



**LUPUS
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

NEWSFLASH

The Newsletter of LUPUS EUROPE

April 2010

Dear Friends,

It has been sometime since the last Newsflash was issued, however, it is now back again to update you on the activities within LUPUS EUROPE.

We wish you pleasant reading,
Trustees of LUPUS EUROPE

*** From the Board of Trustees ***

Change of Secretary

At the start of the year, Nele Caeyers was offered a position with EULAR as Co-ordinator of Patient Partnering in Research. This was a wonderful offer to Nele and tribute to the work that she has previously carried out. Accepting this post, however, meant that Nele had to step down as Secretary of LUPUS EUROPE. The Trustees were sorry to lose Nele from this role but so pleased for her that she had been offered such an interesting and prestigious post. We all wish her well.

We are pleased to announce that Ferial Bouabida (Lupus France) accepted the invitation to become Co-opted Secretary. Unfortunately, Ferial has been ill in hospital and, therefore, unable to attend Trustee Meetings in January and March. Thankfully, she is now feeling much better and anxious to begin her new role. As Co-opted Secretary Ferial is hoping that she will be fully elected to the post by Council at the Annual Convention.

Our thanks go to Tony Bonello, Co-opted Communication Advisor and ex-Secretary, who so kindly stepped in to take the Minutes of Trustee Meetings whilst Ferial was ill.

Trustee Meetings

The Trustees met 23/24 January and, again, 26/27 March in London. Minutes of the Meetings have been distributed.

Website

The new website www.lupus-europe.org is now up and running. It is still 'work in progress' so, please let us know if you find anything missing or incorrect.

For any changes/inserts to the website please contact Simone Müller-Pretis at:
projects@lupus-europe.org

UK CHARITY COMMISSION REGISTERED ADDRESS:

St James House, 27-43, Eastern Road, Romford, Essex, RM1 3NH, United Kingdom | Registered Charity No. 803768

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

EU Application for Operating Grant

An application has been submitted for fund raising from the EU Directorate General for Health – DG SANCO – Operating Grant. The application is based on the Strategic Plan which was presented at the 2009 Convention in Strasbourg and will follow the perspectives described within. Details of the plan and the perspectives will be presented at the coming Convention in Budapest

The main purpose is to be in a position to set up a staffed office from which LUPUS EUROPE can be administered and fund raising can be centred. This would ensure our goals for the future are met.

If you want to know more please contact Kirsten Lerstrøm: vicechair@lupus-europe.org

LUPUS EUROPE Register 2010

A revised LUPUS EUROPE Register was issued during January. However, some entries may be incorrect and need amending. Please take a look at your country/group page and, if the information is incorrect in any way, notify Simone with the correct details so that she can ensure the Register has current updated information.

The Register can be downloaded from: www.lupus-europe.org
Please send your amendments to the Register to Simone: projects@lupus-europe.org

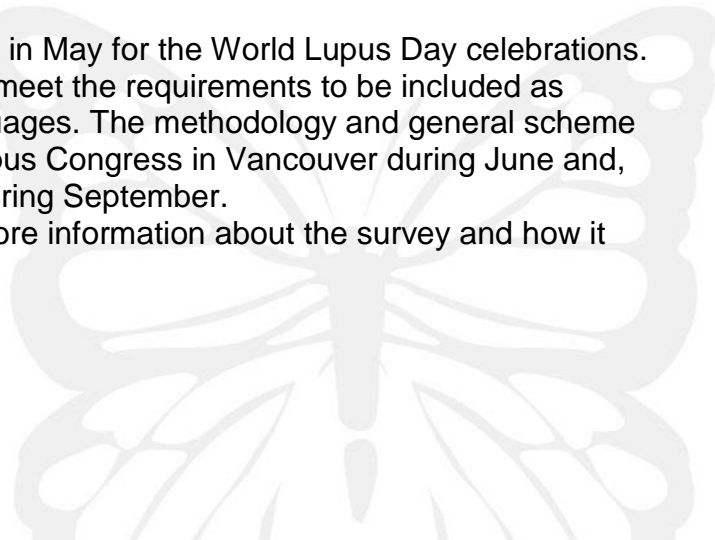
***** Meet the Patient *****

LUPUS EUROPE has presented 'Meet the Patient' events arranged for the staff of the Belgian pharmaceutical company UCB at the UK base in Slough and the headquarters in Belgium. Similar events are planned during the Spring in Germany and Scandinavia. These occasions are a fantastic way of making the voice of European lupus patients heard and of informing pharma companies of the problems for which new medications are needed.

***** Survey II "Living with Lupus" – Career/Work situation *****

A surprising result from the survey last year was that a large majority of people with lupus found having lupus had made a highly significant effect on their life. We would like to investigate this further and have initiated a survey to find out more information.

This second on-line survey will be launched in May for the World Lupus Day celebrations. The survey has been carefully designed to meet the requirements to be included as scientific research and it will be in five languages. The methodology and general scheme will be presented at the 9th International Lupus Congress in Vancouver during June and, also, at the next Convention in Budapest during September. All member countries/groups will be sent more information about the survey and how it can be accessed in the next Newsflash.



***** World Lupus Day 2010 *****

WORLD LUPUS DAY – 10th MAY

A World Lupus Day page is planned for the LUPUS EUROPE website. Please let us know of the events your country/group is organising to mark this special day and your news will be loaded onto the page. Attachments of posters/pictures will be welcome and, if suitable, will also be included.

Please send your news to Simone: projects@lupus-europe.org

WORLD LUPUS DAY – 10th May – Text message by phone campaign

Last year, LUPUS UK initiated the project whereby each member of LUPUS EUROPE was asked to text 10 people who do not have lupus. This project is being repeated again this year. Please take part and send the following text:

**Today is
World Lupus Day**
please forward this message
to 10 more people
and help spread the message
throughout the world

For more information please contact Yvonne Norton: chair@lupus-europe.org

WORLD LUPUS DAY – 10th May – LupusCrossing

Following the success last year of the LupusCrossing project when almost 300 butterfly postcards were sent to Simone Müller-Pretis, the German Lupus Group are planning to produce a special poster depicting some of the postcards and the messages received for World Lupus Day.

For more information please contact Simone: projects@lupus-europe.org

For information on the butterfly postcard project 2009 visit: www.postcrossing.com

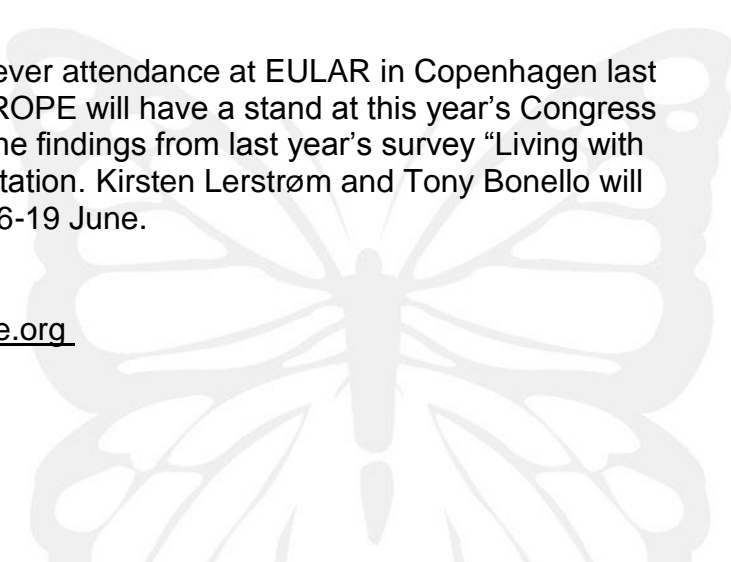
For information on World Lupus Day visit: www.worldlupusday.org

***** EULAR 2010, Rome, Italy *****

Following on from the success of our first-ever attendance at EULAR in Copenhagen last year, it has been decided that LUPUS EUROPE will have a stand at this year's Congress in Rome with Lupus Italy. An Abstract on the findings from last year's survey "Living with Lupus" has been submitted for oral presentation. Kirsten Lerstrøm and Tony Bonello will represent LUPUS EUROPE at the event 16-19 June.

For more information visit: www.eular.org

or contact Kirsten: vicechair@lupus-europe.org



***** 9th International Congress on SLE *****

The 9th International Congress on SLE will take place in Vancouver, Canada, 24-27 June. The Congress takes place every three years when all with an interest in lupus worldwide gather to pass on their knowledge and to learn more of lupus. This year, for the first time, LUPUS EUROPE will have a presence and will be represented by four Trustees – Chair, Vice-Chair, Treasurer and Trustee I.

LUPUS EUROPE will also take part in the IC3 Industry Course UCB “Facing the Butterfly – a review of patient related developments in lupus” (working title) with a presentation by Kirsten Lerstrøm on the aim and main parts of our survey from this year.

For more information visit: www.lupus2010.com
or contact Yvonne: chair@lupus-europe.org

***** GSK Orange Day *****

The pharmaceutical company GSK (GlaxoSmithKline) has initiated a novel way for staff in all departments and locations to assist patient organisations.

All staff will have the opportunity to dedicate one day in the year to a patient organisation of their choice. This will be known as Orange Day (orange being GSK corporate colour). GSK staff working with LUPUS EUROPE have expressed a wish to help lupus patients through their lupus organisation.

Any member group of LUPUS EUROPE having GSK based in their country can apply for help/support for one day in the year. The day will be chosen by the member group or in consultation with GSK but must be taken before the end of 2010.

For more information please contact Yvonne: chair@lupus-europe.org

April 2010
The Trustees
LUPUS EUROPE

