



# iLOOMination

*A newsletter from Looms For Lupus*

## Looms For Lupus

Welcome to the iLOOMination Newsletter, dedicated to bringing you updates on support, education, advocacy and resources on Lupus, Fibromyalgia, Mental Health, Health Equity and more!

*March, 2024*

## Advocacy



### Advocacy Updates

Looms For Lupus is working hard to advocate for federal and state laws and some of our priorities for 2024 are Utilization Management, Copay Accumulators, PBM transparency, Research Advocacy, Health Equity.

As an active steering committee member of the All Copays Count in California Coalition, we applaud introduction of Legislation to Protect Patient Assistance in California. ***Assembly [Bill 2180](#) Would Ensure California Health Plans and Pharmacy Benefit Managers (PBMs) Count Copay Assistance Towards Patient Cost-Sharing Requirements.*** (Copay accumulator policies can hurt patients and their families. If you or someone you know want to share your story, please email us at [info@looms4lupus.org](mailto:info@looms4lupus.org).)

Looms for Lupus is supportive of HR 5074, the **Kidney Patient Act**. According to the

National Institutes of Health, as many as 5 out of 10 adults who have lupus will have kidney disease and 8 of 10 children with lupus. HR 5074 just passed out of the Ways and Means Committee with a vote of 41 - 1.

## Support



### Support Groups

Support groups are a great way to connect, learn and support one another. Join us March 9, 2024 at 9:30am PST. -11:00am PST Virtually or In person: Baldwin Park Community Center 4100 Baldwin Park Blvd., Baldwin Park, CA 91706 [Register here](#)

### Grupos de Apoyo

Los grupos de apoyo son una excelente manera de conectarse, aprender y apoyarse mutuamente. Únase a nosotros el Domingo 10 de Marzo a las 9:00am PST via Zoom. [Regístrese aquí](#)

### Platica con Las Hmnas Mata

Únete a la Platica con Las Hermanas Mata cada Segundo Sabado de el Mes a las 8:00am PST en vivo vía nuestra pagina de Facebook, YouTube y Twitter. Platica, Apoyo y Concientización sobre Lupus, Fibromialgia, Salud Mental y Familia en Español.

## Special Announcements:



### The Alondra Barragan Scholarship Fund

**Applications are open:** The Alondra Barragan Scholarship Fund is a wonderful initiative by Looms for Lupus to support students with lupus who are pursuing their academic goals. This scholarship fund has been created in honor of Alondra Barragan, a beautiful, intelligent, loving, and caring young lady who had a love and passion for education. Despite her illness, she never let it stop her from pursuing her dreams.

The scholarship fund will be awarded to one or more students every year, and recipients will receive a minimum award of \$500 made payable to the educational institution at which they are enrolled. **Deadline 4/15/2024**



**Lupus Paid Opportunities:** Share your opinion on instructions for a lupus medication where the goal is to make sure that the instructions are easy for any lupus patient to understand & follow.

Are you ready to use your lupus experiences and insights to help the entire lupus community? Are you in Houston, Phoenix, or LA this spring? Then sign-up for more info now! The Opportunity The Insighters® is currently working with a healthcare company that makes FDA-approved lupus treatments on an important (and paid!) patient initiative in key cities across the US. **You will be paid \$200 (plus a guaranteed \$50 travel stipend)** where you will get to share your opinions on instructions for a lupus medication. **The goal is to make sure that these instructions are easy for any lupus patient to understand & follow.** These interviews will be informational only—you will not be asked to actually try or buy any medication. **Apply now - Your voice is important!**  
[Apply Now](#)



**Use your voice:** Looms For Lupus is working with The Light Collective, a patient-led non-profit, to explore how patient communities use health technologies to manage health challenges. We invite members of our community who are 18 years or older and consider themselves to be a patient (person with health challenges), a caregiver, and/or an advocate of a person with health challenges (past or present) to participate in a 10-15 minute survey on these issues. This study is being carried out in collaboration with Dr. Maya Rockey Moore Cummings at Johns Hopkins University with the support of the Robert Wood Johnson Foundation. If you have questions about the study, please contact Co-Investigator Jill Holdren ([jill@lightcollective.org](mailto:jill@lightcollective.org)). If you are interested in participating, please click on the survey link and carefully read the consent page before clicking "Continue" to begin the survey.  
[Survey](#)

## Health Awareness

### March is Autoimmune Awareness Month

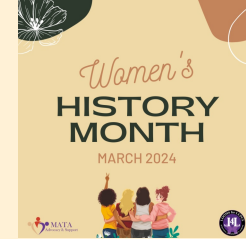
March is Autoimmune Disease Awareness month. Did you know that Lupus, Rheumatoid Arthritis, Sjögren's are all autoimmune diseases? Click here [To learn more](#) about Autoimmune Diseases, awareness, advocacy..



March is Women's History Month

March is Women's History Month, a time to recognize and celebrate the incredible achievements of women who have shaped our world. From trailblazers who fought for equality to visionaries who shattered glass ceilings, their impact is immeasurable.

[Learn more](#)



### March is National Kidney Month

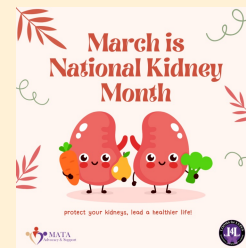
Let's talk kidneys! Our kidneys filter waste, regulate blood pressure, and keep us balanced. Stay hydrated, eat well, and exercise! Did you know that lupus nephritis is a kidney issue linked to lupus?

Symptoms include blood in urine, swelling, and high blood pressure.

Spread awareness and take care of those amazing kidneys!

#KidneyHealth #Lupusnephritis

[Learn more](#)



## February, 2024 Event Highlights

### City of Baldwin Park Black History Celebration

We had a wonderful time at the Black History Month Community Celebration on February 17, 2024. We provided resources and information about lupus, which disproportionately affects BIPOC communities. We also learned from the other exhibitors and speakers, who showcased the rich and diverse history and culture of the Black Community.



### Community Empowerment Symposium-Lupus Care & Navigating Health Coverage

We hosted the Community Empowerment Symposium: Lupus Care & Navigating Health Coverage on Feb. 24, 2024. Honored to have Dr. Samy Metyas from Covina Arthritis Clinic, Celia Valdez, Maternal and Child Health Access and Healthcare Advocates Juana and Estela Mata. We learned, provided resources, shared healthy and sweet treats and refreshments.



Special thanks to City Councilmember Alejandra Avila, Aurinia Pharmaceuticals, Daniel G. Garza and Leila Valette, Aiarthritis.

### Sen. Bradford live discussion about lupus and the kidneys!

We were proud to partner with **Aurinia Pharmaceuticals Inc** in advocating to address the unmet needs of people living with **#LupusNephritis**, which has a higher prevalence among specific racial/ethnic groups.

This FREE event took place on Thursday February 22, 2024 at the Charles R. Drew University of Medicine and Science Keck Lecture Hall.

Speakers included **Senator Steven Bradford**, **Dr. Sheetal**



**Desai MD**, Board Certified Rheumatologist and **Juana Mata** a person living with lupus moderated by Tiffany Marie.



### California Life Sciences' 11th annual Life Sciences Academy

On February 27th, 2024, our president and healthcare advocate Estela Mata was part of the panel discussion on how life sciences innovation drives patient access and health equity along with Dee Stahly, Dexcom, Jennifer Zims moderated by Assemblymember Mia Bonta. In attendance were, legislators including Assemblywoman Blanca Rubio from our district #48, industry leaders and special guest Lieutenant Governor Eleni Kounalakis all working together and discussing topics such as mental health, women's health, health equity and so much more!!!

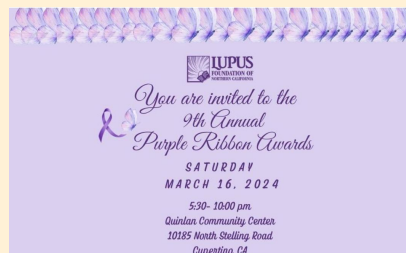


## Upcoming Events \ Eventos

March 16,  
2024

### 9th Annual Lupus Foundation of Northern CA Ribbon Awards

We are excited to announce that **Juana Mata** will be one of the speakers at 9th Annual Lupus Foundation of Northern California Purple Ribbon Award on Saturday March 16, 2024. During this event they recognize the men, women, and groups that have shown outstanding commitment and contributions to the cause of lupus with the Purple Ribbon Award. [Tickets](#)



March 23,  
2024

### The Wellness Center's 10th Anniversary Celebration!!

Join us in celebrating a decade in community wellness. Stop by the **Looms For Lupus Booth** for resources on lupus, fibromyalgia, mental health and advocacy.

Date: Saturday, March 23rd

Time: 11:00 AM - 2:00 PM

Location: The Wellness Center  
1200 N. State St, Los Angeles, CA 90033



Únase a nosotros para celebrar una década de bienestar comunitario y visite el puesto de **Looms For Lupus**, tendremos muchos recursos e información para uds.

Fecha: sábado 23 de marzo

Hora: 11:00 a. m. - 2:00 p. m.

Ubicación: The Wellness Center  
1200 N. State St, Los Angeles, CA 90033

# iLOOMinating Stories



## Judy's Story

Judy Carbajal-Diaz, a lupus survivor, facing blindness and multiple ailments. Despite her diagnosis, she volunteered for 25 years at the police department, taught preschool and kindergarten. When medication caused legal blindness, she refused to give up. Her friends provide support, and she encourages others never to give up. Judy now attends The Braille Institute, learning Braille. Additionally, Judy's determination extends to karate classes, proving that resilience knows no bounds. She's not only learning to play the guitar for herself but also for her 3-year-old grandson, Luke. Judy wants him to remember his Nana playing music just for him. Her message to others is to remember, even in the darkest moments, there's always someone willing to lend a hand. Keep searching for that help—it's out there waiting for you.

We want to iLOOMinate you! Email us your story and a picture to be featured in the newsletter. [Email us](#)

Subscribe to our newsletter [Subscribe](#)



Donate



Looms For Lupus | 4230 Maine Avenue, #906, Baldwin Park, CA, CA 91706

[Unsubscribe estela.mata@looms4lupus.org](mailto:unsubscribe.estela.mata@looms4lupus.org)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by [estela.mata@looms4lupus.org](mailto:estela.mata@looms4lupus.org) powered by



Try email marketing for free today!