### **Lupus News Corner**



### Lupus Awareness Month

Although this past May–Lupus Awareness Month–wasn't quite like others, the LRA has initiated efforts for people with lupus to connect. To help our community cope with the effects of COVID-19 in May and beyond, the LRA has unveiled a series of enlighteningly educational videos hosted by Shayla Shorter, PhD.

The Learning from Lupus series is now available on the LRA's website and YouTube channel.

### Forum for Discovery

In the era of COVID-19, the LRA is working hard at keeping every aspect of every vital initiative on track. That's why our Forum for Discovery-our collaborative scientific meeting-will be presented virtually on October 27, 2020. This invaluable meeting gives LRA-funded researchers the opportunity to share important discoveries made through their research.

# Staying Connected: Lupus and COVID-19

- What parallels exist in the overreactive immune response seen in lupus and COVID-19?
- Are people with lupus more or less at risk for COVID-19?
- Are medications used by people with lupus more or less effective in COVID-19?

These are just a few of the question that were answered in the LRA's live webcast Lupus and COVID-19: What You Need to Know on May 21st. If you couldn't attend-or want to hear it again- go to our website www.lupusresearch.org

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
- O pinterest.com/lupusresearch
- instagram.com/ σ lupusresearchalliance





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### **VOLUME 1, 2020**

#### **A MESSAGE FROM LRA PRESIDENT & CEO ON COVID-19 AND LUPUS**

These are challenging times for everyone-and each of us must stay focused. For the **Lupus Research Alliance** (LRA) this means safeguarding the health of the lupus community within the new context of the COVID-19 global pandemic.

It is imperative that all of us stay calm, safe, and abreast of the most relevant updates on the many ways this pandemic could impact our lives-and I strongly urge you to regularly check our website at lupusresearch.org for important posts.

This information is so vital to the lupus community that the LRA has added a special COVID-19 **Updates** section to our home page.

Amid all the troubling stories of recent weeks, we were able to relay positive news to allay fears within our community regarding the use of hydroxychloroquine (better known as Plaquenil)-the most commonly prescribed treatment for lupus.

New data from the Centers for Disease Control shows that use of this drug as a treatment for COVID-19 has been ineffective.

I promise you that the LRA is here for you. Please visit our website and visit it frequently. Our updates are grounded in science and could save the life of someone you love.

Kenneth M. Farber President and CEO

P.S. Stay safe! Stay connected! And remember the LRA has your back.

LUPUS

# A 1-2 Punch Approach **To Treating Lupus**

With the objective to develop treatments that target the underlying disease pathways in *individual* patients, Dr. Mackay and her team are developing an approach that packs a 1-2 punch.

#### Why focus on changes in the gut microbiome?

lupus nephritis.

Leaky gut may, in some instances, play a critical role in lupus nephritisa condition that occurs when lupus autoantibodies attack the kidneys-



The challenge of finding more effective treatments for lupus-according to Dr. Fabienne Mackay, PhD-lies in the nature of the disease itself. "Lupus is not one disease, but rather a set of syndromes in which no one treatment will work for all," she explains.

They are investigating whether the removal of harmful immune cells, combined with changes in diet, can alter the gut microbiome-thereby reducing immune system attacks.

The link between bacterial imbalances and other immune-related diseasesmost notably inflammatory bowel disease-has already been established. So, there is clear logic to look for similar imbalances in lupus-including such life-threating consequences as

Describing herself as "long intrigued by the microbiota". Dr. Mackay explained, "There is growing evidence of patients with lupus presenting with leaky gut syndrome. This leakage may trigger inflammation-and injury-as microbial matter enters the blood stream as a pathogen."



Dr Mackay, who leads a dedicated team of researchers at the University of Melbourne Australia, is a recipient of the LRA's 2019 Distinguished Innovator Award.

leading to impaired kidney function or failure.

Lupus nephritis is just one of the many manifestations of the disease that Dr. Mackay hopes to address. She and her collaborators have found, for example, that certain high-fiber diets protect mice both from lupus and from Type 1 diabetes. Both are diseases in which the immune system attacks itself. But with the right diet, she has found that the levels of circulating autoantibodies can be vastly reduced.

"Based on this knowledge," Dr. Mackay says, "we aim to explore the effects of various diets on lupus, including the High Amylose Maize Starch diets that have been effective in our team

Continued on Page 2

### IN THIS ISSUE

A 1-2 Punch Approach	
To Treating Lupus	1-2
Faces of Lupus	3
Lupus News Corner	4



#### **BEING SMART ABOUT RESEARCH**

When it comes to solving the mysteries of lupus, we must explore all potential avenues of discovery-including the brain.

This is why the LRA is funding important research and a clinical trial to address neuropsychiatric lupus-the wide range of symptons involving the brain that can vary from "brain fog" to stroke to psychosis.

We're also working with the Harvard Brain Tissue Resource Center on an initiative that will help recover donated brains from deceased individuals with lupus.

The decision to register to donate an organ for research is not an easy one-but making such a commitment is a priceless gift and legacy that will most definitely advance lupus research and lead to the way in finding new treatments for others for generations to come.

If propelling lupus research in this way is something you would consider, please go to www.lupusresearch.org/ **brainbank** for a full brochure on this important subject.

Or, you can call the LRA at 646-884-6084 and leave us a message and we will get back to you.

#### Continued from Page 1

## A 1-2 Punch Approach **To Treating Lupus**

member, Professor Charles Mackay's study of Type 1 diabetes."

As promising as this dietary approach may be, Dr. Mackay cautions that treatment by diets alone may not be enough. Undertaking a second line of inquiry, she is testing an approach that involves first depleting key pathogenic immune cells. This is followed with diets that are bacterial metabolite interventions.

If Dr. Mackay's one-two approach is on the right track, she may have found a way to correct autoimmunity and restore normal immunological tolerance in lupus patients.

Moving forward, Dr. Mackay will investigate whether high-fiber diets actually create positive changes in the metabolites-and set in motion biological processes with healing properties.

"If we can successfully harness this kind of knowledge, we can develop treatment with surgical precisionrather than simply hoping that diet will work for every patient," Dr. Mackay summarized her work.

Dr. Mackay is one of the most distinguished figures in the world of lupus research-but she would be the first to say that research is only one part of the equation.

"The grant from the LRA has given us the support we need to design and carry out thorough research studies. We wouldn't have the resources to undertake this work without the LRA," says Dr. Mackay. "And I'm truly grateful because research-like mine and the other investigations that this great organization funds-must go on!"

Dr. Mackay's groundbreaking earlier work in gene function will greatly aid the new LRAfunded initiative.

This giant in the field of lupus research played a pivotal role in the development of the first new drug for lupus in over 60 years, and the first to show that the overproduction of BAFF (B-cell activating factor) is a driving factor in lupus.

#### MAKING RAPID DISCOVERIES THROUGH A **POWERFUL PARTNERSHIP**

In August of 2019, the LRA had the great fortune to form a unique new partnership with Bristol Myers Squibb (formerly Celgene Corporation) -in the creation of the LRA BMS Accelerator Awards. The aim: Fast-track bold cutting-edge research projects.

To get this initiative off the ground and running, the Celgene Corporation made an extraordinarily generous pledge of \$3 million! Today, the LRA is pleased to announce that-after a rigorous review process-nine of the world's most brilliant lupus researchers have been selected as grantees

"We await good things from these top-flight investigators as they broaden the understanding of the underlying mechanisms of disease ... address how much the disease varies from person to person ... and identify novel biomarkers," said Kenneth M. Farber, President and CEO of the LRA.

### FACES OF LUPUS **Advocating for Others with Lupus** And Raising Critical Funds for Research

Enthusiastic ... charming ... exuberant-these are qualities Lauren Maley has in spades-so much so that you might not easily grasp the extent to which lupus has impacted her young life.

Officially she has been coping with lupus for the past five years-but in reality, it has been much longer.

A false-negative lupus test resulted in years of suffering and a late start to treatment. "I went for test after test, biopsy after biopsy with nothing conclusive-as I was getting sicker and sicker," said Lauren.

At this point in Lauren's life, she was traveling a tough, lonely road-coping with all the angst of embarking on a career ... and lupus.

Despite having the disease, Lauren, with a sharp eye and blazing ambition, made a name for herself as a dealer in the competitive art world. She sold works of art valued at more than a million dollars annually.

Patrons relied on her knowledge and taste. But Lauren could not rely on her own health. "I had so many complex

### MEET THE LRA BMS ACCELERATOR AWARDS RECIPIENTS Joel Guthridge, PhD

Marta Alarcon-Riquelme, MD, PhD

Andaluza Progreso.

New Drug Targets for Lupus Through Mechanistic Modeling of Multi OMICs Data Fundacion Publica

MD, PhD Longitudinal Systemic

Biomarker Identification and Organ-specific in SLE Identified via Microbiome-Host Interactions Cornell University

Patrick Gaffney, MD Epigenome Profiling in Human SLE Oklahoma Medical **Research Foundation** 

Dissecting Molecular Heterogeneity of SLE Patient Treatment Response Oklahoma Medical **Research Foundation** Michelle J. Kahlenberg,

Ilana Brito, PhD

Heterogeneity in Lupus The Regents of the University of Michigan

Vivian Kawai, MD Virtual Transcriptome and Proteome in Lupus Pathogenesis and Heterogeinity Vanderbilt University

2



symptoms, skin rashes, memory issues, constant fatigue, and weight loss," shared Lauren.

Fortunately, Lauren is one of the lucky ones. The latest FDA-approved lupus drug (the first in 60 years) has been working for her! But instead of focusing on herself, Lauren looks for ways to help others.

She has raised an astounding \$10,000 participating in the past few LRA Walk with Us to Cure Lupus events in Los Angeles.



Lauren Maley (third from right) is an ardent supporter of the LRA-and a great fundraiser, too!

Chandra Mohan, MD, PhD Urinomics as a Guide to the Renal Immune Landscape in SLE University of Houston

Victoria Werth, MD Immunologic Mechanisms for Heterogeneity of Cutaneous Lupus Erythematosus The Trustees of the University of Pennsylvania

"I support this incredible organization because it not only funds the most groundbreaking research-it also devotes 100% of every dollar a donor gives directly to the research," said Lauren.

And knowing that progress in research depends on participation in clinical trials, Lauren has expressed interest in ioining one-once her doctor gives her the green light to become involved at this level.

Lauren is also outspoken when it comes to protecting the health of people with lupus. "What the general public doesn't realize is that people with compromised immune systems already lived in fear of infectionbefore COVID-19," shared Lauren. "So, the pandemic is an even scarier time for us."

Lauren's concern for others offers a breath of relief and a precious glimmer of hope-especially these days.

#### MAJOR PRIZE AWARDED

The LRA is delighted to announce the recipient of our 2020 Lupus Insight Prize. The prize-which

recognizes the work of an investigator who has charted new ground in lupus research-goes to Jane Salmon MD, from the Hospital for Special Surgery.



Dr. Jane Salmon

Stay tuned. A future 2020 Lupus Research Update issue will feature a full article on Dr. Salmon's extraordinary work.