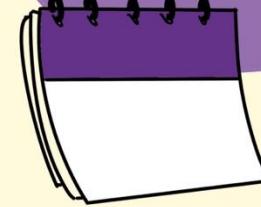




Activity Report 2025

Index

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

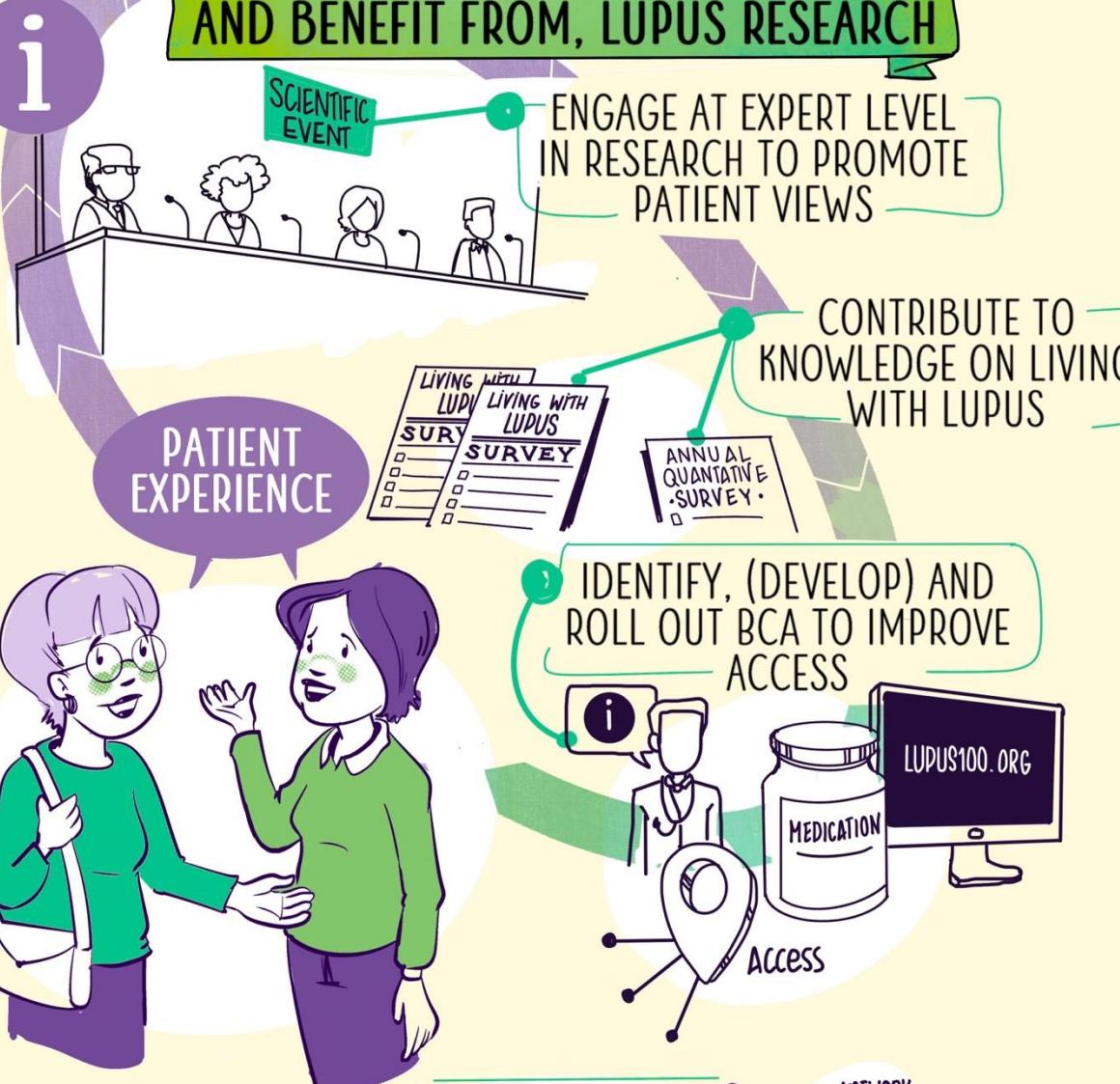


LUPUS EUROPE

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



HEARD & ACTIVE

LUPUS EUROPE IS HEARD AND ACTIVE



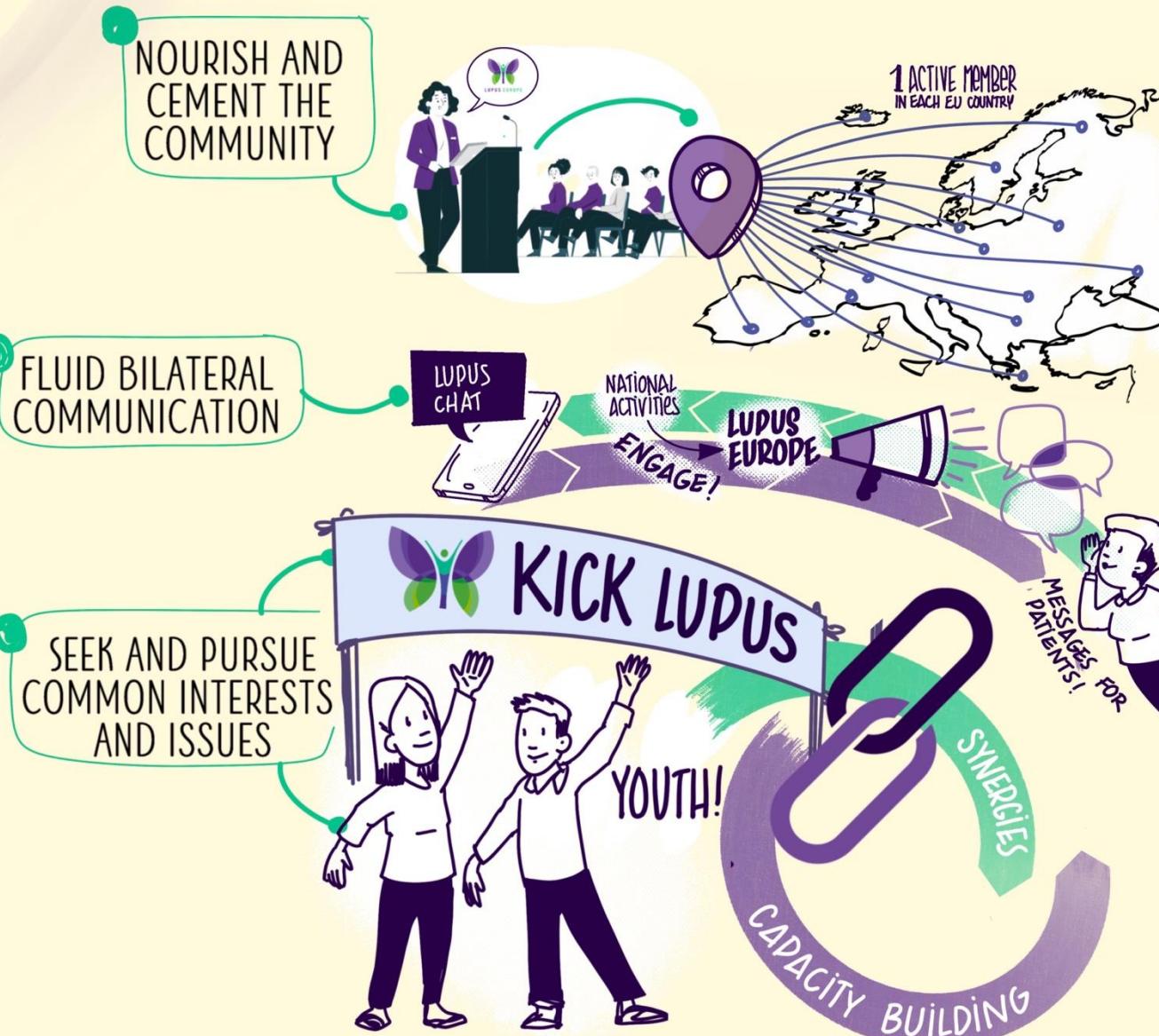
SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A SUSTAINABLE ORGANISATION



MEMBERS

MEMBER ORGANISATIONS ARE ENTHUSIASTIC AND EMPOWERED



LUPUS FOCUS EUROPE
SUCCESSION PLAN & ONBOARDING

RESEARCH

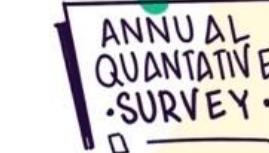
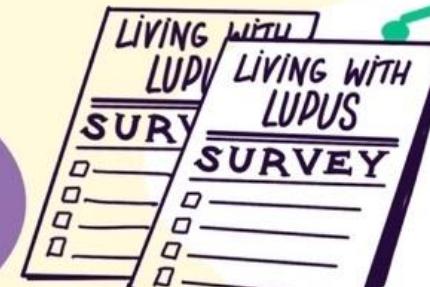
PEOPLE WITH LUPUS PARTICIPATE IN,
AND BENEFIT FROM, LUPUS RESEARCH

i

SCIENTIFIC
EVENT

ENGAGE AT EXPERT LEVEL
IN RESEARCH TO PROMOTE
PATIENT VIEWS

PATIENT
EXPERIENCE



CONTRIBUTE TO
KNOWLEDGE ON LIVING
WITH LUPUS

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



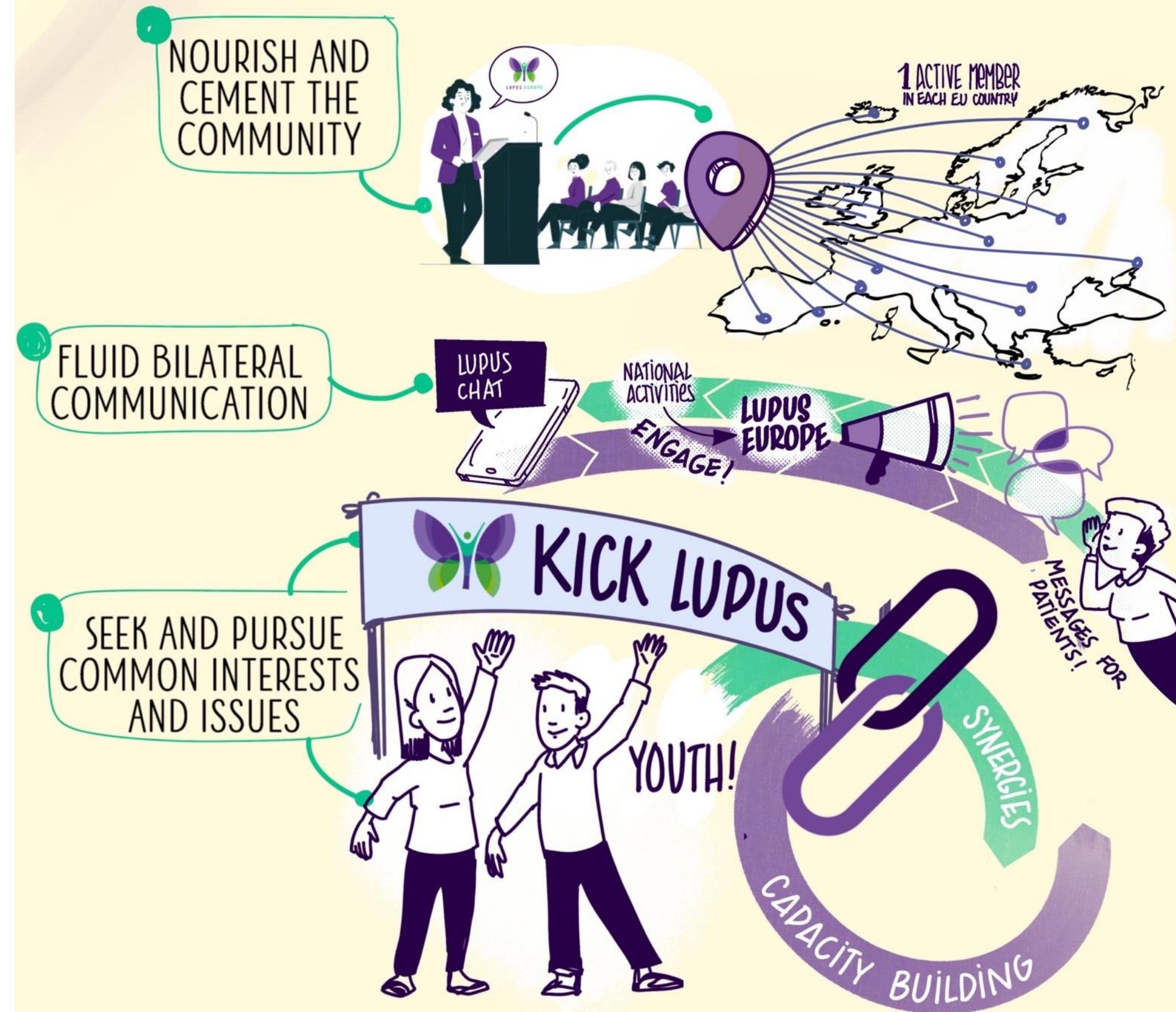
| Strategic Objectives | pillar | 2028 Deliverables | Action Plan - Specific 2025 Stretch Goals |
|--|---|---|---|
| PEOPLE WITH LUPUS in Europe participate in, and benefit from, lupus research | > Engage at Expert level in scientific research to promote E2E patient views | <p>A 35 Person's trained and energized Patient Advisory Network acting as liaison and resource to value-adding scientific projects and clinical trials, in priority with:</p> | <p>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</p> <p>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</p> |
| | European Medicine Agency | | <p>Compared to other POs, Lupus Europe assessed "very good" with regards to bringing patient views to EMA</p> <p>List of 10 EMA eligible/available people by December 2025</p> <p>Design a plan to keep EMA eligible volunteers energised and motivated</p> <p>EMA lupus requests staffed and delivered</p> |
| | Industry | | <p>Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views in industry projects</p> <p>Accepted industry projects delivered (see PAN list)</p> |
| | Academia | | <p>Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views to academics/clinicians</p> <p>Academia accepted requests supported (see PAN List)</p> <p>Continued support to 3TR</p> <p>Continued support to TRM-SLE project</p> |
| | Research requests vetted by Medical advisory board are relayed for broad distribution | | <p>All vetted research relayed</p> |
| | European Reference Networks | | <p>Compared to other POs, Lupus Europe assessed "Very good" with regards to its engagement in promoting patient views by ERN ReCONNECT</p> <p>Create task force for RarERN Path - 831 stories from 14 languages. Booklet available. Database created and used by December 2025.</p> |

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

MEMBER ORGANISATIONS
ARE ENTHUSIASTIC AND EMPOWERED



| 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 ReCONNECT 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) lupusgt 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 |
| | | 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 |
| | >Partner with the best and most relevant players | 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 | Lupus Europe considered as an excellent contributor by ERN ReCONNED and ERN Skin identify a doctor that is either in ERNSkin for lupus or that could be from a hospital in ReCONNED and Skin AIBD |
| | | 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 |
| >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 | Move to 20 languages by December 2025 (including 2 language spoken by immigrants) Define how we can best use the Insights based on the use of Lupus100 to generate specific improvements Broaden the reach and accessibility of LupusGPT. Implement voice activation All educational videos and webinars to be subtitled in English. |

SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A
SUSTAINABLE ORGANISATION



LUPUS → FOCUS → EUROPE
SUCCESSION
PLAN & ONBOARDING

| 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 enhancing 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 successfully 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