



**LUPUS  
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

# NEWSFLASH

The Newsletter of LUPUS EUROPE

25-01-2011



## ***St. Katharine's in London, December 2010***

Dear Friends,

**Happy New Year !**

**We hope you have all had a good start to a year that looks very promising for LUPUS EUROPE. Thanks for the greetings, wishes and photos you sent us. For Christmas we were blessed with a very special gift – finally an International Consensus on Definition of Disease Flare in Lupus was reached. This year could be the year where we will have a new medical treatment for lupus approved in 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

– perhaps on the market already in the third quarter. Last time this happened was in 1958! In April LUPUS EUROPE will take part in the 8<sup>th</sup> European Lupus Meeting Porto 2011 and in May an information stand is planned at the EULAR Congress 2011 in London. Just to mention some of the important events during the year ahead.

In this NewsFlash you can read all about these and much more.

We wish you pleasant reading.  
Trustees of LUPUS EUROPE

### \*\*\* International Consensus on Disease Flares in Lupus \*\*\*

In December we finally received news on the International Consensus on how to assess a lupus flare. This has been lacking especially in lupus clinical trials for cross reference of results and also for correspondence between clinical practices – and for our own benefit. The Lupus Foundation of America has been the driving force behind this and proposes it should be agreed.

The definition reads: “A flare is a measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or laboratory measurements. It must be considered clinically significant by the assessor and usually there would be at least consideration of a change or an increase in treatment.”

Further information please see the article posted on <http://www.lupus-europe.org/info-center/news-archive/archive/2011/01/05/consensus-on-flare-definition-in-lupus/>

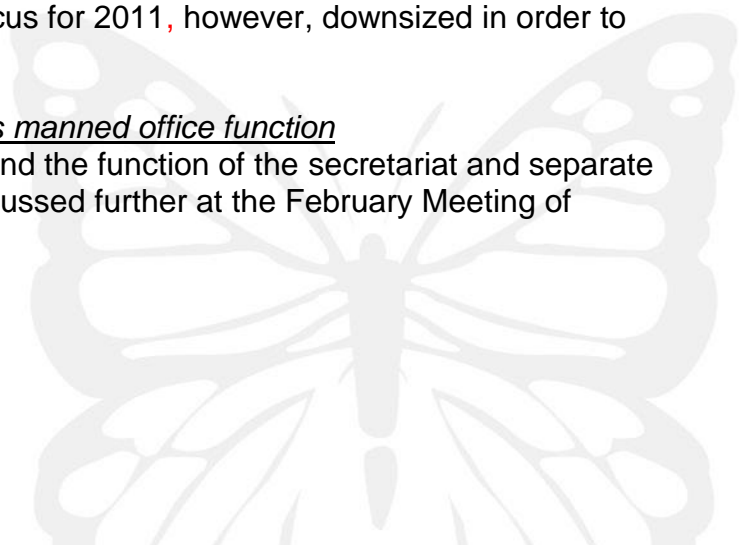
### \*\*\* From the Trustees \*\*\*

In early December, a Meeting of Trustees took place in London at the Royal Foundation of St. Katharine, unfortunately under great influence from weather, strike and illness. Minutes will be distributed separately, but in this NewsFlash you can find the most important items with consequence on the activities in 2011.

In Budapest, Council approved Work Plan 2011 as presented in connection with the application for EU Operating Grant. Sadly, the application was not successful so the Trustees decided to keep the aims and focus for 2011, however, downsized in order to meet the situation at hand.

### No Secretary General but a less ambitious manned office function

Plans for job description, announcement and the function of the secretariat and separate funding have been drafted and will be discussed further at the February Meeting of Trustees.



### Saving on travel and meetings

Meetings and travel will be economized, so that we will take advantage of arranging other commitments while attending the two big events during spring. In Porto meetings are planned with the Medical Advisory Panel and also partners within the industry, and in London a meeting of Trustees will follow EULAR.

### Abstracts submitted

During the past three months much hard work has been carried out on analysing and presenting the results for the scientific events this year. Four abstracts have been filed:

1. "Disease symptoms and coping strategies in patients with lupus"  
8<sup>th</sup> European Lupus Meeting, Porto – Apr 7-9 2011  
(based on the combined European and US results of the 2009 survey)
2. "Disease symptoms, treatment satisfaction and coping strategies in patients with lupus"  
International Society of Pharmacoeconomics and Outcomes Research – ISPOR –  
16<sup>th</sup> International Meeting, Baltimore, MD – May 21-25 2011
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
4. "Developing a patient-driven survey to examine the impact of lupus"  
PARE, EULAR Congress 2011, May 25-28 2011

*Further information on these abstracts only if and when they (hopefully) are accepted for the occasion and to be published in the respective publications. contact Kirsten Lerstrøm [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org)*

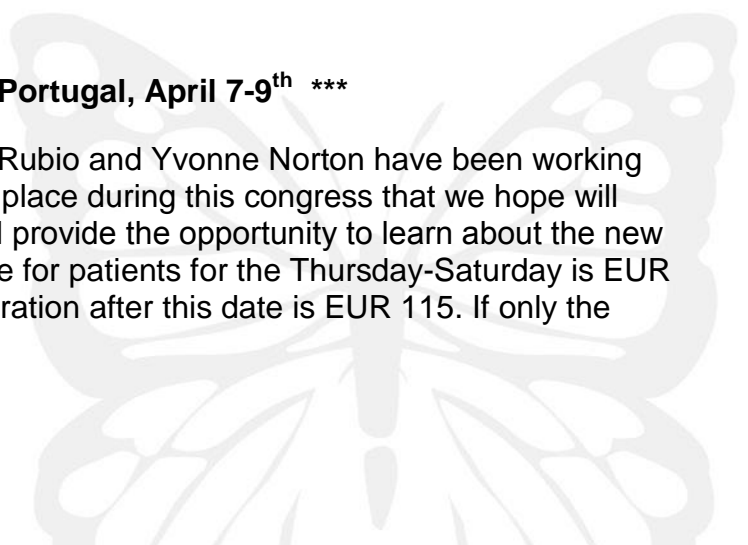
### **\*\*\* Photos from LUPUS EUROPE Convention 2010 in Budapest \*\*\***

In December a new facility was launched for delegates to the convention in Budapest. A Picasa web-album was created and people added photos so that now 347 great pictures are available online. The album is only accessible by invitation – this was sent to the e-mail addresses as per Webmaster Simone Müller-Pretis list after the convention.

*If you have not received the invitation and would like to know more please contact Kirsten Lerstrøm [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org).*

### **\*\*\* 8<sup>th</sup> European Lupus Meeting, Porto, Portugal, April 7-9<sup>th</sup> \*\*\***

Over the winter, Rosa Gonçalves, Blanca Rubio and Yvonne Norton have been working on designing a patient programme to take place during this congress that we hope will bring attention to patients' perspective and provide the opportunity to learn about the new frontiers of lupus research. Registration fee for patients for the Thursday-Saturday is EUR 100 if registered before March 15<sup>th</sup>. Registration after this date is EUR 115. If only the



Saturday, then the fee is respectively EUR 10 and EUR 15. Trustees of LUPUS EUROPE encourage delegates from the national groups to attend.

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

### **\*\*\* World Lupus Day 2011 in Europe \*\*\***

This year we would like to be able to post information on all the activities taking place around Europe celebrating World Lupus Day.

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.

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](http://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.

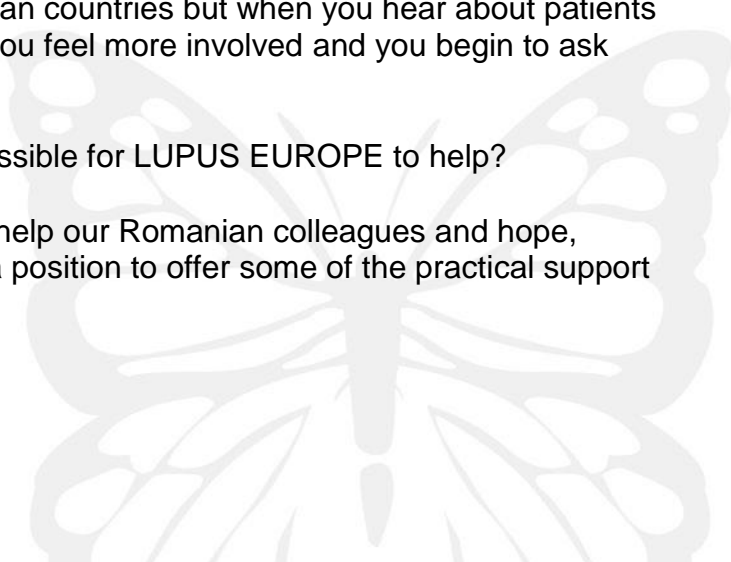
In Denmark the 6<sup>th</sup> WLD conference will take place in Copenhagen and, as always, will be arranged in close collaboration between Lupus DK and the hosting tertiary Rheumatology department. The theme is "Lupus in your Life" with presentations on different aspects of consultations and clinical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

### **\*\*\* Awareness \*\*\***

In The Netherlands members of the Dutch Lupus Group were shocked when they read about the difficult situation for patients with lupus in Romania in the article about the Budapest Convention of LUPUS EUROPE in the Dutch magazine. People are aware of the differences in healthcare in the European countries but when you hear about patients with the same illness that you have, then you feel more involved and you begin to ask questions.

Can we, as a national group, help? Is it possible for LUPUS EUROPE to help?

The Trustees are seeking to find a way to help our Romanian colleagues and hope, following their February meeting, to be in a position to offer some of the practical support that LES Romania requests.



**\*\*\* Lupus Awareness \*\*\***

Last year the Cyprus Lupus Group organized an event for Lupus Awareness Month in a shopping mall with a party for the young ones. Visitors to the mall were given leaflets about lupus and about the Cyprus Lupus Group. It was a big succes and great fun for everyone.



*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](mailto:secretary@lupus-europe.org).*

**\*\*\* 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.

*Please check with [www.eular.org](http://www.eular.org) for details on the congress, or contact Kirsten Lerstrøm [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org).*

**\*\*\* Breaking News! \*\*\***

See item - *Abstracts submitted 1*

The abstract submitted for 8<sup>th</sup> European Lupus Meeting, Porto, Portugal, April 7-9<sup>th</sup> has been accepted for poster presentation!

More details in the next NewsFlash.

25<sup>th</sup> January 2011  
Marja Kruithof  
Secretary LUPUS EUROPE

