



“Knitting a Community of Hope”  
“Tejiendo Una Comunidad de Esperanza”

# Looms for Lupus

## 9 YEARS AND COUNTING!

It is amazing to see the impact that a patient driven, patient focused small nonprofit can make. Looms for Lupus, a 501 (c) (3) non profit organization was founded by Aracely, Juana and Estela, the “Mata Sisters” over nine years ago. In 2011, Juana, the eldest of seven siblings, almost lost her life to Lupus. Living with Lupus was overwhelming and scary for Juana, her husband and two sons. As her treatments began, it became difficult for the entire family. The word “Lupus” was unknown to the family and there was little information about Lupus. Finding information in Spanish for their mom became very difficult. As Juana began treatments for Lupus, she had to undergo chemo treatments. It was during this time she found joy in loom knitting, as a way to relief stress.

The Mata family is very close knit and loom knitting became part of their family gatherings. Sunday afternoons included gathering in the living room to work together and support each other. Loom knitting and supporting each other gave them hope. It was then, the idea sparked! The Mata sisters knew there was a need for more information about Lupus, resources, awareness for minorities, especially Hispanic families, and they wanted to fill that gap. Their vision was to have a space where other families experiencing similar situations would feel supported, get resources, and learn ways to relieve stress; A place where they would share and learn from others on how to continue living with an autoimmune, chronic condition. The primary vision for Looms for Lupus was to inspire others to continue living, not giving up, and together *knit a community of hope*. It became easy to begin with this view as the slogan for this organization: “Knitting a Community of Hope”, “Tejiendo una Comunidad de Esperanza”.

Looms for Lupus primary goal is to provide an environment for education and outreach to Lupus, Fibromyalgia survivors and their family members through multiple avenues, such as hands on workshops, informational clinics, bilingual resources and psychosomatic support groups. Since 2011 Looms for Lupus, Juana and Estela “The Mata sisters”, alongside Ruth Padilla-King, LCSW facilitate the in person support group at the Kaiser Permanente Educational Outreach Program in the City of Baldwin Park. The Mata Sisters also host a Facebook Live Spanish Support group every second Saturday of the month.

Since 2009, Looms for Lupus (i.e. Team Mata, the Mata Sisters) have been actively volunteering, partnering, hosting and advocating for Lupus and overlapping conditions, such as Fibromyalgia, and mental health. Juana and Estela’s passion for helping others goes beyond the support groups. They have become national and international advocates, partnering with other organizations to raise awareness, advocate and support the lupus, fibromyalgia and mental health community. They serve as board members, patient advisory committee members for various national and local Lupus organizations. They are members of patient support networks, national research programs, and are also active with the mental health consortium led by their Congresswoman Grace F. Napolitano.

Looms for Lupus looks forward to continue working closely with the community, organization and business in growing a community of hope.

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### SPECIAL POINTS OF INTEREST

- Lupus and Fibromyalgia
- Art Therapy
- Mental Health
- Educate and Empower

### 2019 PROVED TO BE A PRODUCTIVE YEAR!

Looms for Lupus reached to the local, state and national levels.

Looms for Lupus has expanded outreach and advocacy by:

Hosting and volunteering on three patient educational symposiums.

Attending various Lupus and Rheumatology conferences.

Participated in two Lupus and Fibromyalgia Advocacy Days in DC. March focused on Lupus, while September focused on Fibromyalgia.

Facilitated 12 Bilingual In person support groups and 12 Spanish Facebook live support Groups.

Obtained 14 proclamations!

13 Lupus Proclamations in 10 cities across Los Angeles County.

1 Lupus Proclamation in Coachella Valley by the state of California by Senator Susan Rubio and World Lupus Day from Congresswoman Grace Napolitano.

1 Mental Health Proclamation from the City of Baldwin Park.

## ADVOCACY—YOUR VOICE MATTERS, LET YOUR VOICE BE HEARD

**Advocacy-** is to speak on behalf or in support of another person. There are many ways to advocate for a cause. You can meet with legislators in DC to share your story, write to your legislators from the comfort of your home, or meet with them at their local offices. Your voice matters, let your voice be heard.

**Lupus Advocacy-** In March Juana and Estela had the opportunity to join other Lupus advocates and share their story with legislators in Washington DC. In September 2019 Lupus Research Alliance, a world's largest funder of lupus research released an article highlighting the results from the Advocacy titled "Lupus Research Alliance Advocates win Big with 2019 Federal Funding". This article highlights the Department of Defense Lupus Research program \$5 Million increase and a \$2 Billion increase to the budget for the National Institutes of Health of which approximately \$106 million will go to Lupus Research. For complete article click here:

<https://www.lupusresearch.org/lupus-research-alliance-advocates-succeed-2019-federal-funding-approved-congress/>

**Fibromyalgia Advocacy-** In September 2019, Juana, Estela, and Estela's daughters Cassidy and Isabella attended the first Fibromyalgia DC Advocacy day with Melissa Talwar, International Support Fibromyalgia Network amongst other Fibromyalgia Advocates. To learn more about the 2019 visit to DC click here: <https://supportfibromyalgia.org/advocacy-fibromyalgia/>



## *"Kaiser Permanente EOP Partnership"*

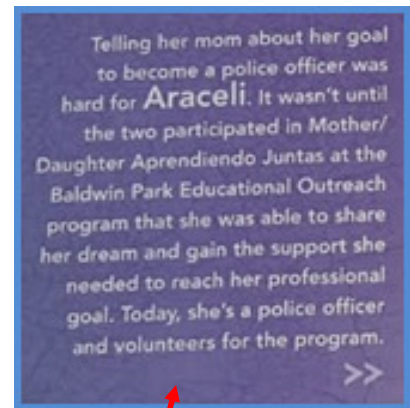
### **Kaiser Permanente Educational Outreach Program (KPEOP)**

The **Educational Outreach Program (EOP)** provides education and support services in San Gabriel Valley section of Los Angeles County. The focus of EOP is to provide programs and activities that improve school performance, promote family communication, teach skills that are needed to meet various life tasks and alleviate stress, create opportunities for the development of leadership skills for both youth and their parents so that they can address issues that have an impact on their community, and increase awareness of professional opportunities in the health field for young people.

To learn more about KPEOP go to: <https://community.kp.org/about/program/educational-outreach-program>

KPEOP has been providing services to the of the San Gabriel Community including the Mata Family for over 26 years. In 1994 Esperanza Mata and Araceli Mata participated in the Mother Daughter Aprendiendo Juntas program. This program empowered Esperanza to become Araceli's educational, emotional and number one supporter. Since then, Estela and her daughters Cassidy and Isabella joined the program and they all continue to volunteer and attend the annual conference.

KPEOP was a place that provided support to the Mata family, the relationships built were lifelong. They too wanted to be part of the KPEOP family and provide support to others. For over 9 years Looms for Lupus has been part of the KPEOP family, the "Mata Sisters and Ruth Padilla-King, LCSW facilitate the support group every second Saturday of the month.



## PATIENT \ CAREGIVER SYMPOSIUMS

Connecting with the community is key. In 2019 Looms for Lupus chose to be part of a great education symposium trilogy put together by Lupus and Allied Diseases Association, Inc. (LADA, Inc.) entitled “Enhancing Lives by Empowering the Lupus Community”. The first symposium was held in Hawaii, both Juana and Estela volunteered and interacted with Lupus Warriors, caregivers and loved ones.

The second was in San Francisco where Looms for Lupus teamed up hosting the event alongside More than Lupus and LADA, Inc. This second event was just as informative and as engaging as the first. The third stop was Colorado, The Mata Sisters volunteered, and were able to put their Spanish speaking skills to use.

Looms for Lupus is proud to have participated in these three amazing events, and did we mention they were FREE! It was great to engage with the community and work alongside other patient focused organizations like LADA, Inc., More than Lupus, Sjogren’s Lupus Foundation of Hawaii and Lupus Colorado.



*“Mental Health is as important as our physical health”*

## MENTAL HEALTH IS IMPORTANT

Mental Health is important regardless of age, gender or ethnic background. Mental health is our cognitive, behavioral and emotional well being.

Our emotions and thoughts are important, Mental Health is as important as our physical health. Living with a chronic illness such as Lupus, Fibromyalgia or other chronic illness can be life changing and affect the way you feel, in many cases you may experience depression and or anxiety. It is estimated that one third of people with chronic illness have symptoms of depression. Recognizing the symptoms and addressing them is important. Some Common Symptoms of depression may include:

- Loss of interest or pleasure in daily activities
- Weight loss or weight gain
- Lack of feeling (apathy)
- Problems with concentration
- Sleep disturbances\insomnia
- Fatigue\Loss of energy

- Irritability
- Thoughts of suicide

It is normal to feel sad, lonely and depressed at times but if your feeling become overwhelming and affecting your daily life, it is important to seek medical advice and talk to your doctor.

Getting help is important because your doctor can test you for depression and help with treatment options. Don’t be ashamed to seek help.

**Get Help in a Crisis. Help is available 24/7**

Call **911** if you or someone you know is in immediate danger or go to the nearest emergency room.

National Suicide Prevention Lifeline:

Call **1-800-273-TALK (8255)**

En Español **1-888-628-9454**.

**Crisis Text Lifeline**

Crisis Text Line- Text “HELLO” to **741741**

## WHAT IS LUPUS AND FIBROMYALGIA?

**Lupus** is an autoimmune disease that attacks the immune system. With Lupus the immune system causes inflammation and attacks itself, its healthy tissue in the body and organs such as the skin blood, heart, kidneys, brain and heart. A couple facts about Lupus: According to Lupus Foundation of America, Lupus affects approximately 1.5 million Americans. Men, Women and Children can get Lupus. 90% of people with Lupus are women, 15% are children. Lupus is not contagious. It is more prevalent in women of color, racial and ethnic minorities.

**Fibromyalgia** is a chronic disorder that causes pain throughout your body, fatigue, problems with sleep, thinking and memory. A few facts about Fibromyalgia: According to the American Chronic Pain Association Fibromyalgia affects an estimated 6 to 12 Million people in the US. The cause is unknown, it is not contagious. Individuals who have Fibromyalgia may be more sensitive to pain. Women are twice as likely to have fibromyalgia, but men and children can get it as well. Fibromyalgia is a common overlapping illness to those living with Lupus or Rheumatoid Arthritis .

## LUPUS AND FIBROMYALGIA SUPPORT



***Art Therapy during Looms for Lupus In Person Support Group***

According to Lupus Foundation of America there is an estimated 1.5 Million Americans with Lupus and 5 million worldwide. Lupus is disproportionately most common in minorities, African American, Hispanic\Latino and Asian . According to the American Chronic Pain Association Fibromyalgia affects an estimated 6 to 12 Million people in the US, 2 to 4 % of U.S. population. Like Lupus Fibromyalgia is most prevalent in women, but also children and men can have it to.

Since its inception, Looms for Lupus recognized the need for support in the Lupus and Fibromyalgia Communities. Looms for Lupus has been striving to fill the gap with both in person and virtual support groups. Looms for Lupus provides support, resources, hands on workshops, informational clinics, bilingual resources, and psychosomatic support groups. The support groups are offered every second Saturday of the month at the Kaiser Permanente Educational Outreach Program in Baldwin Park, CA 9:30am to 11:30am and Via Facebook Live in Spanish at 8:00am PST.

Each month there is a different topic of discussion, Art therapy, and hands on workshops, such as Loom Knitting, canvas painting, and journaling. Depending on the topic , guest speakers such as health nutritionist, yoga instructors, Licensed clinical therapist are invited to present. Some examples of Art therapy are Canvas painting (shown above), rock paint, vision boards, loom knitting. Loom knitting is a form of stress relieving art; Juana and her family utilized the art of loom knitting to support one another and relieve stress.. Those interested in learning how to loom knit are given all materials and taught how to loom knit, for free. In December almost all attendees learned how to loom knit and were gifted the looming kit. A gift of a skill that can be utilized to relieve stress, improve mental health, motivate, encourage and create empathy. A gift that never stops giving!

## ART THERAPY

Art Therapy is beneficial in numerous ways. It may alleviate symptoms of depression, improve communication skills, build self esteem, reduce stress , motivate and improve mental health.

The Mayo clinic has incorporated Art Therapy monthly support. To learn more about the In the Loop article published in 2018 titled “ Doctors Dance, Pain ad Create their way to Better Care, they highlight ways in which their providers get together monthly to improve mental health through art therapy click on the link <https://intheLOOP.mayoclinic.org/2018/10/11/doctors-dance-paint-and-create-their-way-to-better-care/>

## SHARE YOUR STORY

Sharing your story is so important because it can bring awareness, educate and empower others. During one of the Mental Health Consortium meetings led by Congresswoman Grace F. Napolitano Juana & Estela had the opportunity to share their stories of living with chronic conditions, the impact it can have on mental health and the different modalities and support they provide to the community through the in-person support groups and Facebook live support groups.

Teaching and learning stress relieving

techniques during the support groups is a great way to teach others skills that they can use at home. Looms for Lupus practices mindfulness, meditation and breathing techniques and incorporates Art therapy.



## YOU ARE NOT ALONE

Living with a chronic condition is not easy. *You are not alone.*, Connecting with others living with Lupus, Fibromyalgia or an overlapping illnesses can help. You can share and learn from others,.

Looms for Lupus offers both In person support groups in Baldwin Park and Spanish online support for Lupus and Fibromyalgia. For other Lupus Support groups in the LA area, or to find one close to you please visit <https://lupusla.org/patient-community/>



Looms for Lupus, Inc.  
501 (c) (3)

Looms for Lupus primary goal is to provide and environment for education and outreach to Lupus, Fibromyalgia survivors and their family members through multiple avenues, such as hands on workshops, informational clinics, bilingual resources and psychosomatic support groups.



## LOOMS FOR LUPUS UPCOMING EVENTS

January & February 2020

- 1/30/2020 - Join us at the Us In Lupus Night of Beauty-Noche de Belleza Event <https://www.usinlupus.com/>
- 2/11/2020—In-Person Bilingual Lupus & Fibromyalgia Support Group at the Kaiser Permanente Educational Outreach Program in Baldwin Park, CA
- 2/11/2020– Facebook Live Grupo de Apoyo en Espanol via la pagina de Looms4lupus
- 2/22/2020– Visit our Booth at The Lupus Project in Los Angeles -<https://www.thelupusproject.com/>
- 2/29/2020– We are Teaming up with More than Lupus to host “How Lupus Affects the African American Community” Symposium in Portland <https://www.morethanlupus.com/events>

Looking to be a volunteer? Please email [info@looms4lupus.org](mailto:info@looms4lupus.org)

**Make a difference and donate!**

Our primary goal is to continue to provide support, resources and patient programs.  
All donations are tax deductible.