

# Lupus News Corner

## Megastar Champions Lupus Research

**Selena Gomez** once again has proven to be a great friend to the Lupus Research Alliance. This time the megastar has teamed up with PUMA to design and promote the “Phenom Lux” shoe and matching socks to benefit our organization.

“It’s been really fun to work so closely with PUMA on the design of this shoe. I’m also proud to partner with them in helping to affect lives and bring attention to a cause that is very important to me personally,” said Ms. Gomez.

The Lupus Research Alliance is extremely grateful for the continued support Ms. Gomez gives to the organization and for her star power to bring awareness about lupus. “It’s no exaggeration to say Selena has propelled lupus awareness and that’s because she has been brave enough to tell her story,” said Kenneth M. Farber, President and CEO of the Lupus Research Alliance.



Selena Gomez for PUMA “Phenom Lux”

## Supporters Dove IN to Freeze OUT Lupus



Plunge to Freeze Out Lupus

Family, friends, and colleagues of people with lupus donned bikinis and swim trunks for our **2018 Plunge to Freeze Out Lupus** on February 3. They bravely dove into the icy Atlantic to raise both awareness about lupus and funds for the Lupus Research Alliance.

Despite the frigid temperature, camaraderie, goodwill, and a shared sense of purpose kept everyone warm ... and ready for another year of advances in lupus research.

Plungers — and those who cheered them on — also felt an inner glow knowing they helped advanced lupus research with the thousands of dollars raised.

## The Power of the Purse

The stylish 9th Annual **Lupus Handbag Luncheon and Silent Auction** will take place on May 22 at the Plaza in New York City. The fashion industry will again be out in full force, donating nearly 100 handbags by top designers for the silent auction.

As in years past, friends from entertainment, fashion, society, and the lupus community will be in attendance to ensure that the luncheon will once more be a trendy, sophisticated, and highly successful fundraising event.



Because our Board of Directors funds all administrative and fundraising costs, 100% of donations received support lupus research programs.



Visit [lupusresearch.org](http://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.



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



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# LUPUS RESEARCH UPDATE



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## The Extra X Chromosome in Women Is It a Factor in Lupus?

While no one is invulnerable to lupus, it is well established that the genes associated with this autoimmune condition are much more heavily biased toward women. In a fascinating new study funded by the Lupus Research Alliance, **Laura Carrel, PhD**, wants to discover why women are at great risk.

This forward-thinking Lupus Research Alliance grantee may have latched onto an important connection for lupus research: the extra X chromosome females inherit from conception.

Working in her lab at the Pennsylvania State University College of Medicine, Dr. Carrel focuses on a basic question: *Could chromosomal differences between males and females be a crucial factor in predisposing women and girls to lupus?*



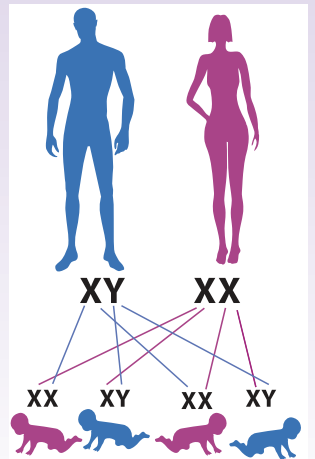
Dr. Laura Carrel

Dr. Carrel is ideally suited for the task. She has been passionate about understanding the role of the X chromosome and consequential gender discrepancies at the molecular level ever since she was a graduate student at Stanford University. A solid background in general genetics and gene regulation inform her new focus on lupus — while bringing a fresh lens and greater diversity to our conversation at the Lupus Research Alliance.

In her investigation, Dr. Carrel is looking at chromosomal activity for clues. “Females have two genetically identical X chromosomes, and one shuts off early on in development. However, it turns out that 10-20% of genes escape silencing and are expressed in both X’s,” Dr. Carrel explained. She hypothesizes that this level of gene activity on the inactive chromosome might be a factor in lupus.

To test her theory, Dr. Carrel is studying the immune cells of women with and without lupus to determine if X chromosome genes are more active in lupus patients. “We all recognize that females have a high prevalence of the disease compared to men. My team and I are hoping to identify these genes so we can discover why they are being overexpressed in female patients with lupus,” said Dr. Carrel.

While men carry both an X and a Y chromosome, women carry two X chromosomes. Although it has been known that most genes on one copy of the X are silenced, research now shows that the largely inactive copy may be doing more behind the scenes than previously understood. Dr. Laura Carrel is investigating whether these molecules are a factor in lupus.



If she proves that a specific gene is aberrant, Dr. Carrel’s next questions become: *Is it true in all immune cells in all individuals, or is this very specific to lupus patients? And if it is specific to lupus patients: Are there DNA signatures that are underlying particular genes?*

Dr. Carrel is eager to investigate further. “I want to know if there is something we can predict that is making this gene irregular. If so, could this be an area to target?”

The Lupus Research Alliance advances the work of experts like Dr. Carrel, providing them with the means to accurately and thoroughly conduct their studies. “If you come up with an idea that may be considered too ‘risky’ or ‘preliminary,’ backing can be difficult to find,” said Dr. Carrel. “But the Lupus Research Alliance is open to funding all research that is valid and relevant, even for investigators like me who are bringing a different perspective to lupus research.”

## IN THIS ISSUE

The Extra X Chromosome in Women Is it a Factor in Lupus.....	p.1
Advancing Research Exponentially An Update on AMP.....	p.2
Good Food ... Good Wine A Great Chance to Fight Lupus.....	p.3
Lupus News Corner.....	p.4

## Accelerating Medicines Partnership

Lupus research has taken a giant step forward with the formation of the **Accelerating Medicines Partnership (AMP)**.

This public/private partnership between the National Institutes of Health, the U.S. Food and Drug Administration, 12 biopharmaceutical and life science companies, and 13 non-profit organizations — including the Lupus Research Alliance — aims to speed the process of discovery.

Here are a few goals of AMP:

- Accelerate the identification of new biological targets to ensure a more stable foundation with lower expectancy of failures in late-stage clinical trials.
- Improve clinical trials through better understanding and identification of targets and biomarkers.
- Gain insight into specific biological pathways, leading to more rational drug design and tailored therapies.

*“The Lupus Research Alliance has long known that collaboration works,”* said Kenneth M. Farber, the organization’s president and CEO. *“Today, we understand more than ever that, to bring us closer to a cure and better treatments for lupus, there needs to be a true alliance across the whole research community.”*

This collegial initiative is already making gains (see Dr. Jill Buyon’s update to the right) — hastening the process of discovery at the molecular level and further investing in research to vastly improve treatment options for lupus patients.

## Advancing Research Exponentially An Update on AMP

by Jill Buyon, MD

Lupus nephritis (LN), one of the dreaded complications of lupus, causes patients to suffer, sometimes for decades, with no new treatment in sight. But now is the time to leverage technology for major advances, which is exactly what the **Accelerating Medicines Partnership (AMP)** is doing.

AMP covers a lot of ground. In terms of lupus research, it seeks to find new targets that are treatable in LN ... that will change the course of LN ... and perhaps even give us clues about preventing the disease. We hope that it may indicate which patients might do best on which therapies — so that, if successful, we can harness the idea of personalized therapy.

In Phase 0, for the first time, we mastered the art of dissociating cells from a human kidney diseased by lupus. It became clear that we could take very tiny pieces of kidney and analyze what the cells are telling us. Equally important, we found that tissue could be cryopreserved in a way that allowed us to procure such tissue from across the nation.

We have also learned more about what tubular cells are expressing when they have been exposed to certain cytokines, such as Interferon Alpha. Cytokines play an important role in disease pathogenesis.

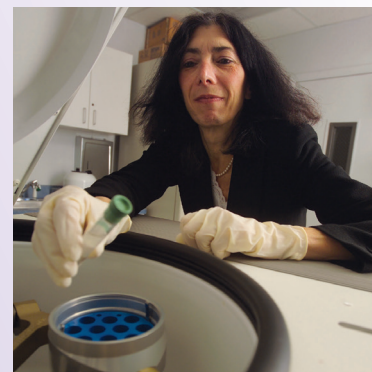
Antibodies to that particular cytokine are actually in a clinical trial, so it will be exciting to see if that therapy makes sense. And we have gained a new perspective on different inflammatory cells in the kidney: B cells, T cells, and macrophages.

In Phase 1, we collected over 100 LN biopsies, 72 of which met our inclusion criteria. We now plan to collect renal biopsies from 200 patients with LN. So far we are at about 88% of target enrollment, which is remarkable. Interestingly enough, we can’t enroll patients as fast as the technology is developing. We’re very strongly positioned to embrace technology as it comes along.

When we started the study, we were only able to look at 96 cells per kidney. Then in the next phase, we could see 300-400 cells in the kidney. And now, we’re into the thousands of cells per kidney with the new technologies.

I am so thrilled to be part of this incredible network because many of the most brilliant minds in the field are collaborating as a network with the single aim of finding breakthroughs in lupus research.

**Dr. Jill Buyon** is a widely acclaimed physician in New York City who has devoted her career to helping women with lupus — primarily those who are pregnant or are contemplating pregnancy. She has received major awards from the American College of Rheumatology and the LFA for her extraordinary contributions to medicine.



Dr. Jill Buyon

## Good Food ... Good Wine A Great Chance to Fight Lupus

The inaugural **Pour for a Cure: Taste Wine, Fight Lupus** event took place on September 9, 2017 in Santa Rosa, right in the heart of wine country — California’s breathtaking Sonoma County.

It was a day of pairings. Good food and wine ... two wonderful supporting families — the Seto Family and Helene and Larry Edelman, who ensured the event’s success ... and two organizations collaborating to fight lupus — the Lupus Foundation of Northern California and the Lupus Research Alliance.



The host families are passionate about supporting these organizations because each has in some way been touched personally by lupus.

The Edelmanns welcomed some 200 supporters for lunch and an afternoon of cocktails, wine and beer

tasting at their ranch on a hill in Santa Rosa. In addition to the tasty pours from wineries that included the Boisset Collection, Far Niente Winery, and Holy Craft Brewing Co., guests also had the opportunity to take in stunning views of the city and surrounding vineyards that stretched out for miles.

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The Seto Family and Helene and Larry Edelman are passionate about supporting lupus research because their lives have been personally touched by lupus.

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*“The perfect weather ... food ... wine ... and setting were only surpassed by the graciousness of the families who orchestrated this fantastic event,”* said Erica Mangham, Western Region Development Manager for the Lupus Research Alliance.

The entire day had a festive air but guests were there for a serious reason — to put an end to lupus.

Everyone who attended Pour for a Cure walked away with the sense that the Lupus Research Alliance and the Lupus Foundation of Northern California were beautifully collaborating together — and that they also were part of the answer. This afternoon event raised more than \$100,000!

With the success of last year’s event, all signs point to another Pour for a Cure happening in 2018. Stay tuned!



## Promising Studies Funded

The Lupus Research Alliance will fund nine new **Novel Research Grants** that explore lupus from many angles — testing new theories about what causes lupus and why it has such a widespread effect in the body. We congratulate each of the following awardees and wish them continued success.

**Andre Ballesteros-Tato, PhD,**  
University of Alabama at Birmingham  
*Knocking out Destructive T Cells While Preserving Protectors*

**Betsy Jo Barnes, PhD,**  
The Feinstein Institute for Medical Research  
*Turning Down an Autoimmune Inheritance*

**Jason S. Knight, MD, PhD,**  
University of Michigan  
*Tracing the Path to Organ Damage*

**Frances Lund, PhD,**  
University of Alabama at Birmingham  
*Zeroing in on Rogue B Cells*

**Keisa Williams Mathis, PhD,**  
University of North Texas Health Science Center at Fort Worth  
*Nicotine Substitute May Reduce Brain Inflammation*

**Laurence Morel, PhD,**  
University of Florida  
*Depriving Immune Cells of Sugar Saps Energy for Attack*

**Alessandra B. Pernis, MD,**  
The Hospital for Special Surgery  
*Flipping the Off Switch*

**Ziaur Rahman, MD, PhD,**  
Pennsylvania State University College of Medicine  
*Retooling Antibody Factories*

**Amr Sawalha, MD,**  
University of Michigan  
*Taking Down the DNA Ornaments*

The Lupus Research Alliance Novel Research Grant program provides three-year, \$300,000 grants to investigators proposing exceptionally creative, high-risk, high-reward research on lupus and its complications.