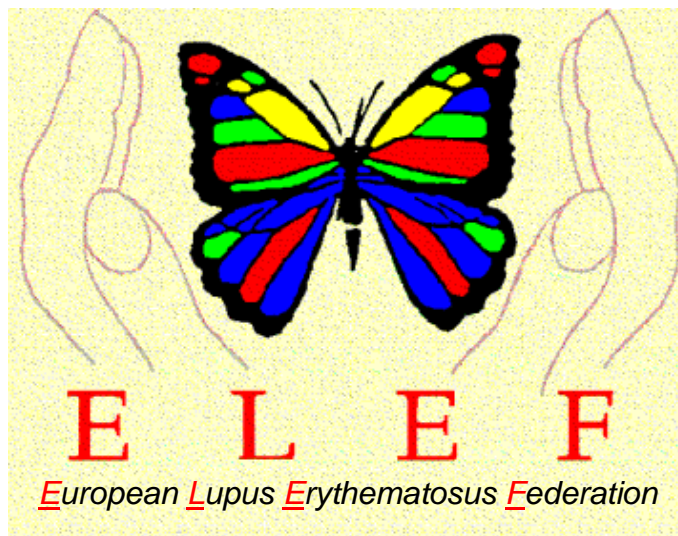


Lupus Group

- Name:
- Address:
- Contact details:
- Telephone:
- Email:
- Web site:



ELEF is the common body for all European Lupus Groups. We meet in September at the ELEF convention.

We aim to bring our cause to the attention of all relevant bodies and counterparts in Europe.

Our *Common Cause* should bring forward the complexity of our disease to all relevant people and bodies.

Our *Common Cause* project should bring both awareness and understanding to our cause throughout Europe.

Our *Common Cause* should bring results of better care of our disease by providing improved knowledge of our worst problems to be solved and clearer picture of our situation.

Our *Common Cause* should show the differences in problems we encounter on daily basis in Europe being a Lupus patient.

Our *Common Cause* should also inspire to new ways of solving some of the most precedent problems, we're facing at the moment.

For more information contact your national ELEF delegate – your country's international contact – or go to ELEF's website for further information:

 www.lupus-europe.org

INVITATION



ELEF COMMON CAUSE

Is there one problem, which has our highest priority in all countries? - on which we can launch a unified campaign?

This question arose on the basis of the newly defined EULAR Recommendations for Management of SLE in Europe - recommendations defined by doctors and to be implemented as standards for our health care. But what is OUR real issue?

ELEF Medical Advisor, professor Matthias Schneider, asked this question in his article in the ELEF Caring & Sharing, winter 2006 "Management of Systemic Lupus Erythematosus – "First Evidence-based Recommendations".

Prof. Matthias Schneider invites us to make this a special ELEF project - the one question, project, idea or trial that has to be answered and followed through.

An issue like this should be an ongoing process. So we suggest that it will start locally, be gathered nationally and then collected internationally; An European Project.

It is a fantastic project to be unveiled through a true evolutionary process - just like a butterfly – an egg, pupic, larva and full bloom ...

We can make this happen. So we start locally –

ELEF COMMON CAUSE – WHY?

All Lupus patients in Europe will speak with one voice.

ELEF will use the power of the voice of all Lupus patients to obtain financial support to solve the raised issue.

The researchers can focus their research on patients' preferences, which may shorten the time needed for patients to benefit from research.

ELEF COMMON CAUSE – WHAT?

What issue could we agree upon - and what subject will truly unify our common cause?

- At first, most important will be the open, unbiased discussion of all relevant issues, nothing in this exchange is really right, nothing is completely wrong
- Then the group locally and, later, nationally will have to decide on topic, idea or area of interest based on the arguments presented in the groups.
- The foremost problem as discussed nationally will be communicated internationally.

ELEF COMMON CAUSE – HOW?

- **What?** - make this a topic at one of your gatherings
- **Who?** – **YOU** submit your suggestion for the most important issue to be focused on. State your reasons why, if you want, or just return the slip with your topic to your local representative.
- **Where?** - the total presentation of important issues in each member country and the argumentation will be *the* topic for a *workshop* at the next *ELEF Convention*.

- **How?** - at the Convention the discussion will lead to a decision on how to move further - what should we seek funds for and where, who should be in charge of concept making and creation of promotional support.

Topic No. 1 will define the scope of the campaign to follow:.

- Will it be a campaign using merchandise (posters, pamphlets, t-shirts etc.) to bring attention to our cause?
- Or will it be a question of communicating directly to officials and politicians with specific goals for research and/or social provisions by letters or lobbyism?
- Or will it prove to be the great task of bringing awareness to all through mass media campaigns?
- Or ...?
- **Follow-up** - at the next ELEF Convention, the results will be followed-up - what worked and why as well as, what did not work.

ELEF COMMON CAUSE – WHEN?

- Initiated January 2007
- ELEF Medical Advisor Prof. M. Schneider
- Designed September 2007 - ELEF Convention Mainz, Germany
- To be presented to all ELEF members by ultimo 2007
- To be campaigned nationally in order to discuss topics and collect responses before or at the national World Lupus Day, May 10th 2008– national group
- Dead line July 1st 08 for national responses to ELEF
- ELEF Secretary
- Evaluation and final definition of project September 2008 - ELEF Project Advisor
- Establishment of project group September 2008 - ELEF Convention to further campaign design to be communicated throughout Europe
- Launch of campaign Spring 2009 throughout Europe according to the decided project scope of campaign.

RESPONSE SLIP

As a Lupus patient, what is the main Topic (problem) that **YOU** would like ELEF to address?

- The one question, project, idea or trial that has to be answered and followed through:

Topic No. 1:

Why:

Member of *Local Lupus Group*: _____

To be submitted to your local group as noted on the reverse or sent by mail to your national group:

 Email-address@nationaldomain.XXX