



LUPUS
EUROPE

*Uniting People with
Lupus
throughout Europe*

Strategic Plan

1 Nov 2009 – 31 Oct 2012

Member Countries:

Belgium, Cyprus, Denmark, Finland, France, Germany, Hungary, Iceland,
Ireland, Israel, Italy, Malta, The Netherlands, Norway, Portugal, Slovenia,
Spain, Sweden, Switzerland, United Kingdom

Introduction

LUPUS EUROPE was officially formed September 2008 in Palma de Mallorca, when the Council of the former European Lupus Erythematosus Federation (ELEF) voted, at the Annual Convention, on a change of name.

LUPUS EUROPE was chosen as the Council felt that the new name pronounces strongly that member countries are uniting and caring for lupus patients throughout Europe.

Following agreement with the Charity Commission, the new name came into effect at the closure of the 19th Convention of ELEF on 13th September 2008.

Why does LUPUS EUROPE need a Strategic Plan?

It is important for any organisation - private, public or voluntary - to plan for the future. As a patient-orientated charity, LUPUS EUROPE needs to look at the services expected by member countries and the best way these can be delivered using our limited resources. We must make sure that plans for the future include services which are appropriate and timely, and which provide good value for money for our members.

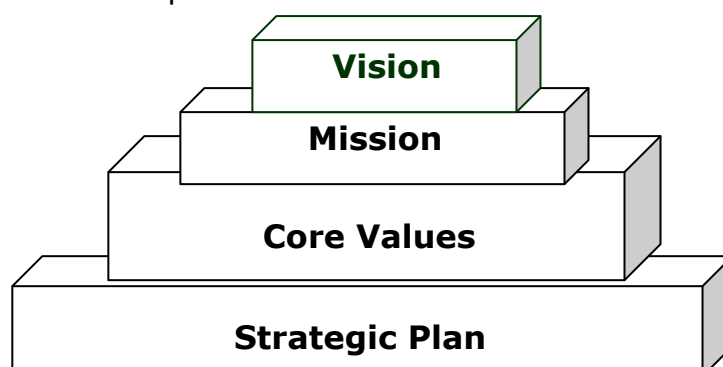
The Trustees have spoken and listened to member countries to establish what the various needs are. These discussions have helped to shape the priorities for the future and to make sure that what the Trustees are aspiring for LUPUS EUROPE to deliver is consistent with what member countries need.

The Trustees are proud of what LUPUS EUROPE has achieved over the last twelve months and will continue to drive forward and to build on the really good work that is already taking place.

The Trustees are committed to delivering on the priorities that have been identified and are using the pace and passion that is in place within LUPUS EUROPE to move forward in a fast and responsive way for member countries.

The climate which we live in today is changing and the challenging economic pressures which face Europe as a whole will impact on our organisation. The Trustees will strive to develop and improve connections with medical professionals, the pharmaceutical industry, other similar charities and key stakeholders to the lupus cause so that the services and information offered by LUPUS EUROPE will prosper and grow.

LUPUS EUROPE's Vision, Mission and Core Values sit at the top of everything the organisation does and the Strategic Plan will help enable the implementation of these plans, hopes, beliefs and aspirations.



VISION

That all people with lupus throughout Europe have guaranteed access to competent health carers and high quality treatment and are ensured all the support required to live a comfortable life.

MISSION

To make lupus a well-known illness throughout Europe and, in partnership with the medical profession, secure high quality standards of treatment and support for people with lupus, their families and their carers. To encourage and support the health and social systems of member countries, to allow people with lupus to live independent lives and be recognised as equal members of society.

CORE VALUES

Transparency: LUPUS EUROPE strives to be open and honest in all actions and, therefore, engender trust in all lupus patients, carers and supporters.

Independence: LUPUS EUROPE is an independent organisation with a professional obligation to promote the interests of lupus patients. LUPUS EUROPE is committed to the protection of lupus patients' rights as well as the interests of carers and supporters. LUPUS EUROPE encourages patient empowerment through awareness and education and supports patients to have a say in their treatment, prevention of disease and promotion of health quality.

Democracy: Within the structure of LUPUS EUROPE, all member countries have an equal say in the running of the organisation.

Impartiality: LUPUS EUROPE recognises every lupus patient as a unique individual, treating them with respect and appreciating their right of comment.

Vitality: LUPUS EUROPE encourages member countries to be strong and lively, to energetically support lupus patients, to provide inspiration to cope with their illness and to see a brighter future.

It is important that LUPUS EUROPE also encompasses the following statement:

CODE OF CONDUCT

LUPUS EUROPE will apply the European Federation of Pharmaceutical Industries and Associations (EFPIA) Code of Good Practice on relationships between the pharmaceutical industry and patients' organisations in relation to any funding received from the pharmaceutical industry and will uphold the same Code of Good Practice in relation to funding received from any other source whilst also building in the above principles.

For the three year duration of the Strategic Plan LUPUS EUROPE is concentrating on delivering two strategic drivers:

1. to raise awareness within key audiences of the work of it does and the impact of the illness.
2. to develop a suite of resources to enable the delivery of the Strategic Plan.

STRATEGIC DRIVER ONE:

By 31 October 2012, LUPUS EUROPE will have raised awareness within key audiences of the work it does and the impact of the illness.

Initiatives to achieve this:

- Enhance membership offering with a view to recruiting new members:
 - establish dialogue with lupus groups that are non-members
 - re-engage lapsed LUPUS EUROPE members
- Enhance relationships with LUPUS EUROPE's key stakeholders
 - scope out and prioritise stakeholders¹
 - establish engagement plans for priority stakeholders
 - appoint appropriate 'account managers' within LUPUS EUROPE to cultivate the relationship with each priority stakeholder
- Develop key messages
 - general lupus and LUPUS EUROPE and stakeholders specific
 - topics - Case for Support/fundraising – core and project
 - utilise optimum route to message (see strategic driver 2)
- Scope out all Europe-specific engagement/networking opportunities
 - crystallise purpose of each engagement/networking opportunities for LUPUS EUROPE
 - prioritise these engagement/networking opportunities
 - develop a (rolling) calendar of appropriate engagement/networking activities
 - ensure relevant/appropriate representation at key events
 - purpose
- Explore what actions could be taken to lobby at European level
- Maximise the opportunities presented by World Lupus Day
 - explore Europe-wide simultaneous action in every member country

¹ For example, member countries, European countries without lupus associations, other patient organisations, patients and carers, national groups, supporters, civil authorities, European Commission, companies and industry, medical staff, funders/prospects, media and the public

Target/expected result:

By 2012 LUPUS EUROPE will be a strategic key player where European lupus issues are concerned

STRATEGIC DRIVER TWO:

By 31 October 2012, LUPUS EUROPE will have developed a suite of resources to enable the delivery of its strategic plan.

Initiatives/activities to achieve this:

- Establish a clear and consistent member understanding
 - embark on a rolling programme of consultation with national lupus organisations/member countries:
 - to better understand their needs/aspirations
 - to better understand how they can support LUPUS EUROPE
 - to clarify funding parameters
 - establish member specific resources
 - Marketing materials –
 - Interactive web-calendar
- Maximise the usage of LUPUS EUROPE's Convention:
 - attract world-class speakers
 - explore the possibility of offering bursaries places to members
 - increase the involvement of members in the convention
 - learn from delegate and speaker feedback
 - issue Convention report
- Embark on a programme of capacity building for the Trustees to build their skills and confidence to enable the delivery of the strategic plan
 - undertake a comprehensive skills audit
 - identify and utilise appropriate opportunities
- Identify and utilise volunteer skills and resources
- Use the key messages (see strategic driver one) to inform a communication plan to support the delivery of the Strategic Plan
 - develop and re-launch LUPUS EUROPE's website to meet an agreed brief
 - develop a range of promotional materials to inform and educate key stakeholders (see strategic driver one)
 - conduct a review of the reach, impact and frequency of *Caring and Sharing* (existing)
 - focus Europe-wide media activity around the opportunities presented by World Lupus Day (and the Convention in the host country)
 - through co-ordinated media activity as far as possible

- adhere to the agreed corporate ID
- Establish a Europe-wide Medical Advisory Panel
- Explore the need and feasibility of the establishment of a centralised office which is appropriately staffed.
- Ensure LUPUS EUROPE's long-term financial security and stability
 - Develop an annual budget with associated cash flow
 - Develop an income generation/fundraising plan to realise €????per annum with a balanced portfolio of diverse income streams.

Target/expected result:

By 2012 LUPUS EUROPE will be a sustainable and professional patient-led organisation



This Strategic Plan for LUPUS EUROPE was presented by the Trustees to the Meeting of Council on 11th September 2009, at the Annual Convention in Strasbourg.

Following ratification, the Trustees assumed responsibility for overseeing its delivery from 1st November 2009.