Network of Women Researchers with Lupus (RILU) in Mexico and Latin America

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INTRODUCTION

Research on lupus remains limited in Latin America, and within academic spaces, **people with lupus continue to be invisible as subjects of knowledge**.
The Network of Women Researchers with Lupus (RILU) emerged to **build situated knowledge from humanistic, cultural, and feminist perspectives**, integrating the lived experience of chronic illness as a legitimate source of understanding.
RILU works under the principles of **patient participation in research (patient perspective)**, recognizing that including the voices of people living with lupus **enriches biomedical and clinical perspectives** with human and social meaning.

AIM

1. **Strengthen the Network of Women Researchers with Lupus (RILU)** in Mexico and expand its scope to other Latin American countries.
2. Promote **collaborative research** that integrates biomedical, social, cultural, and feminist approaches.
3. Encourage **patient participation in research**, incorporating lived experience as a valuable contribution to understanding and addressing lupus.
4. **Make visible the knowledge of women with lupus** within scientific production.
5. **Support and mentor new generations** of researchers, fostering continuity and collective memory.

METHOD

Open call launched by **CETLU in January 2024 (See Figure 1)**.
Regular online meetings to share findings, methodologies, and research progress.
Two cohorts or calls (See Table 1):

- **First cohort (2024):** 41 researchers from **Mexico, Argentina, and Colombia**.
- **Second cohort (2025):** 15 new researchers from Mexico and other Latin American countries.

Age range: **24 to 73 years** (average 39.5).

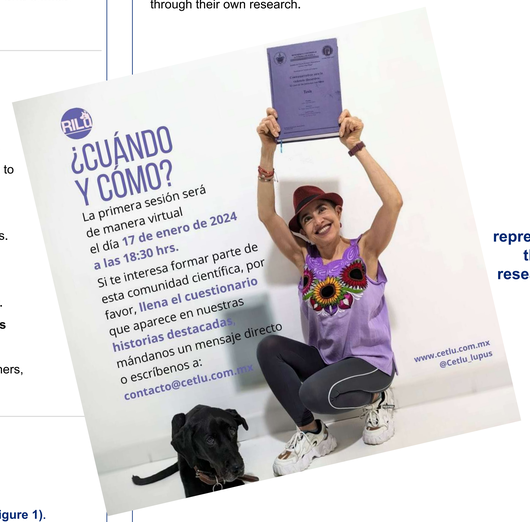
Researchers also living with other autoimmune diseases such as **Sjögren's syndrome, Raynaud's phenomenon, fibromyalgia, psoriatic arthritis, Hashimoto's thyroiditis, spondyloarthropathy, and neuromyelitis optica**, which broadens the collective understanding of autoimmunity.

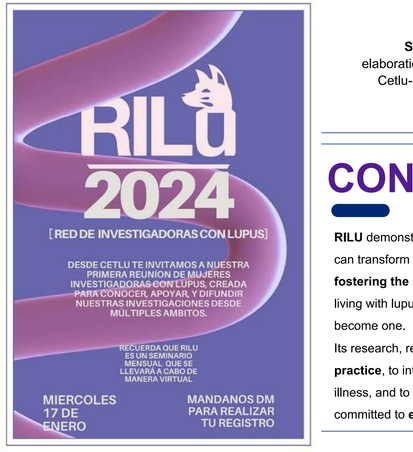
Main research areas across both cohorts (See Figure 2): Psychology (13%), Education (11%), Social Sciences and Humanities (10%), Health Sciences (10%), Medicine (8%), Communication and Culture (8%), Anthropology (6%), Law (5%), and other disciplines (29%).

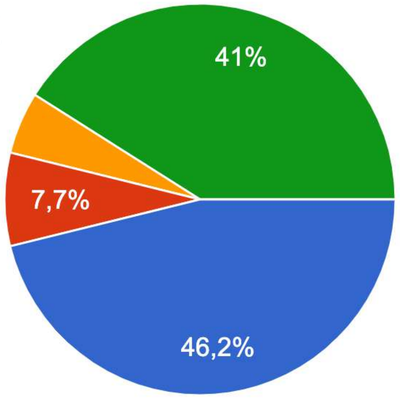
Figure 1. Launch of RILU's first cohort, inspired by the publication of the doctoral dissertation by Laura Athié, president of CETLU, as a motivational example.

One of the most common challenges for people with lupus and other autoimmune diseases is **emotional discouragement** or depression after receiving the diagnosis—particularly when adequate medical information is not provided. In such circumstances, individuals often experience an **identity fracture** (Athié, 2023).

RILU seeks, through **mutual support, community-based learning, and collective formation among women**, to transform that discouragement into a **constructive outlook**, oriented toward the future and toward **active contribution to the lupus community** through their own research.







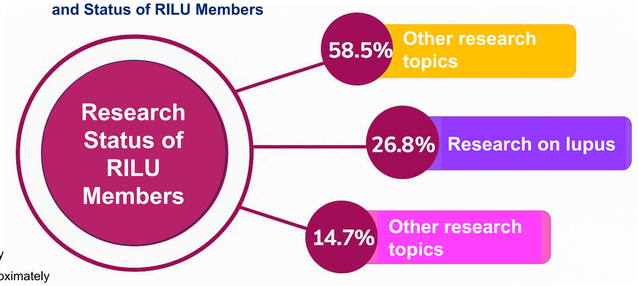
Source: Own elaboration based on Cetlu-RILU (2025)

University: 46.2%
Research center: 7.7%
Civil association: 5.1%
Other: 41%

Figure 2. Affiliations of the women who have joined RILU

As shown, **41%** are not affiliated with any university or research center, while approximately **5.1%** are members of **lupus groups or associations**.
The network therefore helps ensure that the knowledge produced also encourages **returning to university to complete unfinished degrees or pursuing new postgraduate studies**, thus strengthening the link between research and lived experience.

Figure 3. Research areas and Status of RILU Members



Source: Own elaboration based on Cetlu-RILU (2025)

Table 1. Countries represented by the women researchers of RILU

Participation by Country in RILU (2024–2025 Cohorts)

Country	Participation / Cohort	Estimated Percentage	Notes
Mexico	2024 and 2025	~80%	Country with the highest representation. Participants from various states: Puebla, Guanajuato, Morelos, Veracruz, Tlaxcala, Baja California, among others.
Argentina	2024 and 2025	~10%	Researchers from Buenos Aires and Florencio Varela; several living with lupus or Sjögren's syndrome.
Colombia	2024 and 2025	~5%	Participants from Bogotá and other cities, including doctoral students and researchers linked to the National University of Colombia.
Other countries *(Chile, Nicaragua, El Salvador, Venezuela, Peru, France)*	2025	~5%	Each represented by one participant. This group broadens the network's international scope and disciplinary diversity.

Source: Own elaboration based on Cetlu-RILU (2025)

RESULTS

Consolidation of a transdisciplinary network bringing together women with lupus, researchers, physicians, artists, and scholars from different countries.

Agency and self-representation (Ahearn, 2001): members exercise their capacity for action and authorship, producing knowledge from their own lived contexts. Some have started graduate studies or research projects inspired by others in the network, while others are participating as learners, strengthening this community of knowledge.

Three graduate theses directed (1) or and accompanied as part of the review committee (2 and 3) by **Laura Athié**, president of CETLU and researcher living with lupus:

1. ***Language of Memory in the Autobiographical Narratives of Women with Lupus: Positioning, Emotions, and Social Justice*** (Ligia Sofía Torres López, National University of Colombia).
2. ***Cognitive Alterations in People with Systemic Lupus Erythematosus and Their Association with Disease Activity*** (Donají Domínguez Zúñiga, Autonomous University of the State of Morelos).
3. ***The Hospital as a Territory of Violence: The Case of Patients with Lupus*** (Estefanía Salgado Silva, Autonomous University of Tlaxcala).

Coordination of a special Dossier by CETLU A.C. for the *Latin American Journal Culturas Contemporáneas* (University of Colima), including research on lupus, autoimmunity, embodied memory, mental health, pain, vulnerability, and narratives of illness.

Active participation in the **International Congress *Potencia Lupus*** with **posters and presentations from a patient perspective**, integrating the knowledge of researchers living with lupus and other autoimmune and rheumatic diseases into the clinical, social, and emotional understanding of the condition.

Figure 4. Estefanía Salgado Silva, RILU member, explains her research during an interview at the Second International Congress *Potencia Lupus 2025*, held in Guadalajara.

Figure 5. First rrom right to left: Donají Domínguez, RILU member, participates in a panel organized by CETLU A.C. at the First International Congress *Potencia Lupus 2024*, held in Monterrey.

CONCLUSIONS

RILU demonstrates that knowledge **production based on lived experience** can transform the scientific and medical understanding of lupus, while also **fostering the development of agency** (Ahearn, 2001) among researchers living with lupus and among women who, though not yet researchers, aspire to become one.
Its research, reflections, and proposals **seek to humanize biomedical practice**, to integrate subjectivity and emotion into the comprehension of illness, and to strengthen a collaborative, feminist, and situated science committed to **epistemic justice** (Fricker, 2010).

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To all members of RILU (2023 and 2025 cohorts) and to CETLU A.C. **for their decision to join**, for their commitment and leadership in building knowledge **with and from people living with lupus and other autoimmune and rheumatic diseases**..

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