



iLOOMination

A newsletter from Looms For Lupus

Looms For Lupus Corner

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

February, 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.

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. Here is a portion of the press release:

Assembly Bill 2180 Would Ensure California Health Plans and Pharmacy Benefit Managers (PBMs) Count Copay Assistance Towards Patient Cost-Sharing Requirements

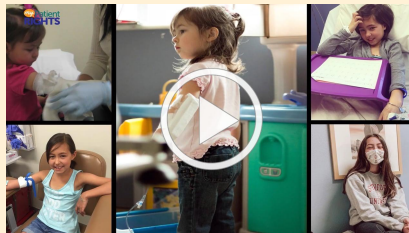
- SACRAMENTO, CA, February 2, 2024 – Today, over 80 national and California-based advocacy organizations that make up the All Copays Count in California Coalition applauded the introduction of Assembly Bill 2180, state legislation that protects chronically or terminally ill patient access to prescription medications. Introduced by Assemblymember Akilah Weber, M.D. (D-79), AB 2180 would ensure that California health insurance plans and pharmacy benefit managers (PBMs) count the value of copay assistance from patient assistance programs (PAPs) toward a patient's deductible and out-of-pocket maximum expenses, thereby banning the growing practice of copay accumulators used by health plans and PBMs to deny patient cost-sharing assistance.

Copay accumulator policies can hurt patients and their families like the Coad family. Last year we met Gerica and heard firsthand how her family was impacted. If you or someone you know want to share your story, please email us at info@looms4lupus.org.

To learn more about the Coad Family story click on the video:

Accumulator Practices Harm Patients — Coad Family Story

A My Patient Rights production sponsored by Chronic Care Policy Alliance and the CCCC



Support



Support Groups

Support groups are a great way to connect, learn and support one another. Join us Every Second Saturday of the month 9:30am PST. -11:00am PST Virtually or In person: Baldwin Park Community Center 4100 Baldwin Park Blvd., Baldwin Park, CA 91706

Grupos de Apoyo

Los grupos de apoyo son una excelente manera de conectarse, aprender y apoyarse mutuamente. Únase a nosotros cada Segundo Domingo del mes a las 9:00am PST via Zoom.

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.

Contact us-Contactanos

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.

Visit our Website for mor
info:

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 (or near) NYC, Philly, 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](#)

Health Awareness

February is American Heart Month

Did you know that heart disease is the leading cause of death in the United States . [To learn more](#)



February is Cancer Prevention Month

The American Institute for Cancer Research spearheads the National Cancer prevention month campaign emphasizing on lifestyle changes to decrease the risk of cancer.

[Learn more](#)



Upcoming Events \Eventos

February 17,
2024

Black History Month Community Cultural Celebration:

Join the City of Baldwin Park, on Saturday, February 17 at 11am, in celebrating the history and culture of Black Americans. Bring the entire family to enjoy the festivities, food, artisans, local merchants, and special performances. The event will take place at the Arts and Recreation Center, 14403-B Pacific Ave., Baldwin Park, CA 91706.

Visit the Looms For Lupus Booth for resources and giveaways!



February 22,

Sen. Bradford invites you to a live discussion about lupus and the kidneys!

We are 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.

Join us for a FREE townhall on Thursday February 22, 2024 at the Charles R. Drew University of Medicine and Science Keck Lecture Hall at 7:00PM to learn about the importance of early and routine screening & treatment options.

Speakers include **Senator Steven Bradford**, Dr. Sheetal Desai MD, Board Certified Rheumatologist and **Juana Mata** a person living with lupus. [Register Here](#)

Sen. Steven Bradford invites you to a live discussion about lupus and the kidneys!

Lupus nephritis, a silent but serious complication of lupus, can lead to permanent kidney damage and even kidney failure.

If you, a loved one or a family member has lupus or has been diagnosed with lupus nephritis, join us for this discussion about the importance of early and routine screening, treatment options, a medical expert and a person with lupus nephritis.

Thursday February 22 7:00 PM PST

Charles R. Drew University of Medicine and Science Keck Lecture Hall
1721 E. 172nd Street
Los Angeles, CA 90059

Speakers:
Sen. Steven Bradford
Deputy Sec. MD, Board Certified Rheumatologist,
University of California, Irvine
Jana, a Person Living with Lupus

Sen. Steven Bradford
Sheetal Desai, MD

To learn more or register, scan the QR code to the left, or:
[CLICK HERE TO REGISTER](#)

Program will follow the latest state and local COVID-19 protocols, such as wearing a mask when asked. Your healthcare team is your primary source of information about testing and the program will respect the privacy of medical professionals.

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February 24,
2024

Community Empowerment Symposium: Lupus Care & Navigating Health Coverage

Looms For Lupus invites you to an in-person & virtual

Community Empowerment Symposium: Lupus Care & Navigating Health Coverage.

Join us on Saturday February 24, 2024, to empower yourself with the knowledge and skills to manage your lupus care and overcome socioeconomic barriers to healthcare and learn about navigating health coverage and accessing financial assistance programs.

Light refreshments will be served. Registration is required: [Register Here](#)

Community Empowerment Symposium
Lupus Care & Navigating Health Coverage

- Empower yourself with the knowledge and skills to manage your lupus care and overcome socioeconomic barriers to healthcare.
- Learn about navigating health coverage and accessing financial assistance programs.

SATURDAY FEBRUARY 24, 2024 9:00AM-12:00PM PST
Teri G. Muse Family Service Center, 14305 Morgan St. Baldwin Park, CA 91706
(In-Person & Virtual Event)

Dr. Samy Mekyas MD, MSc, FACP, FACR
Contra Arthritis Clinic

Celia Valdez
Program Director, Rheumatism and Child Health Access

Estela & Juana Mata
Healthcare Advocates, Coordinated Lupus Mata Advocacy and Support

Aurinia

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iLOOMinating Stories

Kathryn's Story

Kathryn, once a vibrant teacher and lover of culinary adventures, faced an unexpected twist in her journey: a lupus diagnosis. Armed with knowledge, she sought urgent care, making a life-saving decision. The nurse's bluntness revealed the gravity of her situation, yet Kathryn persisted. In a support group, she discovered that lupus patients are like snowflakes—each unique. This is when she realized why her daughter's lupus journey was so different than hers. Later Kathryn also found out that her brother also battled with lupus. Kathryn coping



with fatigue and so many other symptoms, she managed her energy levels by taking life one day at a time. Her advice to others is to educate yourself, connect with fellow warriors, and focus on what you can achieve. Kathryn's mantra? "I try to focus on what I CAN do that brings me satisfaction." Her journey embodies resilience, determination, and unwavering strength even in the darkest moments.

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

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