

COVID-19 Vaccines and the Lupus Community

The United States is in the midst of the biggest, fastest, most important vaccination campaign ever undertaken in our nation's history. As of April 2021, more than 180 million doses have been given—with over 2.5 million doses being administered every day.

Over the past year, the development of vaccines—and getting them in people's arms—has become a global concern. Here, COVID-19-related mortality toll is staggering, with tremendous suffering continuing throughout the US.

So, it is no small wonder that getting vaccinated is the topic on everyone's mind these days, including people in our lupus community. But the concerns of people with lupus are more complicated than just navigating a path to vaccination.

Those living with lupus, as well as their families, need answers to a few key questions: *Are the COVID-19 vaccines recommended for people with lupus? ... Which one should I take? ... Will I experience more severe side effects? ... Are the new vaccines safe for those of us in the lupus community?*

The Lupus Research Alliance (LRA) listens

As the world's largest private funder of lupus research, we take the concerns of people with lupus very seriously. That's why we have taken a proactive stance in evaluating research and communicating the most up-to-date health and safety information since the pandemic erupted one year ago. Right now, vaccine safety is one of our major focuses.

Answering the Core Question

Are COVID-19 vaccines safe for people with lupus?

The answer is yes, almost all rheumatologists recommend people to vaccinate as soon as possible. It's important to understand that most of new covid vaccines rely on recently developed technologies. Over the long run we want to know which of these technologies might be most appropriate for lupus patients. To answer that question, the LRA has taken two important steps. First, we recently gathered experts in vaccinology, immunology, rheumatology, and representatives from the National Institutes of Health and our own Research Committee and Scientific Advisory Board. These experts emphasized they had not found any reasons why the emerging vaccines should not be safe for lupus patients.

At the same time, the group underscored the urgent need to generate clinical and research data on Covid-19 vaccine response in lupus patients.

Following up on these recommendations, the LRA and its affiliate **Lupus Therapeutics**, engaged key investigators to design and conduct such a study—and we are investing \$3 million into this research effort.

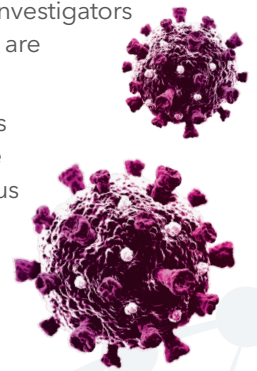
Because the safety of the lupus community is paramount to the LRA, this research initiative will evaluate the immune responses to various types of COVID-19 vaccines among people with lupus—as they are approved by the U.S. Food and Drug Administration (FDA) for emergency authorization.

Empowering Our Community

In many ways the COVID-19 pandemic has drawn attention to lupus and the broader need to understand the nature of a hyper-activated immune system. At this crucial juncture, so much can be learned, not only by our research, but from those living with lupus.

This was the reason behind the launch of our campaign called **Learn from Lupus** to share what the lupus community, researchers, and the LRA can teach the rest of the world in this COVID-19 reality, and beyond.

The LRA is committed to helping keep our community safe—and informed on every front that safeguards the lives of people with lupus.



“The plain fact is—that like other viruses—COVID-19 is going to be around for a long time—and it’s going to be manageable. What we learn today is going to be important in developing vaccines for the future.”

—Kenneth M. Farber, President and CEO

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BOLD PARTNERSHIPS = FRUITION OF BOLD IDEAS

The LRA has joined forces with **JDRF International and the National Multiple Sclerosis Society** in a bold new initiative to accelerate discovery in autoimmunity.

This is no ordinary grant mechanism. A consortium of eight top-flight investigators has been formed and they will collaborate, share data in real time, and create more than the sum of the following impressive projects.

Amit Bar-Or, MD

Linking multiple disease compartments in T1D and MS
University of Pennsylvania

Chris Cotsapas, PhD

Identification of pathogenic pathways through genomic engineering to identify shared genetic effects on patients with T1D, SLE, and MS
Yale University

Kevan Herold, MD

Analysis of antigen specific T cells in response to immune therapies in MS and T1D
Yale University

Thomas Pieber, MD

COMET Common Mechanisms in Autoimmunity
University of Graz, Austria

William Robinson, MD, PhD

Dissecting the Genetics and Host Interactions of EBV-Related Autoimmunity
Stanford University

Ansuman Satpathy, MD, PhD

3D and Single-cell Epigenome Technologies for Autoimmune Disease
Stanford University

Alexandra-Chloe Villani, PhD

Single-cell genomics dissection of common immune networks driving autoimmunity
Massachusetts General Hospital

Julie Zikherman, MD

Nr4a family as marker and mediators of B cell tolerance across autoimmune disease: from antigen discovery to treatment
University of California, San Francisco

Heterogeneity: The Core Issue in Lupus

Lupus is a complex disease that is heterogeneous in nature—meaning that symptoms are many and can vary widely from patient to patient and even within a patient. While one person may develop a rash, another may have high blood pressure or a host of other symptoms, such as joint pain, anemia, and kidney damage.



Evidence indicates that heterogeneity is at the root of understanding more about lupus. With so many possible triggers, lupus can cause a variety of disease manifestations.

Heterogeneity also makes it difficult to predict the impact on different organs and the long-term outcomes in individual patients. Such diversity rules out the “one size fits all” approach to treatment.

In recent years, under the aegis of **Turning Complexity to Cure**—the LRA’s focus regarding heterogeneity has aimed at improving the success rate of clinical trials and developing more effective treatments that target the underlying disease pathways in each patient.

As an organization, the LRA believes that the time is right to bring personalized medicine to lupus treatment—and is working on many fronts to seize the moment.

These efforts require collaboration. And so, the LRA is issuing a new grant program that calls on the best minds in different areas of research to work together in multi-disciplinary teams. The new funding program called the **Global Team Science Award** provides up to \$3 million over three years—the largest lupus research grants ever given by any non-governmental, not-for-profit institution.

This grant-making process will build teams of outstanding scientists from around the world to combine their findings and approaches in diverse fields including technology, information processing, immunology, and clinical research.

The approach of our **Global Team Science Award**—unlike other collaborative grants in which researchers work on their own projects under one umbrella—requires that all team leaders work on a common project from distinct perspectives.

“Recent advances in technology development and human immunology provide an unprecedented opportunity to make major advances in the molecular deconstruction of lupus heterogeneity, and the Global Team Science Award aims to mobilize these efforts.” said **Teodora Staeva, PhD**, Chief Scientific Officer of the LRA. *“This is an exciting time in lupus research.”*

Bolstering Diversity To Accelerate Research and Systemic Change

As an organization, the LRA is committed to promoting diversity, equity, and inclusion in all our work—not only because it is the right thing to do, but because lupus is a disease that disproportionately impacts people of color—particularly women.

While it has been long established that 90 percent of those with lupus are women and that it is up to three times more prevalent in women of color than Caucasian women, recent evidence raises even greater cause for concern. Previously ranked among the top 20 causes of death in all women, this figure rose to shocking new levels. Lupus is now recognized as the 5th and 6th leading cause of death among Black and Hispanic women ages 15-34.



In an effort to address those most at risk, the LRA is expanding our **Diversity, Equity and Inclusion Programs (DEI)** in 2021, beginning with the implementation of two new initiatives.

In the research arena, our new **Career Development Awards to Promote Diversity in Lupus Research** fosters greater engagement of underrepresented minority scientists at various stages of their careers through a combination of grant funding and mentorship.

And to make sure that new drugs are tested among those patients most likely to need them, our **Community-based Health Action Network to Generate trial participation and Eliminate disparities, or CHANGE Project**, aims to increase clinical trial participation and retention among minorities diagnosed with lupus in the United States through a community-driven approach.

The LRA’s DEI Programs will ensure that people of color have more of a say and better representation in both the research and clinical trials. As the program grows, more updates will be forthcoming. Stay tuned!

Distinguished Innovator Awards Announced

On March 25, 2021, the LRA proudly announced the two exceptional recipients of the Dr. William E. Paul Distinguished Innovator Award in Lupus and Autoimmunity: **Jacques Banchereau, PhD** and **Ignacio Sans, MD**.

Both projects funded by this grant are investigating different mechanisms that trigger an autoimmune response in people with lupus. Their findings could lead to the development of more precise treatments to prevent lupus onset or progression. For more in-depth information of each of these studies, please visit us at www.lupusresearch.org

TWO NEW DRUGS RECEIVE FDA APPROVAL

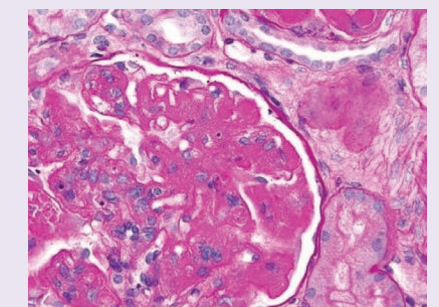
“This is a historic moment in lupus with two new drug approvals for lupus nephritis in just over a month,” enthused **Kenneth M. Farber**, LRA President and CEO.

The LRA is excited to share that the U.S. Food and Drug Administration (FDA) has approved the use of voclosporin (Lupkynis™) as the first oral treatment specifically for adults with active lupus nephritis in combination with standard care.

Voclosporin followed the recent approval of belimumab (Benlysta®) by the FDA as new treatments for lupus nephritis in December of 2020.

Recognizing the persistent gap in lupus nephritis care, the LRA has devoted considerable resources to studying ways to better diagnose, monitor, and manage this most common complication of lupus. Among the more than 40 funded research grants focused specifically on lupus nephritis, many have laid the groundwork for critical advances in development of new drugs like these.

The LRA applauds **Aurinia Pharmaceuticals** and **GlaxoSmithKline (GSK)** on their success in developing new treatments for lupus nephritis.



Lupus nephritis is a disease of the kidneys—and a serious complication of lupus.

LRA in Action

The Power of Advocacy

Ten new grant applications for promising lupus research have been recommended for funding under the Lupus Research Program within the Congressionally Directed Medical Research Programs at the **Department of Defense!**

The LRA and advocates across the country helped establish this vital program which has been allocated \$35 million in its first five years. Forty-eight grants have been awarded and the funding opportunities for fiscal year 2021 will be available shortly.



Our Voices Heard Virtually

Despite the restrictions imposed by COVID-19, lupus advocates gathered virtually in March 2021 to ask Congress to increase the funding of the above-mentioned **Lupus Research Program from \$10 million in fiscal year 2021 to \$15 million for fiscal year 2022.**

As in previous years, members of Congress heard directly from those most impacted by lupus—patients and their families. There's power in the stories of individuals—as evidenced by the expanding allocation of government funds to fight lupus.

Thanks Straight from the Top

"I want to extend gratitude to every donor who continued to support the LRA throughout the pandemic. Not only were we able to keep our vital lupus research on track—you gave us the means to remain a calm and reliable source of information during incredibly challenging days.

This newsletter attests to the fact that you enable the LRA to break new ground in lupus research.

Thank you!"

Kenneth M. Farber, President and CEO



Kenneth M. Farber

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.



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:

 facebook.com/lupusresearchalliance

 twitter.com/lupusresearch

 youtube.com/lupusresearchorg

 pinterest.com/lupusresearch

 instagram.com/lupusresearchalliance

 lupusresearch.org/community



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