

Lupus Update
ADVANCEMENTS IN LUPUS TREATMENTS, VACCINES, ADVOCACY AND MORE.

Foundation News
EVERYTHING WENT VITRUAL IN 2020. MEDICAL ADVISORY COUNCIL + MORE.

The latest lupus news, and about what's been happening at the Lupus Foundation of Northern California.

2020

2020-21

winter newsletter

www.lfnc.org

Lupus Updates

Breaking News About Lupus Treatments

It's been a busy and crazy year for all of us, but we're closing another year of progress towards finding a cure for lupus.

On December 18, 2020 "GSK announced positive headline results for a two-year clinical trial of Benlysta® (belimumab) for treating lupus-related kidney disease. The phase 3 study met all of its designated endpoints while demonstrating a favorable safety profile. The U.S. Food and Drug Administration (FDA) has already approved Benlysta for use in treating mild to moderate lupus. This new trial specifically examined its effectiveness for treating lupus-related kidney disease. The company news release ([link at end of newsletter](#)) has more information about the study results."

It was just over 10 yrs ago when the Lupus Foundation of Northern California travelled to Washington DC with GSK and the Lupus Research Alliance (LRA) to help them recruit numerous patients for their Benlysta trials. In 2011, Benlysta was approved for SLE and just this December, it has been approved for lupus nephritis. It took us 60 yrs to get the first lupus

drug approved with Benlysta, but just 9 yrs for it to be expanded and approved for more lupus patients. We're confident that the additional therapies in the pipeline will continue to accelerate and be available to help all lupus warriors live stronger, better lives, with the ultimate goal of finding a cure. We couldn't make this happen without support of our entire lupus community. **Advocacy Wins!**

"Every year we continue to make progress building the bridge between life with lupus today to life without lupus tomorrow. We will find a cure."

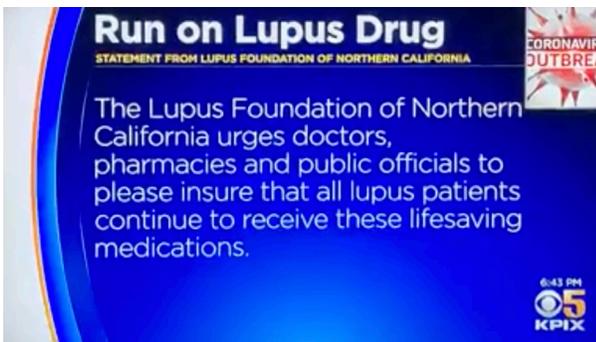
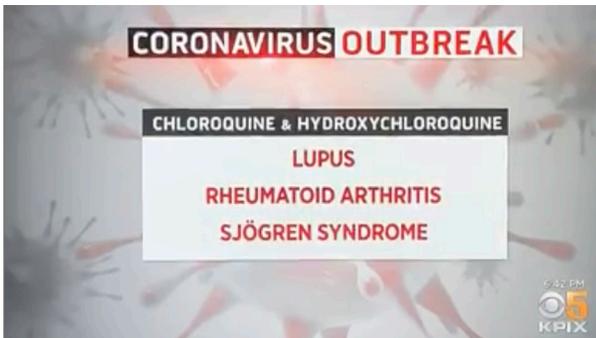
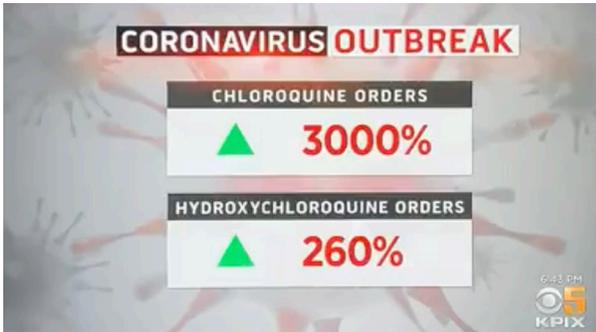
*–Jay Remley, Vice Chair,
LFNC Board of Directors*

Funding for Lupus Research

As part of the Lupus Research Alliance National Coalition, representatives from the Lupus Foundation of Northern California visit Washington, DC, every March to join our partners from across the country to advocate for research funding from Congress. As just one example of what is possible when a community comes together for common cause, just this December 28, 2020, "Both sides of Congress—the House and the Senate—



LUPUS FOUNDATION OF NORTHERN CALIFORNIA



voted to provide \$10 million for the Lupus Research Program at the U.S. Department of Defense—exactly what LRA advocates requested at our virtual Hill day in March. The same federal spending bill also provides a significant boost to the National Institutes of Health, bringing that total budget to \$42.9 billion for biomedical research which is an increase of \$1.25B over last year’s budget. In addition, the U.S. Food and Drug Administration will receive a total of \$3.2 billion in discretionary funding, which is \$43m above last year’s enacted level.” (Lupus Research Alliance, Website - link at end)

Access to Critical Medications

Earlier this year, when an early use authorization (EUA) was issued for the use of hydroxychloroquine (brand: Plaquenil) as a possible treatment for COVID-19, there nearly immediately became a supply shortage that adversely affected lupus patients who rely on this medication. The Lupus Foundation of Northern California took fast action to help protect access to hydroxychloroquine—a treatment which has long been used in the treatment of autoimmune diseases including in patients with SLE—when patients were facing difficulties in fulfilling prescriptions.

What we did:

The Foundation joined forces with other rheumatology organizations to collaboratively sign a letter by the American College of Rheumatology (ACR) inviting Rheumatology Patient and Provider organizations to support asking Governors to provide an adequate supply of hydroxychloroquine and chloroquine for people with lupus and RA.

The LFNC contacted local news and media outlets and were able to produce a public service announcement with the help of local news channels and the LFNC 2020 Face of Lupus, Julie Viscuso, who

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graciously offered her statement and story about how important this medication is for lupus patients.

We partnered with our network of physicians, and researched online resources for locating strategies for retaining or getting access to hydroxychloroquine and shared resources that could help patients retain access, including phone numbers of pharmacies that had stock available.

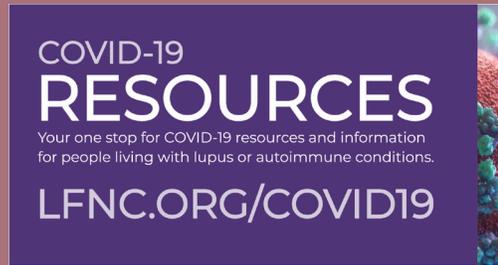
As a result of these actions, lupus patients were able to continue receiving their medications despite the shortages and leverage strategies by which to locate the medication should their pharmacist state there wasn't availability. It has since been declared that hydroxychloroquine for COVID-19 is not approved and the EUA was revoked. The LFNC continues to monitor the situation and guide patients to ensure they have access to this essential treatment.

Learn more about hydroxychloroquine and lupus via the resources / links at the end of the newsletter.

COVID-19 Resources + COVID-19 Vaccine and Lupus

We have been working to gather essential and reliable resources about lupus and COVID-19, which can be found at www.lfnc.org/covid19 and we have also been hearing from the experts about how lupus and COVID-19 interact and how the virus affects those with lupus.

The Lupus Foundation of Northern California has been monitoring the situation and sharing communications about the pandemic and the



Coronavirus COVID-19 Information for those with Lupus.

The Lupus Foundation of Northern California takes seriously the threat the Coronavirus presents to individuals living with lupus and autoimmune conditions. During this global outbreak of the novel coronavirus COVID-19 we wish to provide our community with reliable information from qualified sources.

The information provided via the COVID-19 Resources page on our website, lfnc.org/covid19, may be helpful for you or loved ones who are at heightened risk. In addition to content we have created through partnerships and consultations with medical professionals and other officials, we provide links to basic virus information and updated situation summaries, and recommendations, from the CDC, County of Santa Clara (for residents living locally), and other credible sources. We also provide useful links to important information specific to lupus patients, from sources such as the Lupus Research Alliance, and the American College of Rheumatology. We will update information on this page often, please refer back frequently.

Please read this information carefully and contact your physician if you show signs of being ill.

– Lupus Foundation of Northern California

effects to lupus patients via email and our social media channels, and earlier this year the foundation became an official supporter of the COVID-19 Global Rheumatology Alliance, whose mission is to “collect, analyze and disseminate information about COVID-19 and rheumatology to patients, physicians and other relevant groups to improve the care of patients with rheumatic disease.”

There is still a lot unknown about COVID-19 and the vaccines that are being studied and developed to prevent COVID-19. Currently there are two vaccines made by different companies that have been approved in the U.S. The Lupus Foundation of Northern California is closely monitoring the FDA’s approval process and latest research so that we can keep you informed. Go to the resources page or to www.facebook.com/LupusOnline/videos to hear the latest insights from physicians.



Foundation News

As we continue dealing with COVID-19 we want to let all of you know that we continue to be available for essential and expanded support, and to offer our assistance during these extraordinary challenging times. We know the current state of affairs won't change in the near term, so we encourage everyone to check on a friend and to reach out if you're feeling isolated or having a down day.

Programs & Resources Available Now

The Lupus Foundation of Northern California continues to offer programs and new resources for lupus patients, including Lupus Support Groups, the Lupus Buddy Program, #Lupus101, and Physician & Specialist Referral

LUPUS SUPPORT GROUPS

Lupus Support Groups are still meeting in all regions, virtually, and offer safe spaces to talk with peers. Locate your group via our Support Group Listing.

LUPUS BUDDY PROGRAM

If you or someone you know has lupus and wants to talk to a fellow lupus patient, individually, please look at our nationwide Lupus Buddy Program.

EXPANDED LUPUS 101 VIDEO LIBRARY

Visit the lupus 101 video library and subscribe to our YouTube channel to see the latest in this educational video series, where we bring experts from cross-functional disciplines and specialties to discuss lupus topics and answer your questions about lupus—in English and Spanish!

PHYSICIAN REFERRALS

Locate rheumatologists and other physicians who specialize in lupus near you or contact us directly at 408-954-8600 if you need help locating a specialist or medical professional to learn about referrals.

LIVING WELL WITH LUPUS PROGRAM

This wellness program is about helping people living with lupus get access to or learn new or different ways to find positivity and some relief for the physical stresses and emotional strain that comes with a diagnosis of lupus.

Pandemic Changed Everything

During the past 10 months, amid the global COVID-19 pandemic, the foundation has worked tirelessly to convert all programs and services to virtually run events and activities, and continues to identify opportunities to assist those with lupus and autoimmune conditions in new and unique ways, including:

- Phone access to our outreach team
- Offering wellness events online, which will pick up with additional events in 2021
- Expanded library of lupus educational videos in the Lupus 101 Library; in English and Spanish.
- Broader communications through social media and email
- Adding access to direct primary care via new referrals for physicians providing telemedicine and online advice
- Virtual office hours and virtual chats live, with skilled physicians
- Virtual support group meetings and ramping two new support groups to reach new patient groups: Youth Lupus Support Group and a Spanish Speakers Lupus Support Group
- New partnerships and collaborations with Lupus Foundations in the Western United States, to allow for us to adapt to the new pandemic situation and expand our support to many more patients in California, Oregon, Colorado and beyond.

Lupus Medical Advisory Council

Since our Foundation's founding, 43 years ago, lupus patients have requested medical guidance and critical support for the evolving landscape of lupus research, breakthroughs, and the ever changing challenges confronting lupus patients. To address these needs, Lupus Foundation of Northern California Board members Dr. Tzielan Lee, M.D. and Kirsten Gee Maeda are spearheading the creation of our Foundation's multidisciplinary Medical Advisory Council (MAC) in 2021 that will be a leading body of experts on lupus clinical care with a purpose to:

- Identify current state-of-the art lupus research for dissemination to lupus patients family members, and caregivers who make up the lupus community
- Interpret research findings and translate data into useful information and programs
- Increase knowledge of lupus diagnosis, intervention, and care management among healthcare providers
- Increase the knowledge of lupus treatments and care management among affected families and the public
- Translate the results of new research for use in education and building awareness.
- Identify gaps and barriers in lupus research, diagnosis, and treatment

These are some of the important objectives of the newly formed lupus MAC.

Board of Directors Updates

This year, long standing and esteemed Lupus Buddy Program facilitator, Sobia Saleem, officially joined the LFNC Board of Directors. Sobia, who launched our first-in-the nation Lupus Buddy

"The Lupus Foundation of Northern California was home for me as a newly diagnosed lupus patient. Over the years, I have watched the foundation grow their programs and touch the lives of so many patients and their families. The LFNC has transformed the experiences of lupus warriors here at home in Northern California as well as across the country. I am so proud to serve on its Board and help support the Foundation's mission." –Sobia Saleem

Program in 2015, brings experience in advocating for lupus research to members of Congress, has spoken at patient focused drug development events with the FDA, and is a longtime national

patient champion for lupus breakthroughs. The Lupus Foundation of Northern California is proud to welcome Sobia to the Board of Directors.

COVID-19 Impact to Fundraising

The COVID-19 pandemic has significantly affected the ability of the Lupus Foundation of Northern California to operate as normal, and the Foundation's two major fundraisers for 2020 were seriously impacted or canceled, even after venue deposits had been made. The team swiftly pivoted and adjusted to craft smaller, online fundraisers, including our annual Outrun Lupus 5K Run/Walk, which had over 100 participants as a virtual-only event. This event, while tremendously important and successful as a brand new event, raised approximately 20% of what is normally raised with upwards of 400-800 attendees annually. **Thank you to all participants, sponsors and donors!** The team also produced two online auctions for lupus, one silent auction in March, and the other a live virtual event in December which included entertainment, patient stories, collaboration between the Lupus Foundation of Northern California and the Lupus Foundation of Southern California and a festive time with host Cierra Johnson from NBC Bay Area. **We thank all of the gracious donors, sponsors, and participants!** These events combined to raise approximately one third of what is typical of the Foundation's annual charity gala event which had to be canceled completely this year. The event—including our annual Purple Ribbon Awards—is still on the horizon, likely as a virtual event, for 2021.

The support and generosity of the lupus community during this year has been tremendous and we are grateful for the continued encouragement and financial contributions that have been given this year, despite the challenges everyone—including donors—have faced. These charitable contributions truly allow programs and services to operate and patients to receive support, and for advocacy and research collaborations to persist until times are back to a more normal state.



Double your gift at:
www.lfnc.org/donate



Enter to win at
www.lfnc.org/drawing

An anonymous donor has graciously pledged to match all donations dollar-for-dollar until the total matched reaches \$20,000! Donate before February 12, 2021 to double the impact of your gift.

"...and you know, be grateful for those small things, and don't give up."

–Ena Williams,
Living With Lupus



Watch Ena's Story:



"...left the class feeling empowered and a lot less scared, equipped with the information and resources to not only understand how lupus was treated, but how to live with lupus and still have a full life."

–Hannah de Groot,
Living With Lupus



Watch Hannah's Story:



Sources and Links:

Lupus Research Alliance, "Lupus Advocacy Delivers Again!"
<https://www.lupusresearch.org/lupus-advocacy-delivers-again/>
Lupus Research Program:
<https://cdmrp.army.mil/lrp/default>
Hydroxychloroquine and lupus:
www.lupus.org/resources/drug-spotlight-on-hydroxychloroquine

The COVID-19 Global Rheumatology Alliance
<https://rheum-covid.org>
Ena William's Lupus Story
<https://youtu.be/ycBI-enzNds>
Hannah de Groot's Lupus Story
<https://youtu.be/pqvbPoOf7ds>
Cultivate Gratitude, Bid in Peace Auction Replay
<http://www.lfnc.org/lupus-auction>

Looking forward...



...to 2021



THANK YOU

We help more patients because of you.

