



LUPUS EUROPE

Projects for 2021





LUPUS EUROPE VISION

**A fulfilling life
for all people with lupus in Europe
until we have reached a world without
lupus**

Strategy 1 - People with lupus participate in, and benefit from, lupus research

- ▶ Further grow PAN and establish a support structure for on-going engagement
- ▶ As soon as possible F2F, Patient panel on "Lupus in the long run" (senior with Lupus)
- ▶ If F2F allows, 1st ERN endorsed course on Lupus for Patient Advocates (Pisa 2021)
- ▶ Publication on LWL in 2020, HcQ + More details in other media
- ▶ LWL abstracts at EULAR
- ▶ Engage Pisa and Karolinska universities on "economic cost of Lupus"
- ▶ Launch "Clinical trials.match" and "survey centre" on Lupus Europe web

Engage at Expert level in Research to promote Patient views

Patient Advisory Network - liaison and resource to projects and Trials

Contribute through Research on living with lupus

Patient Panel every year

Update Living with Lupus survey

Research on the Economic Cost of lupus

One quantitative Survey each year

Foster broader participation in, and dissemination of, research

Education and Access on Research/Clinical trials

Relay Research requests

Patient abstracts in scientific events

Participate in key European scientific Lupus events

Disseminate news & outcomes collected

Strategy 2 - Member Organisations are enthusiastic and empowered

- ▶ BRATISLAVA 2021!!
- ▶ 3 Webinars min.
- ▶ Re-engaging low activity members
- ▶ Sustain Lupus Chat once a year at least
- ▶ One Co-Opt to the Board from Youth Group
- ▶ Boost Capacity Building Programme
- ▶ Translate 5 key brochures in multiple languages (Pdf via web)
- ▶ #KickLupus!

Nourish and cement the community

Great Annual Convention relayed in our national groups

One active member in each European country

Members sharing via Modern collaboration platform

Fluid bilateral Communication

LUPUS EUROPE's messages available to patients

Two webinars a year

Members actively engage in projects / Networks

Lupus Chat in place

Seek and pursue common interests and issues

LUPUS EUROPE Youth group

Initiatives linked under "Kick Lupus" theme

Voices of lupus campaign

Promote and share WLD initiatives

Strategy 3 - Lupus Europe is heard and acting

- ▶ Beef up Web content
- ▶ Get exercise videos "EULAR certified and distributed"
- ▶ Increase regularity of Newsflash
- ▶ Obtain 2nd EPAG delegate in ERN ReCONNET
- ▶ Increase interactions with EMA
- ▶ Recruit extra 3 PAN for EMA engagements
+ identify potential extra volunteers
- ▶ Use more extensively EURORDIS tools/Knowledge

> Be Heard

Modernised and sustainable Web presence

Clear messages & toolkits for each key audience

Attend priority events with clear message / outcome

Newsflash every trimester

> Partner with the best and most relevant players

Selected partners to achieve our goals efficiently

Roundtables /webinars w. Academics, POs, industry

Be the voice of people with lupus in the ERN

Win-win with World Lupus Federation

Sustainability - Priorities 2021

- ▶ Bring 4th part time support (focus on PAN) and organise roles more structurally
- ▶ Constant outreach searching for new Trustees and volunteers
- ▶ Maintain positive collaboration with key partners
- ▶ Finalise move to Brussels

> Resources	>European Scale	> Focus
Sustainable Funding	<i>Brexit impacts</i>	Focus on LUPUS and EUROPE
Grow secretariat	Work done by those best placed	Focus on most important activities
Co-opt advisors and working networks bring Capacity	Active relation with Medical board	combine efficiency & individual satisfaction
<i>VAT and Incorporation</i>	Quality communication and collaboration tools	Succession plan + Onboarding process

ANY QUESTION?

Contact us:

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