

Strategic Plan 2023-2028

Our Board of directors



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Annemarie, Elfriede, Ricky

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

PATIENT
EXPERIENCE

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

HUMAN CAPACITY
AND CAPABILITIES

VOLUNTEERS
70 → 3500
HOURS PER
YEAR!

PLAN
1. _____
2. _____
3. _____

NETWORK
OF VOLUNTEER
TRANSLATORS

HEARD & ACTIVE

LUPUS EUROPE IS HEARD AND ACTIVE



PARTNER WITH BEST AND
MOST RELEVANT PLAYERS



SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A
SUSTAINABLE ORGANISATION

3 YEARS
VISIBILITY
ON FUNDING

FINANCIAL
CAPACITY

STREAMLINED
CONTRACTING

MEMBERS

MEMBER ORGANISATIONS
ARE ENTHUSIASTIC AND EMPOWERED

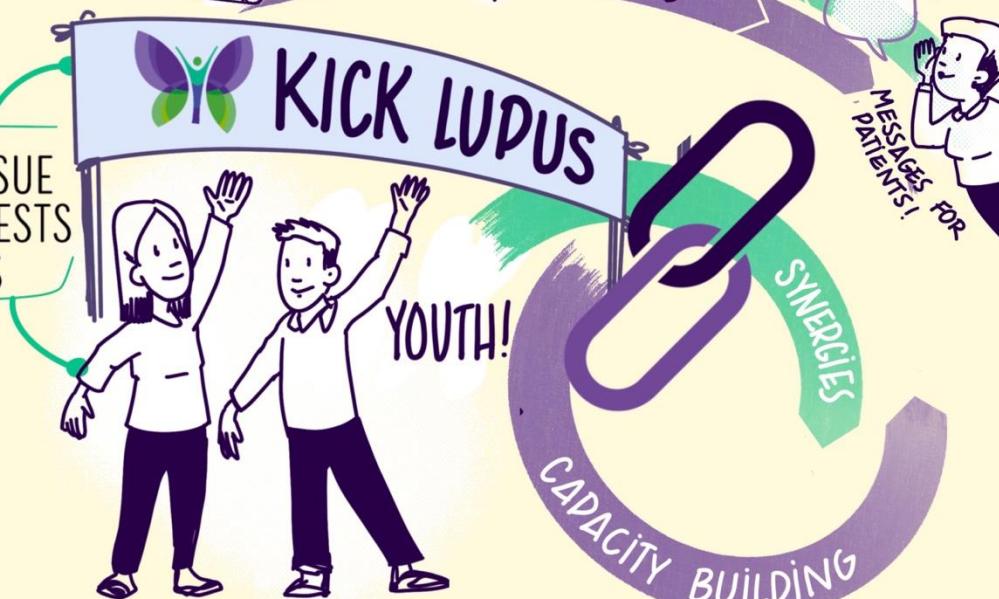
NOURISH AND
CEMENT THE
COMMUNITY

FLUID BILATERAL
COMMUNICATION

SEEK AND PURSUE
COMMON INTERESTS
AND ISSUES

LUPUS FOCUS EUROPE

SUCCESSION
PLAN & ONBOARDING



RESEARCH

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

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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
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:
		European Medicine Agency
		Industry
		Academia
		Research requests vetted by Medical advisory board are relayed for broad distribution
		European Reference Networks
	> Contribute to knowledge on living with lupus	A Patient panel every year to advance knowledge of "Living with lupus"
		Organisation or deployment of at least one quantitative survey each year
		Two broad-scale surveys on aspects of Living with Lupus over the five years
	> Identify, (develop) and roll out best practices to improve access to lupus care	Improved Patient-Doctor communication (-> shared decision making)
		Each year, one area of access spotlighted to identify gaps, and equip national groups to seek improvements (psychological support, lupus nurses, physiotherapist, work, medication, ...)
		Patient abstracts in the main program of key scientific events



MEMBERS

MEMBER ORGANISATIONS
ARE ENTHUSIASTIC AND EMPOWERED

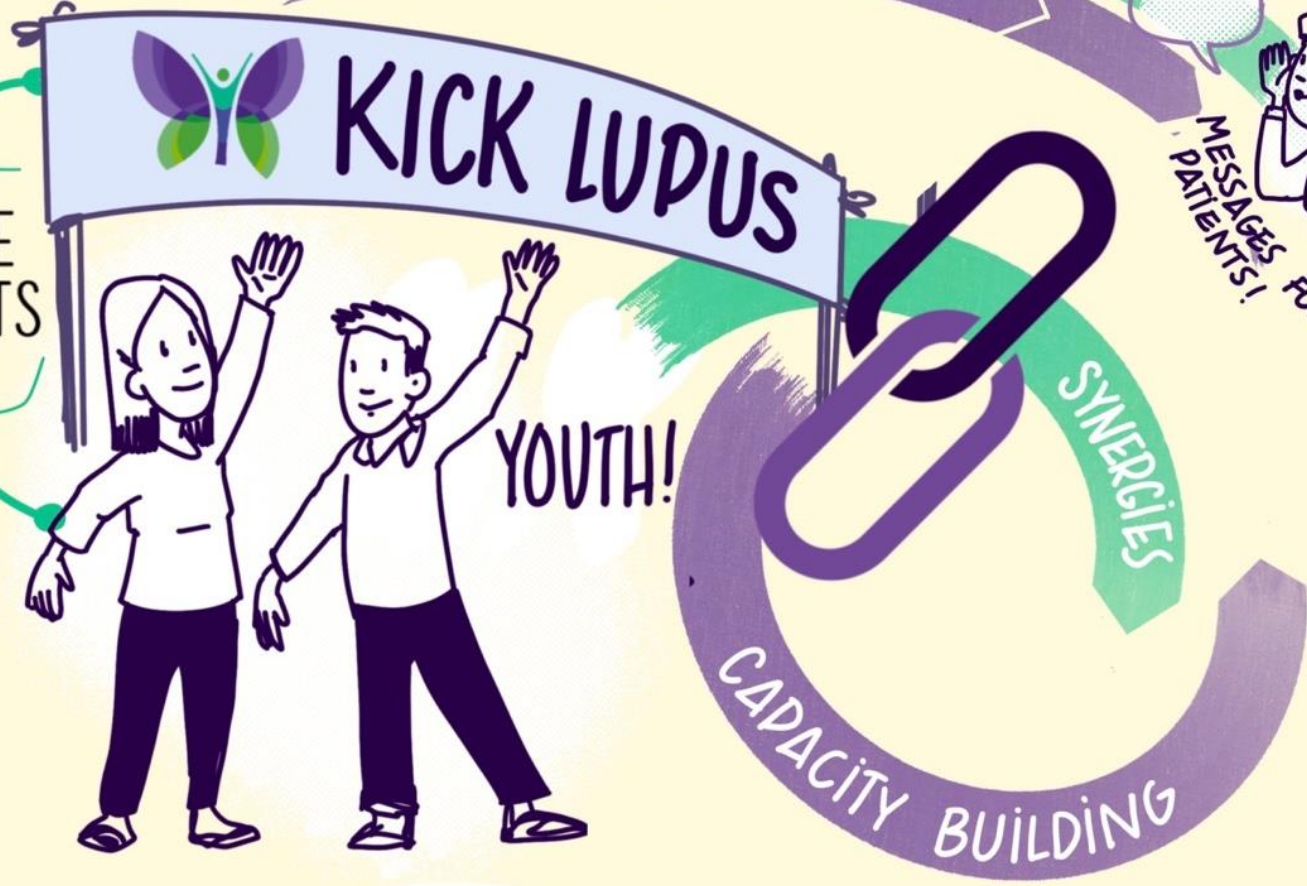
NOURISH AND
CEMENT THE
COMMUNITY



FLUID BILATERAL
COMMUNICATION



SEEK AND PURSUE
COMMON INTERESTS
AND ISSUES



Strategic Objectives	pillar	2028 Deliverables
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
		An active member in five more European countries (Target: all countries have a member group)
	> Fluid bilateral communication between LUPUS EUROPE and national groups	Two webinars a year, connecting our community (broader than members)
		An interim six-monthly/half year review with members to share progress, seek input and support
		National group activities are relayed by Lupus Europe
		Members Chat is in place with most members
		Most members actively engage in projects or collaboration networks, relaying our requests nationally
		LUPUS EUROPE's messages are made available to patients in most countries , including through social media and web
	> 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
		Operational networks that bring together people with common interests
		Lupus Europe contributes to higher members capacity and capabilities
		Synergies amongst members

HEARD & ACTIVE

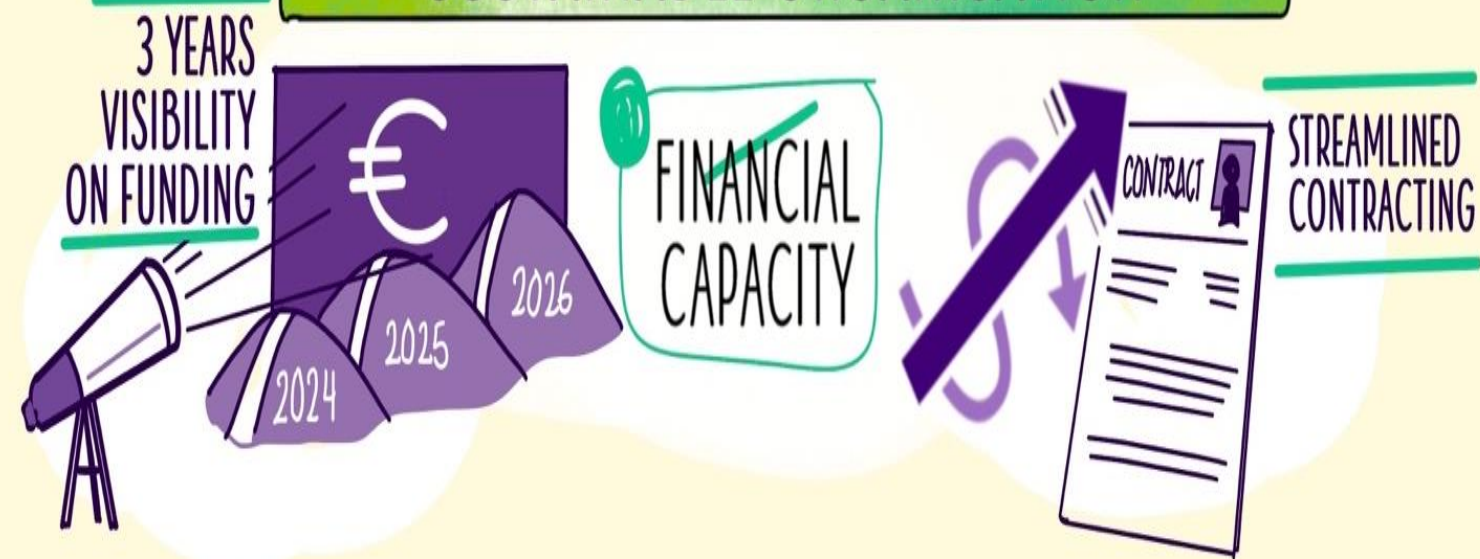
LUPUS EUROPE IS HEARD AND ACTIVE



Strategic Objectives	pillar	2028 Deliverables
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)
		LUPUS EUROPE delegates attend key European Lupus events, with a clear message track/expected outcome and report back to the community
		Design and implement a social media strategy to deliver our key messages effectively to each target group
		Roundtables or webinars with industry to better meet the needs of people living with lupus
	>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
		Active collaboration with Medical Advisory board: All Lupus research include a medical advisor, young rheumatologists included in Youth group, Doctors invited to key events
		Twice a year coordination meeting with medical partners to synergise programs
		We are THE voice of people with lupus in the ERNs in charge of Lupus
		LUPUS EUROPE's messages are made available to patients in most countries, including through social media and web
	>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
		Improved Information - Bring quality information to European patients and GPs in the national language of 95%+ through Lupus100 and LupusGPT

SUSTAINABILITY

ATTRACT BEST RESOURCES TO BUILD A SUSTAINABLE ORGANISATION



Strategic Objectives	pillar	2028 Deliverables
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
		By 2028, 70 volunteers deliver 3500 volunteering hours annually
		Lupus Europe Volunteering plan formalised and implemented (recruiting, onboarding, training support, follow up, policies & procedures, rewards and recognition)
		A Network of volunteer translators is available (and used) to routinely bring our messages to each member country 's national language
		We operate in a way that combines a high level of efficiency with individual satisfaction, while bringing sustainability
	> Ensure Sustainable sufficient funding	Sustainable funding providing 3 years visibility
		Move to simplified / standard legal agreements
	> 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
		By 2028 Lupus Europe has succesfully rotated its key leadership positions (Chair & General Secretary)



THANK YOU!

Lupus Europe initiatives are made possible thanks to the financial support of

