

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

## PEOPLE WITH LUPUS in Europe participate in, and benefit from, lupus research

### Engage at Expert level in Research to promote Patient views

- Patient Expert Group - 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

## MEMBER ORGANIZATIONS are enthusiastic and empowered

### 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

## LUPUS EUROPE is heard and acting

### 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

### Resources

- Sustainable Funding
- Grow secretariat
- Co-opt advisors and working networks bring Capacity

### European Scale

- Work done by those best placed
- Active relation with Medical board
- Quality communication and collaboration tools

### Focus

- Focus on LUPUS and EUROPE
- Focus on most important activities
- combine efficiency & individual satisfaction
- Succession plan + Onboarding process



### LUPUS EUROPE's 2018 Board:

Kirsi Alain Annemarie  
Katharine Sara Anne Jeanette