LUPUS EUROPE

Activity Report 2026

Agenda

1. Opening – Strategic Plan
2. Board report on 2025 activities and 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

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

LIVING WITH LUPUS SURVEY

ANNUAL QUANTATIVE SURVEY

PATIENT EXPERIENCE

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

MEDICATION

LUPUS100.ORG

ACCESS

HUMAN CAPACITY AND CAPABILITIES

SUSTAINABLE SECRETARIAT

AS BACKBONE SUPPORT

NETWORK OF VOLUNTEER TRANSLATORS

PLAN

VOLUNTEERS

70 → 3500 VOLUNTEERS HOURS PER YEAR!

HEARD & ACTIVE

LUPUS EUROPE IS HEARD AND ACTIVE

CLEAR MESSAGING

BE HEARD

2X / YEAR WEBINAR

LUPUS-EUROPE.ORG
LUPUS100.ORG

EDUCATION

AWARENESS

ACCESS

CAMPAIGN

SOCIAL MEDIA STRATEGY

PARTNER WITH BEST AND MOST RELEVANT PLAYERS

SELECT PARTNERS

ACHIEVE GOALS

MEDICAL ADVISORY BOARD

ACADEMICS & INDUSTRY

BE THE VOICE

OF PEOPLE WITH LUPUS IN THE EAN

SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A SUSTAINABLE ORGANISATION

3 YEARS VISIBILITY ON FUNDING

2024

2025

2026

FINANCIAL CAPACITY

CONTRACT

STREAMLINED CONTRACTING

MEMBERS

MEMBER ORGANISATIONS ARE ENTHUSIASTIC AND EMPOWERED

NOURISH AND CEMENT THE COMMUNITY

1 ACTIVE MEMBER IN EACH EU COUNTRY

FLUID BILATERAL COMMUNICATION

LUPUS CHAT

NATIONAL ACTIVITIES

ENGAGE!

LUPUS EUROPE

MESSAGES FOR PATIENTS!

KICK LUPUS

SEEK AND PURSUE COMMON INTERESTS AND ISSUES

YOUTH!

SYNERGIES

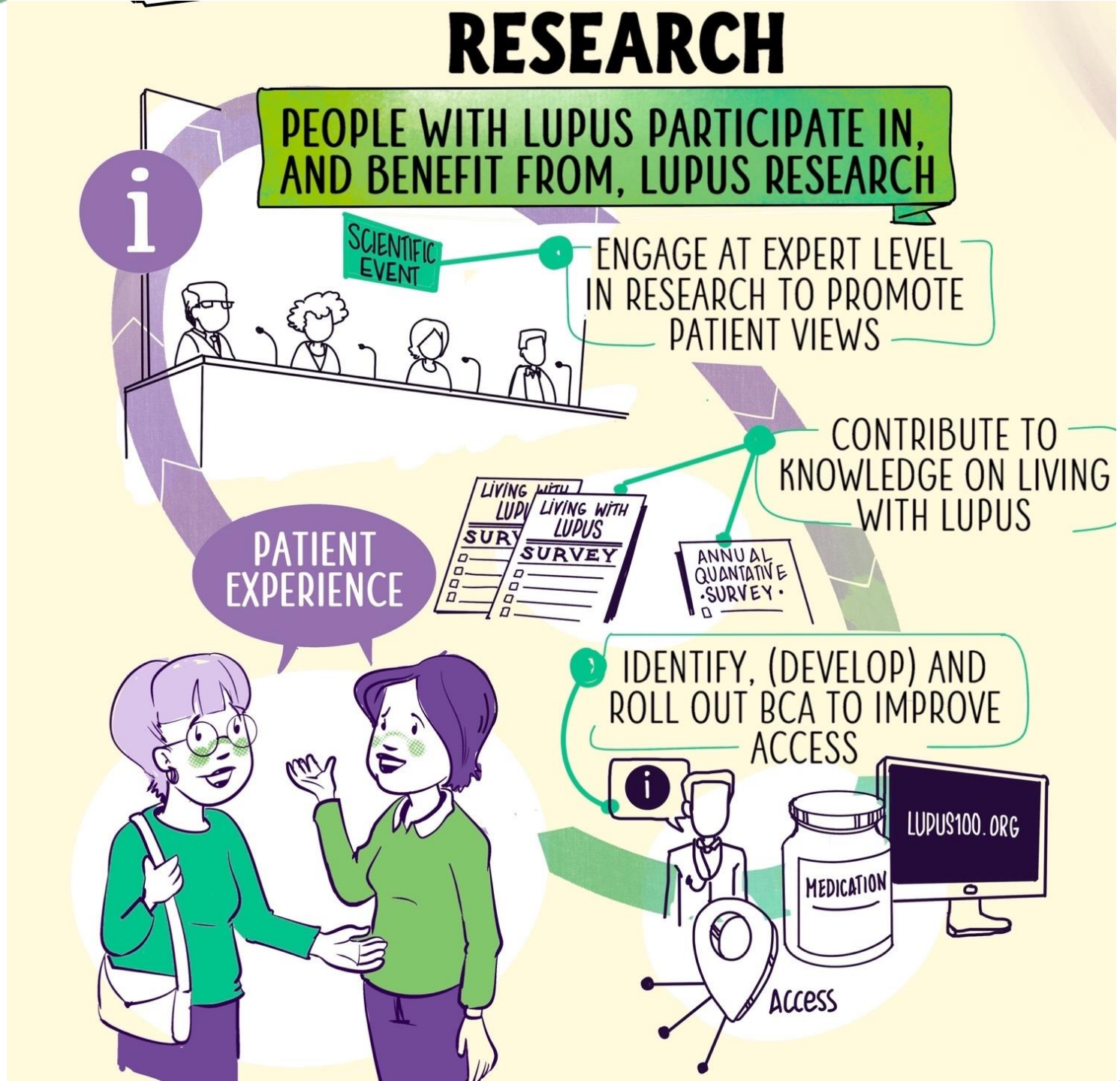
CAPACITY BUILDING

LUPUS FOCUS EUROPE

SUCCESSION

PLAN & ONBOARDING

RESEARCH



LUPUS EUROPE

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 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:	A	Run an induction academy for minimum of 5 new members (including minimum 1 youth, 1 man) 30 trained and energised PAN members by December 2026
			B	Three core trainings for volunteers in 2026: First aid mental health training available for all volunteers and open for National Members. CAR-T training. Continue and build on "how to tell your story". Continue range of on demand soft skills.
		European Medicine Agency	D	Compared to other POs, Lupus Europe assessed "very good" with regards to bringing patient views to EMA
			B	List of 10 EMA eligible/available people by December 2026
			C	Plan to keep EMA eligible volunteers energised and motivated approved. Implement plan in 2026
			A	EMA lupus requests staffed and delivered
		Industry	A	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views in industry projects
			A	Accepted industry projects delivered (see PAN list)
		Academia	C	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views to academics/clinicians
			B	Academia accepted requests supported (see PAN List)
			A	Continued support to 3TR (last year of programme)
			A	Support to DORIS+ Project (defining Deep Remission)
			A	1 publication on patient engagement benefit in TRM-SLE project

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
		Research requests vetted by Medical advisory board are relayed for broad distribution	B	All vetted research relayed
		European Reference Networks	B	Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views by ERN ReCONNET
			B	Have consensus meeting for RarERN Path. Stories database finalised and used by December 2026.
			A	831 stories from 14 languages analysed and available in electronic booklet format and a publication based on the stories by December 2026.
	> Contribute to knowledge on living with lupus	A Patient panel every year to advance knowledge of "Living with lupus"		Omitted in 2026 to create Room for National Group Leaders Summit
			B	Lupus Alert research project to screen for vulnerabilities in lupus - Manuscript publication by December 2026
			B	Support REMEASURE Project, to develop and validate a patient-driven definition of remission in SLE and align it with the clinician-based DORIS framework, & include in this project the definition of a flare project. Development of survey & rollout by December 2026
		Organisation or deployment of at least one quantitative survey each year	B	Systematically relay accepted surveys to the research subgroup. At least one survey a year relayed to the research subgroup.
		Two broad-scale surveys on aspects of Living with Lupus over the five years	A	Survey on sexuality and lupus developed collaboratively. Rollout in 2026

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
	> Identify, (develop) and roll out best practices to improve access to lupus care	Improved Patient-Doctor communication (-> shared decision making)	C	Inclusion of Patient Doctor communication in Lupus Academy (CME accredited)
			B	Develop a practical guide for patient organisations on how to engage and work with doctors and HCPs on how to signpost people to join patient groups, with a priority on more vulnerable, harder to reach groups.
			A	Prepare and launch Consultation Cards Campaign for World Lupus Day 2026 Create version of Consultation Card with male human - for men with lupus
		Improve Access of all to quality information	B	Initiate lupus100 review of content and update English version
			A	Initiate lupusgpt review of content and update
			B	Lupus 100 finalise rollout by December 2026 with Arabic, Turkish and Polish
			C	Draft Abstracts on three practical tools ready for use by National Groups for national Congresses. Disseminate & build a strategy for use, considering national context
			A	Define a strategy for dissemination growth of lupusgpt
		Each year, one area of access spotlighted to identify gaps, and equip national groups to seek improvements (psychological support, lupus nurses, physiotherapist, work, medication, ...)	C	Launch new webpage on the Lupus Europe website linking to valuable resources on HTA. Launch HTA Summit for volunteers and National Member Groups

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
		Patient abstracts in the main program of key scientific events	A	EULAR Congress quality attendance
			A	ELM 2026 support
			A	ELM2028 support
			A	Lupus2027 (Florence) Support
			B	Min. four abstracts submitted each year with Lupus Europe support
			B	Put process in place to grow volunteer knowledge and familiarisation with abstracts on topics of interest. Two abstracts finalised and submitted through this process
			C	Other congress quality attendance

MEMBERS

MEMBER ORGANISATIONS ARE ENTHUSIASTIC AND EMPOWERED

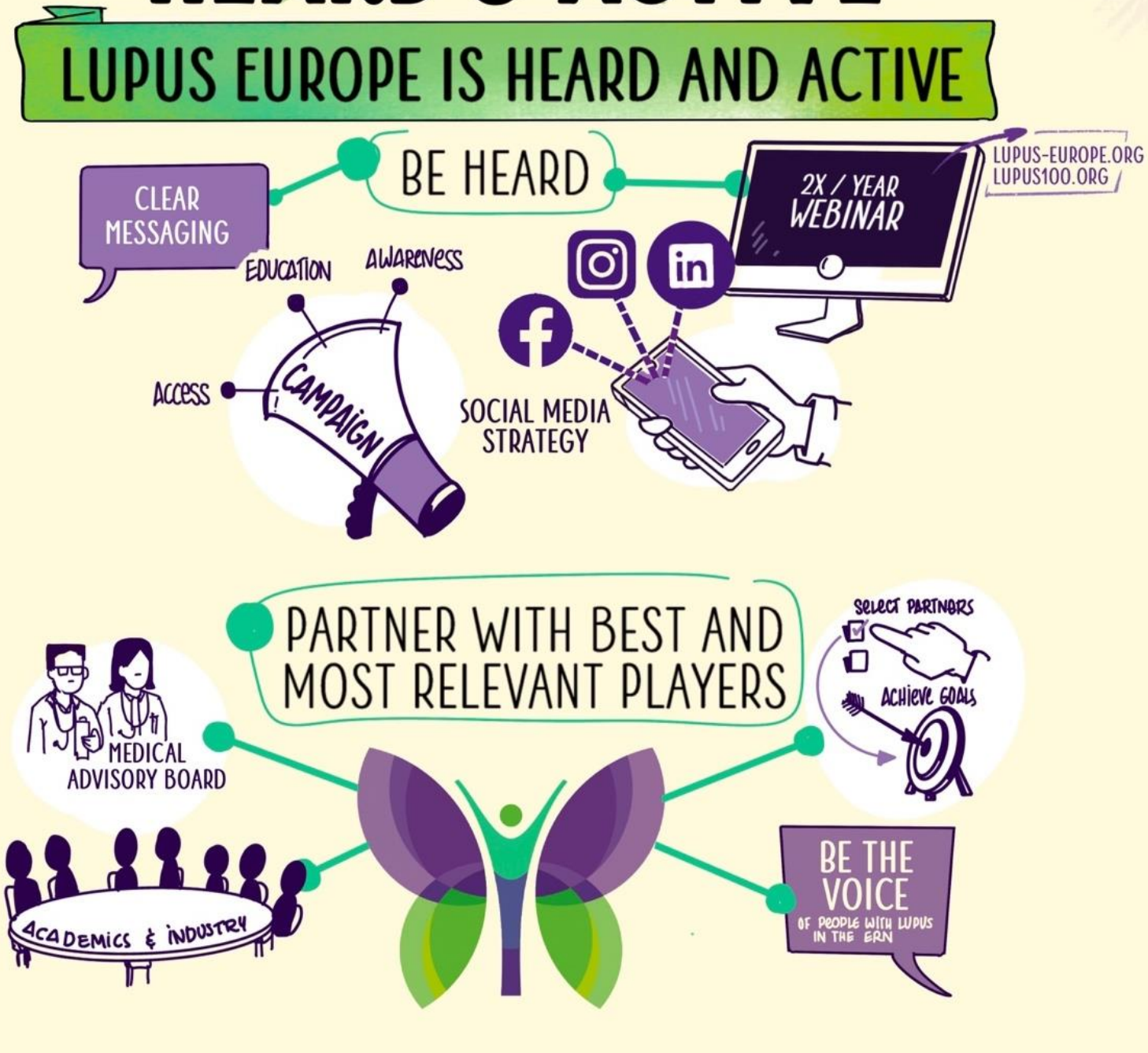


LUPUS EUROPE

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 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	A	Annual Convention in October 2026 in Spain; theme "treatment"
		An active member in five more European countries (Target: all countries have a member group)	C	Continue long term work on missing countries (no new member ready at this point)
	> Fluid bilateral communication between LUPUS EUROPE and national groups	Two webinars a year, connecting our community (broader than members)	A	Two webinars run, with limited Zoom, but broad Facebook Live
			A	Promote ERN ReCONNET webinars
		An interim six-monthly/half year review with members to share progress, seek input and support	A	Six-monthly interim review (GA)
		National group activities are relayed by Lupus Europe	C	National group activities are relayed by Lupus Europe
			B	Volunteering toolkit disseminated to members
		Members Chat is in place with most members	C	Pilot test "Lupus Europe on Tour" for 1-2 'dark' national members or to increase member engagement Target is for one representative of those national members to attend the following Convention
		Most members actively engage in projects or collaboration networks, relaying our requests nationally	B	Effective transmission of min. four requests done in majority of member countries

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
		Step change communication with members	A	identify what the issues are and how we can effectively engage better and help members better
		LUPUS EUROPE's messages are made available to patients in most countries , including through social media and web	C	All educational videos and webinars to be subitled in English.
			C	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	C	Encourage use of KickLupus hashtag
		Operational networks that bring together people with common interests	B	Two Youth Group projects implemented Recruit 3 more young people for the group
			B	A meeting of the Men's group Build contact list of men By December 2026 1 abstract submitted on men
		Lupus Europe contributes to higher members capacity and capabilities	C	At least three projects approved through Members Capacity support programme
		Synergies amongst members	B	Summit of National Group Leaders / Senior Leadership (Q3/Q4) Explore options for possibility of having Summit in own language where needed
			C	Keep current with affordable AI tools for simultaneous and non-simultaneous translation - test translation earbuds and AI software identified
			B	New whatsapp group for national members successful with members engaging and animated by December 2026
			B	Leaflets available to National Members by December 2026
			C	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 by June 2026
			C	Create demo on how to use lupusgpt to generate content for members

HEARD & ACTIVE



LUPUS EUROPE

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
LUPUS EUROPE is heard and active	> Be Heard	Maintain and keep current a dynamic web presence: Lupus-europe.org (organisation	C	Updated strategic plan video by December 2026
		LUPUS EUROPE delegates attend key European Lupus events, with a clear message track/expected outcome and report back to the community	B	Short Post event interviews routinely handled and communicated broadly Top line summary for the Board of each interview
		Design and implement a social media strategy to deliver our key messages effectively to each target group	B	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
			D	Investigate easy podcasts for specific communication targets & make dissemination plan
		Roundtables or webinars with industry to better meet the needs of people living with lupus	A	Two Industry Roundtables a year (one zoom, one F2F)
	>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	B	Continue collaborating with PFMD and EFPIA until decision is made on which way to go
			C	Work on enhancing work with WLF to improve synergies and results Begin organising in person meeting of WLF in 2027 at the occasion of Lupus2027
		Active collaboration with Medical Advisory board: All Lupus research include a	B	Ad hoc regular communication with key Medical board members
			B	Young doctor invited to Convention

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
		Twice a year coordination meeting with medical partners to synergise programs	A	2 Academic roundtable of "Senior" Board (Zoom) 2 Academic roundtable of Young Board (Zoom)
		We are THE voice of people with lupus in the ERNs in charge of Lupus	B	Lupus Europe considered as an excellent contributor by ERN ReCONNET and ERN Skin
			A	identify a doctor that is either in ERNSkin for lupus or that could be from a hospital in ReCONNET and Skin
		LUPUS EUROPE's messages are made available to patients in most countries, including through social media and web	C	All educational videos and webinars to be subitled in English.
			C	Translation of all written key messages for national members
	>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	C	Introduce and encourage use of KickLupus hashtag
		Improved Information - Bring quality information to European patients and GP's in the national language of 95%+ through both lupus100 and lupusgpt	B	Lupus 100 finalise rollout by December 2026 with Arabic, Turkish and Polish
			B	Define how we can best use the Insights based on the use of Lupus100 to generate specific improvements Create top 10 country level questions for all National Members for lupus100
			A	Validate voice activated version of EasyLupus across languages, make a communication/dissemination plan for LupusGPT

S EUROPE

LUPUS EUROPE



Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 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	B	Implement Volunteer coordination capacity within the Board
			B	Map all IT needs
			Z	Secretariat staffing:
			B	Seek opportunities to enhance the organisation's presence in Belgium
		By 2028, 70 volunteers deliver 3500 volunteering hours annually	A	By Dec 2026, 60 volunteers - 3000 hours delivered Launch new tracking method of hours to simplify process for volunteers
		Lupus Europe Volunteering plan formalised and implemented (recruiting, onboarding, training support, follow up, policies & procedures, rewards and recognition)	A	Satisfaction survey amongst volunteers scores >8/10
			B	Renew Confidentiality agreements and volunteer Code of Conduct agreements for all volunteers
			A	Coordination meeting with IT/web volunteer group
		A Network of volunteer translators is available (and used) to routinely bring our messages to each member country´s national language	A	Coordination meeting of translators group. Further develop training and engagement plan

Strategic Objectives	Pillar	2028 Deliverables	ABC	2026 Goals
		We operate in a way that combines a high level of efficiency with individual satisfaction, while bringing sustainability	A	Continue implementing improved welcome, follow-up and recognition by December 2026
			A	Identify back up for all key roles
	> Ensure Sustainable sufficient funding	Sustainable funding providing 3 years visibility	A	All projects funded by April 2026
			C	
		Move to simplified / standard legal agreements	C	
	> FOCUS	We FOCUS on most important activities that are key for LUPUS in EUROPE	Z	
		Succession plan for key Lupus Europe positions, maintained up to date + onboarding process for new trustees	A	Minimum of one special advisor to Board as future prospect
			A	Board meetings
		By 2028 Lupus Europe has succesfully rotated its key leadership positions (Chair & General Secretary)	A	Have bi-monthly 'bureau' meeting Create communication campaign for leadership positions

Thoughts on 2026 priorities

- Convention 2026
- Apply to join the Coordination Board
- PAN Recruitment
- EasyLupus Voice Activation
- National Level Abstracts
- World Lupus Day 2026: Consultation Cards
- Access area spotlighted: Treatment

Convention 2026

- October 2 to October 5, 2026 in Barcelona
- The theme of the LUPUS EUROPE 2026 Convention is: Treatment