forgetting things or even seizures, stroke and psychosis.

To understand the cause of these types of brain involvement, the LRA has teamed with Harvard Brain

Tissue Resource Center (HBTRC) to develop a program to recover donated brains from deceased individuals with lupus.

The incredible people who commit to donate their brains after they pass away are giving the world a priceless gift that can advance lupus treatment for generations to come.

Transforming Goodwill into Research

People make a difference—that’s something the LRA knows for certain. And we don’t have to look any further than our **Walk with Us to Cure Lupus** events.

Walkers—many of whom have lupus or have a close relationship with someone who has the disease—are invested in helping the LRA fund critical lupus research initiatives.

In 2019, the determination of walkers like **Matthew Niskanen** helped to generate nearly \$2 million, bringing the total raised by walks all over the country to over \$41 million! Here’s one reason why: *“I’m not looking for a cure for me,”* said Matthew. *“I’m looking for a cure in case one of my kids gets diagnosed with this disease – and for the kids of other parents. I don’t want them go through what I’ve had to go through.”*

