

# Activity Report 2025

---

# Index

1. Opening – Strategic Plan
2. Board report on 2024 activities & Priorities



STRATEGIC PLAN  
2023 - 2028

# LUPUS EUROPE

**VISION** A FULFILLING LIFE FOR ALL PEOPLE WITH LUPUS IN EUROPE  
UNTIL WE HAVE REACHED A WORLD WITHOUT LUPUS

## MEMBERS

MEMBER ORGANISATIONS  
ARE ENTHUSIASTIC AND EMPOWERED

## RESEARCH

PEOPLE WITH LUPUS PARTICIPATE IN,  
AND BENEFIT FROM, LUPUS RESEARCH

SCIENTIFIC  
EVENT

ENGAGE AT EXPERT LEVEL  
IN RESEARCH TO PROMOTE  
PATIENT VIEWS

CONTRIBUTE TO  
KNOWLEDGE ON LIVING  
WITH LUPUS

PATIENT  
EXPERIENCE

IDENTIFY, (DEVELOP) AND  
ROLL OUT BCA TO IMPROVE  
ACCESS

HUMAN CAPACITY  
AND CAPABILITIES

VOLUNTEERS  
70 → 3500  
HOURS PER  
YEAR!

## HEARD & ACTIVE

LUPUS EUROPE IS HEARD AND ACTIVE

BE HEARD

CLEAR  
MESSAGING

EDUCATION

AWARENESS

ACCESS

CAMPAIGN

SOCIAL MEDIA  
STRATEGY

2X / YEAR  
WEBINAR

LUPUS-EUROPE.ORG  
LUPUS100.ORG

PARTNER WITH BEST AND  
MOST RELEVANT PLAYERS

MEDICAL  
ADVISORY BOARD

ACADEMICS & INDUSTRY

SELECT PARTNERS  
ACHIEVE GOALS

BE THE VOICE  
OF PEOPLE WITH LUPUS  
IN THE ROOM

## SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A  
SUSTAINABLE ORGANISATION

3 YEARS  
VISIBILITY  
ON FUNDING

€  
2024 2025 2026

FINANCIAL  
CAPACITY

CONTRACT

STREAMLINED  
CONTRACTING

NOURISH AND  
CEMENT THE  
COMMUNITY

FLUID BILATERAL  
COMMUNICATION

SEEK AND PURSUE  
COMMON INTERESTS  
AND ISSUES

KICK LUPUS

YOUTH!

SYNERGIES  
CAPACITY BUILDING

LUPUS FOCUS EUROPE

SUCCESSION  
PLAN & ONBOARDING



# RESEARCH

PEOPLE WITH LUPUS PARTICIPATE IN,  
AND BENEFIT FROM, LUPUS RESEARCH

i

SCIENTIFIC  
EVENT

ENGAGE AT EXPERT LEVEL  
IN RESEARCH TO PROMOTE  
PATIENT VIEWS

CONTRIBUTE TO  
KNOWLEDGE ON LIVING  
WITH LUPUS

PATIENT  
EXPERIENCE

LIVING WITH  
LUPUS  
SURVEY

ANNUAL  
QUANTITATIVE  
SURVEY

IDENTIFY, (DEVELOP) AND  
ROLL OUT BCA TO IMPROVE  
ACCESS

i

MEDICATION

LUPUS100.ORG

Access



Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
PEOPLE WITH LUPUS in Europe participate in, and benefit from, lupus research	> Engage at Expert level in scientific research to promote E2E patient views	A 35 Person's trained and energized Patient Advisory Network acting as liaison and resource to value-adding scientific projects and clinical trials, in priority with:	Focus on activation of 5 new members (including minimum 1 youth, 1 man) plus 5 activated from existing members 25 core PAN members by December 2025  Three core trainings for volunteers in 2025: First aid mental health training. HTA training (EUPATI). Continue and build on "how to tell your story". Continue range of on demand soft skills
		European Medicine Agency	Compared to other POs, Lupus Europe assessed "very good" with regards to bringing patient views to EMA  List of 10 EMA eligible/available people by December 2025 Design a plan to keep EMA eligible volunteers energised and motivated  EMA lupus requests staffed and delivered
		Industry	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views in industry projects  Accepted industry projects delivered (see PAN list)
		Academia	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views to academics/clinicians  Academia accepted requests supported (see PAN List) Continued support to 3TR Continued support to TRM-SLE project
		Research requests vetted by Medical advisory board are relayed for broad distribution	All vetted research relayed
		European Reference Networks	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views by ERN ReCONNET  Create task force for RarERN Path - 831 stories from 14 languages. Booklet available. Database created and used by December 2025.

Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
	> Contribute to knowledge on living with lupus	A Patient panel every year to advance knowledge of "Living with lupus"	Localised Patient Panels on "Every voice matters" Second pilot panel in Dusseldorf, define strategy for next steps and start implementation of localised panels in 2025  "Lupus Alert" research project to screen for vulnerabilities (i.e. low literacy) in lupus. By December 2025 screening of vulnerabilities completed
		Organisation or deployment of at least one quantitative survey each year	Minimum of three small surveys deployed to research subgroup. Put a process in place to facilitate surveys by December 2025
		Two broad-scale surveys on aspects of Living with Lupus over the five years	Swiss Knife survey publication in renowned medical paper
	> Identify, (develop) and roll out best practices to improve access to lupus care	Improved Patient-Doctor communication (-> shared decision making)	Inclusion of Patient Doctor communication in Lupus Academy (CME accredited) Launch adapted consultation cards - with doctors and through patient groups. Prepare draft abstract on three practical tools (LupusGPT, Lupus100, Consultation Cards) for use by National groups for national Congress submission
		Each year, one area of access spotlighted to identify gaps, and equip national groups to seek improvements (psychological support, lupus nurses, physiotherapist, work, medication, ...)	Improved access to medication - A toolkit that empowers National groups for impactful interactions with HTA (Background info, conversation guide, facts on lupus, ..) : Webpage on the Lupus Europe website linking to valuable resources on HTA & a webinar on HTA
		Patient abstracts in the main program of key scientific events	EULAR Congress quality attendance ELM 2026 support Min. four abstracts submitted each year with Lupus Europe support Other congress quality attendance



# MEMBERS

MEMBER ORGANISATIONS  
ARE ENTHUSIASTIC AND EMPOWERED

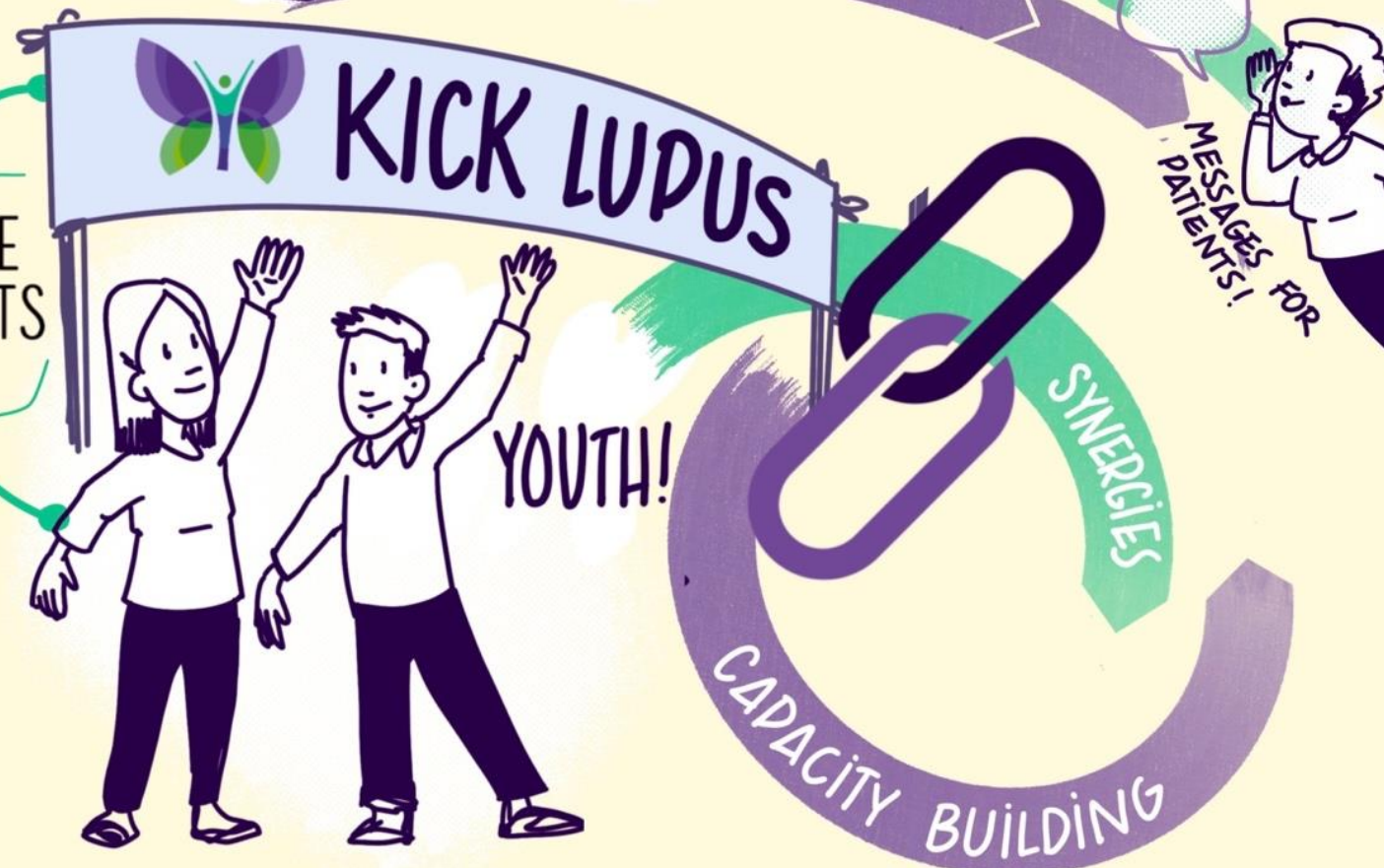
NOURISH AND  
CEMENT THE  
COMMUNITY



FLUID BILATERAL  
COMMUNICATION



SEEK AND PURSUE  
COMMON INTERESTS  
AND ISSUES





Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
MEMBER ORGANISATIONS are enthusiastic and empowered	> Nourish and cement the community of our member groups	Annual Convention meets 80%+ of participants´ needs "Very well", Convention messages relayed effectively in members´ local groups	Annual Convention in October 2025; theme "every voice counts"
		An active member in five more European countries (Target: all countries have a member group)	At least one new member country
	> Fluid bilateral communication between LUPUS EUROPE and national groups	Two webinars a year, connecting our community (broader than members)	Two webinars run, with limited Zoom, but broad Facebook Live Promote ERN ReCONNET webinars
		An interim six-monthly/half year review with members to share progress, seek input and support	Six-monthly interim review 2023 held by Zoom
		National group activities are relayed by Lupus Europe	National group activities are relayed by Lupus Europe  Volunteering toolkit designed and available for all members
		Members Chat is in place with most members	Focus Members Chat to Dark Countries
		Most members actively engage in projects or collaboration networks, relaying our requests nationally	Effective transmission of min. four requests done in majority of member countries
		LUPUS EUROPE's messages are made available to patients in most countries , including through social media and web	All educational videos and webinars to be subtitled in English.  Translation of all written key messages for national members
	> Seek and pursue common interests and issues to boost the operation of the national groups and sing as one choir.	Annual initiatives are run on the main "Kick Lupus" theme	Kick Lupus Hashtag Campaign - One topic each month
		Operational networks that bring together people with common interests	Two Youth Group projects implemented  A meeting of the Men's group, to align on purpose and strategy
		Lupus Europe contributes to higher members capacity and capabilities	At least three projects approved through Members Capacity support program
		Synergies amongst members	Lupus 100 widely used : Move to 20 languages by December 2025 (including 2 language spoken by immigrants)  lupusgpt used to help national groups generate content



# HEARD & ACTIVE

## LUPUS EUROPE IS HEARD AND ACTIVE





Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
LUPUS EUROPE is heard and active	> Be Heard	Maintain and keep current a dynamic web presence: Lupus-europe.org (organisation aspects) and lupus100.org (disease aspects)	Updated strategic plan video by December 2025 Design landing pages for the Lupus Europe website by country with information that includes Lupus100, LupusGPT, Lupus Europe, information on the National Group and that can be accessed by QR code  Add national group activities on the Lupus Europe website through a link to the national website where possible, otherwise link to country page
		LUPUS EUROPE delegates attend key European Lupus events, with a clear message track/expected outcome and report back to the community	Short Post event interviews routinely handled and communicated broadly
		Design and implement a social media strategy to deliver our key messages effectively to each target group	Continue to implement social media strategy (messages, focus, do/don't) and scorecard aligned for min. five platforms (FB, Twitter, Instagram, linkedIn, Youtube), achieving 5% growth rate across all channels by December 2025  Explore Podcasts as a possible additional opportunity for communication
		Roundtables or webinars with industry to better meet the needs of people living with lupus	Two Industry Roundtables a year (one zoom, one F2F) AI programme for simultaneous and non-simultaneous translation - explore how we can improve the quality
	>Partner with the best and most relevant players	Long term quality relations with selected partners - ERN, EULAR PARE, SLEuro, Global Skin, Eurordis, EPF, EFPIA, PFMD, EUPATI, EMA - to achieve our goals efficiently	Define how we can best synergise with PMFD Focus on enhancing work with WLF to improve synergies and results
		Active collaboration with Medical Advisory board: All Lupus research include a medical advisor, young rheumatologists included in Youth group, Doctors	Ad hoc regular communication with key Medical board members  Young doctor invited to Convention
		Twice a year coordination meeting with medical partners to synergise programs	2 Academic roundtable of "Senior" Board (Zoom) 2 Academic roundtable of Young Board (Zoom)

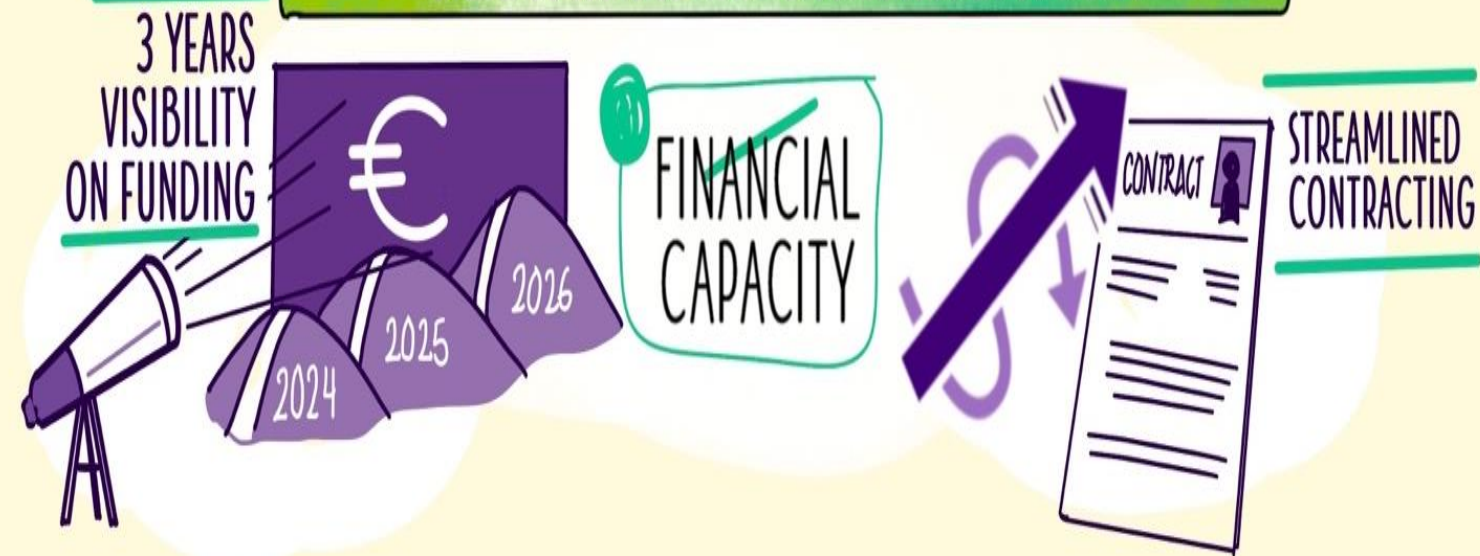


Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
		We are THE voice of people with lupus in the ERNs in charge of Lupus	<p>Lupus Europe considered as an excellent contributor by ERN ReCONNECT and ERN Skin</p> <p>identify a doctor that is either in ERNSkin for lupus or that could be from a hospital in ReCONNECT and Skin AIBD</p>
		LUPUS EUROPE's messages are made available to patients in most countries, including through social media and web	<p>All educational videos and webinars to be subtitled in English.</p> <p>Translation of all written key messages for national members</p>
	>Build action focused awareness that improves the lives of People with Lupus	An annual focused campaign on a selected theme to build Awareness, Education or Access for people living with lupus	Kick Lupus Hashtag Campaign - One topic each month
		Improved Information - Bring quality information to European patients and GPs in the national language of 95%+ through Lupus100 and LupusGPT	<p>Move to 20 languages by December 2025 (including 2 language spoken by immigrants)</p> <p>Define how we can best use the Insights based on the use of Lupus100 to generate specific improvements</p> <p>Broaden the reach and accessibility of LupusGPT.</p> <p>Implement voice activation</p> <p>All educational videos and webinars to be subtitled in English.</p>



# SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A SUSTAINABLE ORGANISATION





Strategic Objectives	pillar	2028 Deliverables	Action Plan - Specific 2025 Stretch Goals
LUPUS EUROPE attracts and uses best resources to build a sustainable organisation	> Build Human capacity and capabilities to deliver the next decade	Sustainable Secretariat delivers a "backbone" support (professional skills and continuity) to our volunteers network	Introduce Volunteer coordinator role  Improve sustainability by enhacing organisation's presence in Belgium
		By 2028, 70 volunteers deliver 3500 volunteering hours annually	By Dec 2025, 60 volunteers - 2750 hours delivered
		Lupus Europe Volunteering plan formalised and implemented (recruiting, onboarding, training support, follow up, policies & procedures, rewards and recognition)	Satisfaction survey amongst volunteers scores >8/10 Volunteering toolkit implemented in Lupus Europe Identify a volunteer to support our technical communication with IT/web support team
		A Network of volunteer translators is available (and used) to routinely bring our messages to each member country ´s national language	35 core translators identified and motivated through their contributions
		We operate in a way that combines a high level of efficiency with individual satisfaction, while bringing sustainability	Continue implementing improved welcome, follow-up and recognition by December 2025 Identify all key roles with no backup
	> Ensure Sustainable sufficient funding	Sustainable funding providing 3 years visibility	All projects funded by April 2025  Long term partners identified for minimum 125k €
		Move to simplified / standard legal agreements	Streamlined contracting is endorsed by majority of Industry in 2025. Continue implementation of co-payment for complex contracts
	> FOCUS	We FOCUS on most important activities that are key for LUPUS in EUROPE	
		Succession plan for key Lupus Europe positions, maintained up to date + onboarding process for new trustees	Minimum of one special advisor to Board as future prospect
		By 2028 Lupus Europe has succesfully rotated its key leadership positions (Chair & General Secretary)	Replacement candidate for JA on track



# Thoughts on 2025 Priorities

- Lupus100 expanding plus top languages spoken by immigrant population
- PAN Recruitment
- Patient Abstracts in key scientific events
- EasyLupus voice activation
- Access area spotlighted: Every voice matters
- Apply to Join the Coordination Board



# PAN Recruitment

- Join the next PAN Academy!
- Very few, open spots for the PAN for people from: Bulgaria, Czechia, Germany, Poland, Portugal, Spain, Switzerland
- Few open spots for youth, seniors and men for people from other countries too!
- You do not need to be an expert in research to apply!



# Convention 2025

- October 3 to October 6, 2025 in Amsterdam
- The theme of the LUPUS EUROPE 2025 Convention is: Every voice matters
- Addressing a vital gap