



**LUPUS
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

NEWSFLASH

The Newsletter of LUPUS EUROPE

02-04-2011



St. Katharine's in London, February 2011, flowers as foretoken of spring.

Dear Friends,

Next week we hope to be in Porto to attend the European Lupus Meeting and present LUPUS EUROPE to specialists from all over Europe and beyond. In many countries summertime started this weekend, a good time to ask you about light. Please answer the question that you also received in an email and read the April NewsFlash. We wish you pleasant reading.

Trustees of LUPUS EUROPE

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

***** Survey “Living with Lupus” Abstracts submitted *****

Four abstracts have been filed:

1. “Disease symptoms and coping strategies in patients with lupus”
8th European Lupus Meeting, Porto – Apr 7-9 2011
(based on the combined European and US results of the 2009 survey) Accepted for poster presentation
The poster presentation will be given by Vice Chair Kirsten Lerstrøm. The abstract will be published in LUPUS
2. “Disease symptoms, treatment satisfaction and coping strategies in patients with lupus”
International Society of Pharmacoeconomics and Outcomes Research – ISPOR – 16th International Meeting, Baltimore, MD – May 21-25 2011
Accepted for poster presentation on May 23rd by co-author Mary Crimmings, Lupus Foundation of America.
3. “Impact of lupus on fatigue, health-related Quality of life and work productivity”
Medical and research professionals, EULAR Congress 2011, May 25-28 2011
Submitted
4. “Developing a patient-driven survey to examine the impact of lupus”
PARE, EULAR Congress 2011, May 25-28 2011 **Submitted**

*Further information on these abstracts contact Kirsten Lerstrøm
vicechair@lupus-europe.org*

***** 8th European Lupus Meeting, Porto, Portugal, April 7-9th *****

Our chair Yvonne Norton will speak at the opening session on Wednesday.
‘So, This is Lupus – from the Patients’ point of View’.

If you want more information on this subject, please contact Trustee Membership Manager Blanca Rubio by mail presidencia@felupus.org or Chair Yvonne Norton chair@lupus-europe.org. For information on the meeting, travel and accommodation go to www.lupus2011.org.



*** World Lupus Day 2011 in Europe ***

Repetition. In order to be able to post information on all the activities taking place around Europe celebrating World Lupus Day we ask you to inform LUPUS EUROPE about your plans. We already received a reply from LUPUS UK, Denmark and The Netherlands.

LUPUS UK will, again, be concentrating on schools using interactive bookmarks and bright posters. The multi-text project (text 10 people who do not have lupus and tell them it is WLD) which has been so successful the past 2 years will also be repeated. The LUPUS UK AGM & National Conference coincides with WLD so this is a great opportunity to promote this special day in UK. LUPUS UK also has a new poster for 2011, Let's Work Together has been produced with thanks to EULAR for the use of their 'cog' logo.

In The Netherlands a lupuswalk will be organised in the city of Utrecht. The lupuswalk will start at the Central Station and end in a park where there will be a stand with information, balloons, small gifts, all signed with the letters www.nvle.org, website of the Dutch Lupus Group. There will also be Tai Chi in the park in order to make people curious so that they will want to see who is there and why they are there. Local television and press will be invited.

In Denmark the 6th WLD conference will take place in Copenhagen and, as always, will be arranged in close collaboration between Lupus DK and the hosting tertiary Rheumatology department. The theme is "Lupus in your Life" with presentations on different aspects of consultations and clinical practice. A press campaign will also cumulate on the day taking onset in testimonies of people with lupus.

If you would like to add information on your events and/or initiatives, please send a short note on this to Secretary Marja Kruithof secretary@lupus-europe.org.

*** Hungary ***

Gábor Varga sent the last newsletter of the Gabriella Schopper Hungarian Lupus Group with many beautiful pictures of the Budapest Convention.

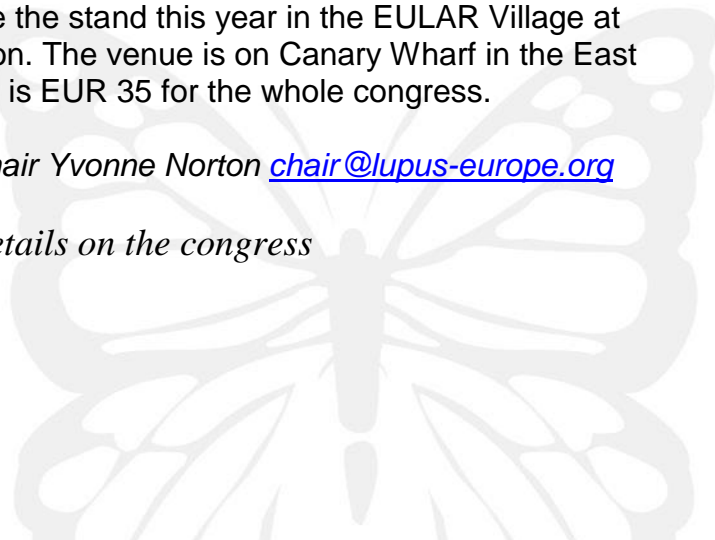
If you want to have a look please inform Gábor Varga gabor@lupusz.hu and he will send you the newsletter Lepke, Hungarian for butterfly.

*** EULAR Congress 2011, London ***

LUPUS UK and LUPUS EUROPE will share the stand this year in the EULAR Village at EULAR Congress 2011 May 25-28 in London. The venue is on Canary Wharf in the East End of London. Registration fee for patients is EUR 35 for the whole congress.

If you attend the congress please inform Chair Yvonne Norton chair@lupus-europe.org

Please check with www.eular.org for details on the congress



***** The Edgar Stene Prize – Fatima Lavoll is Member of the jury *****

Fatima Lavoll has been appointed by the Norwegian Rheumatism Association to sit as jury member on the Edgar Stene Prize. In 2011 the Edgar Stene Prize will be awarded for the essay topic “How Exercise Improves my Life with a Rheumatic Disease”. The winner will be announced at EULAR during the Opening Ceremony

***** Lighting issue *****

LUPUS EUROPE has signed-up to support the lighting issue of the problems that low energy light bulbs can cause a lot of people who are photosensitive. Many lupus patients are affected and wish to be able to continue using incandescent light bulbs, which are being phased out.

It has been reported that some European countries are avoiding the ban by selling incandescent light bulbs as “heat bulbs”. Do you know of this? Is it happening in your country? *If you know of this or have any other news on the banning of incandescent light bulbs from your country please mail Chair Yvonne Norton chair@lupus-europe.org*

***** Meet the Patient – events *****

If any of you or our members are invited to give a presentation at a “Meet the Patient”-event for national health authority institution employees, peer patient presentations or research or other events and want to see an example of such a presentation we are happy to send you the Power Point presentation on this subject.

Please contact Vice-Chair Kirsten Lerstrøm, vicechair@lupus-europe.org for further information.

2nd t April 2011
Marja Kruithof
Secretary LUPUS EUROPE





St. Katharine's in London, chapel

