



**LUPUS
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

NEWSFLASH

The Newsletter of LUPUS EUROPE

14-02-2012



Dear Friends,

Happy Valentine's Day ♥

The year 2012 started with a lot of activities for those who were involved in the organization of the Excellence in Rheumatology Congress in Madrid January 25-28. Please see the pictures and read about this congress and several other items in this NewsFlash.

**We wish you pleasant reading.
Trustees LUPUS EUROPE**

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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

Excellence in Rheumatology 2012, Madrid

Many lupus patients who had registered for this Congress were present at the opening ceremony on Wednesday evening and the welcome reception. On Thursday afternoon the patients' programme started for 25 lupus patients and 25 patients with RA. It was great to be together, to hear excellent presentations, attend a workshop and, especially during Friday afternoon, there was much discussion in the interactive session. You can find the whole programme on www.excellence-in-rheumatology.org at EiR Patients Meeting. In the following weeks, webcasts, presentations and expert interviews from EiR 2012 will be put online. All lupus patients, from thirteen different countries, will spread the information from this Congress in their own country.

Think Tank

Wednesday 25th January, Yvonne Norton, Peter Norton and Marja Kruithof attended the EiR Summit/Think Tank on Pain. Yvonne and Marja participated in the group who discussed the impact of pain and Peter joined the group on improving the pharmacological management of rheumatic pain. The purpose of the Think Tank is to provide direct recommendations to the EiR Institute's Board. "I very much hope that this will develop further and that all those taking part will be included in any feed-back/progress". This was Yvonne's conclusion.

Chair of the Think Tank, Professor Peter Taylor, is sitting at the head of the table.



Panel discussion

Gareth Treharne, Gina Plunkett, Elizabeth Hale, Piet van Riel



Networking during breaks



More Networking

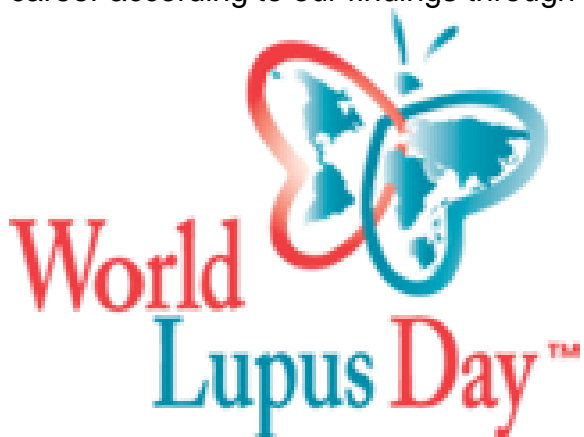


Thursday evening Patients' dinner.



*****Make lupus Work*****

The campaign slogan and theme for World Lupus Day 2012. Artwork is being created based upon the profile pictures of the delegates to LUPUS EUROPE Convention in Copenhagen. We will send you more information as soon as possible. We will supply ready to use material for national campaign together with a fact sheet on lupus and career according to our findings through LEO as well as other relevant sources.



*****Secretariat function for LUPUS EUROPE*****

This is a project that the Trustees have worked for during the past year and half. Now the sponsorship is reaching a stage of operation where announcement on this vacancy can, hopefully, be published this spring.

*****Trustee Meeting in London, February 28-March 1st**

Among other things, the Trustees will discuss the secretariat function, the convention in Cyprus and the coming presentations on international level at IAPO in March and EULAR in Berlin in June.

*****LUPUS EUROPE Convention in Cyprus*** ATTENTION NEW DATE**



Due to problems with hotel arrangements the dates are changed. People involved in the organizing committee from Cyprus have worked very hard and are happy with this outcome. Because Cyprus is head of the European Union in the second half of this year, it is advisable to check flight possibilities at an early date. The Convention will start Wednesday November 14th with a welcome dinner and will end on Saturday evening November 17th 2012.

Announcement and call for delegates will be made in early Spring 2012 by Fatima Lavoll Convention Manager.

*****International Alliance of Patients' Organisations 5th Global Congress - London, March 17-19*****

LUPUS EUROPE has been invited to give an oral presentation at this Meeting. Kirsten Lerstrøm will tell about 'Living with Lupus – development of a European patient-driven survey to examine the impact of Lupus' in the session entitled: Engaging patients for better care. The session will explore different models for capturing patient perspectives and ensuring that these are integrated into decision-making. The session will consider how these processes can be strengthened.

<http://www.patientsorganizations.org/>

*****Publication of LEO Results*****

The preplanning of aim, focus and content is currently being discussed by LUPUS EUROPE, the Medical Advisory Panel, UCB and analysts. The aim is to have a paper of LEO results submitted during spring for the hopeful acceptance by a high-level Rheumatology Journal. Following publication, the national situation in selected countries, based upon the results and where significant to address nationally, can be followed through.

*****8th International Congress on Autoimmunity, Granada, May 9-13*****

During this Congress there will be a Patients' Forum for Spanish patients. Blanca Rubio will open this meeting. For more information see www.kenes.com/autoimmunity
The scientific programme is in English, the patients' programme is in Spanish.



*****LUPUS EUROPE has been invited to give an oral presentation at EULAR 2012 Berlin*****
In the PARE Session entitled "**Less well-known but just as important: some 'other' rare musculoskeletal diseases**"

The session is scheduled for **Wednesday June 6th 17:00 - 18:30** in "Room NEW YORK 3"

More information in the next NewsFlash

Marja Kruithof
Secretary LUPUS EUROPE