



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

# NEWSFLASH

**LUPUS  
EUROPE**

The Newsletter of LUPUS EUROPE

June 2010

Dear friends,

In few days LUPUS EUROPE will prepare to take part in two major events. First, at the annual Congress of EULAR, 16th - 19th June, in Rome and then in Vancouver for the 9th International Congress on SLE where we will participate at a high level this year.

New promotional material of leaflets and poster has been produced for the occasion of EULAR and the International Congress of SLE. You will find information on these events below also where you can find us if you are planning to attend one or both events. It will be a pleasure to see you there.

We wish you pleasant reading.

**\*\*\*Trustees of LUPUS EUROPE\*\*\***

**\*\*\*EULAR Annual Congress 2010, Rome, Italy \*\*\***

*LUPUS EUROPE Poster to be presented at EULAR*

Poster will be presented in PARE Poster area Thursday and Friday 12.00-13.45, Saturday at 10.45-12.00 by Vice-Chair Kirsten Lerstrøm assisted when possible by the co-authors represented by Prof. David Isenberg (University College, UK) and Dr. Marinella Govoni (UCB S.A.).

*Lupus Italy and LUPUS EUROPE share the stand D14-5*

Lupus Italy and LUPUS EUROPE share the stand D14-5 in EULAR Village by the PARE Poster Area. Here Augusta Canzone (Chair LES Roma, Lupus Italy) + other representatives from Lupus Italy, Tony Bonello (Co-opted Communications Advisor) and Kirsten Lerstrøm (Vice-Chair) will welcome all visitors and do our best to promote our cause of bringing awareness to Living with Lupus in Europe.

If you plan to attend EULAR, please bring your own presentation material to our stand to be displayed.

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

### EULAR Scientific and PARE Programme

In the EULAR Scientific Programme you'll find sessions presenting the most recent developments within our world of rheumatism - diagnosis, monitoring and new therapies. In one of these sessions Prof. David Isenberg, member of LUPUS EUROPE Medical Advisory Board, will present the topic "Sero-negative autoimmunity" in SLE : « How can lupus be sero-negative? » (Saturday 19.06.2010, 08.45 - 10.15. Room 3B.).

We are also happy to inform you that our former secretary, Nele Caeyers, will chair a PARE Session on a topic entitled : « Patient participation in research » (Room 10 D.E., Friday 13th June, 13.45-15.15). Besides the concrete sessions focused on SLE then we look forward to these days of news gathering, exchange of information and networking.

Further information on the EULAR Congress Programme at [www.eular.org](http://www.eular.org) or contact Vice-Chair Kirsten Lerstrøm [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org).

### **\*\*\* 9th International Congress of SLE, Vancouver, Canada \*\*\***

The International SLE Congress is a triennial meeting in which patients, physicians and researchers will meet together to share the latest developments in lupus. During 3 days more than 60 of the world's top lupus research and lupus experts will give participants finest information on lupus research and therapies.

We would like to thank UCB S.A. for funding which has allowed LUPUS EUROPE to have a strong presence of four representatives at this major event. We are also grateful to the F. Hoffmann-La Roche Ltd. which has made it possible for us to have our design continued into production of a leaflet which will be included in the official congress bag.

We are grateful for the support of our sponsors in this event.

### A brief look at the programme

International Congress on SLE will have two strands of events - one scientific and the one on patient education running somewhat parallel programmes.

Main idea and focus for the scientific strand is :

- **Identify future opportunities in research; identify, assemble, and facilitate the next generation of leaders and their mentoring with the current leaders in SLE;**
- **Close the gap between what we know what we do and what we could do worldwide in SLE therapeutics, medical and public education, clinical and fundamental research.**

The patient education programme will be presented under three broad categories: Understanding lupus, What is Current and Living with lupus.

This year, LUPUS EUROPE will take part in the program during the closing Symposium, sponsored by UCB, on the Quality of Life and Lupus. It will feature a presentation of the methodology of the current LUPUS EUROPE on-line survey, Career/Work Situation, given by Kirsten Lerstrøm.

The Symposium will be chaired by Prof David Isenberg and will include a Talk on Fatigue and Lupus by Prof Caroline Gordon – both professors being members of the LUPUS EUROPE Medical Advisory Panel. The Symposium will also hear from representatives of the Lupus Foundation of America (LFA) with whom LUPUS EUROPE has an excellent working relationship.

*LUPUS EUROPE is part of the Industry Course 3 "Facing the Butterfly"*

Closing congress is Industry Course 3 sponsored by UCB S.A: "Facing the Butterfly - a review of patient related developments in lupus". The IC has been planned together with our most respected specialists in Europe and in the US, The American Lupus Foundation, UCB and LUPUS EUROPE. This is the only of the three industry courses presenting patients views!

The Industry Course will be chaired by Prof. David Isenberg (University College, UK) who will open the event with a presentation on "New era for the treatment of lupus (biologics and Role of BILAG)". Dr. Kenneth Kalunian (USA) will follow on "Therapeutic Update". Under the heading "Sharing personal knowledge & understanding of lupus - LUPUS EUROPE & Lupus Foundation of America".

Kirsten Lerstrøm will present Survey II Living with Lupus: Career / Work Situation (Methodology and main targets) and Cindy Coney of LFA will present on Coping Strategies following diagnosis. The IC will end by the presentation of Prof. Caroline Gordon (Birmingham University, UK) under the heading "Living with Fatigue".

Yvonne Norton (Chair), Kirsten Lerstrøm (Vice-Chair), Peter Norton (Treasurer) and Fatima Lavoll (Trustee) are all looking forward to meeting up with delegates from member groups as well as from patient groups world-wide to exchange experiences and discuss ideas for working together to create awareness of patient organisations and to better promote lupus.

**\*\*\* EPF Spring Seminar \*\*\***

The European Patients' Forum (EPF) arranged a seminar on Health Technology Assessment in conjunction with the Annual General Meeting in Brussels in May 18-19. Marja Kruithof of NVLE, Netherlands, represented LUPUS EUROPE at this event.

EPF is the « umbrella organisation » of pan-European patient organisations active in the field of European public health and health advocacy. EPF represent 44 patients' organisations. LUPUS EUROPE was admitted as member in March 2009.

Health Technology Assessment (HTA) has become a priority area at EU level, primarily as part of a strategy to ensure the sustainability of healthcare systems, and to enhance EU

cooperation and good practice in this area of HTA. For more information please look here <http://www.eu-patient.eu/Initatives-Policy/Events/Annual-General-Meeting-2010/AGM-Presentations-and-Reports/>

Marja has kindly agreed to give us an introduction to the subject at the convention in Budapest.

**\*\*\* Survey II Living with Lupus: Career / Work Situation \*\*\***

As of June 15th, 1351 people have responded! (French and Italian versions still a little short of the 200 minimum and the German version leaping in front with 477!)). This reporting the actual responses from all countries is produced for your information and to be used as reference for presenting at EULAR and the International Congress in Vancouver. According to the plan in Fact Sheet Survey next update will be by July 1st.

A basis is needed of more than 200 respondents per language! This in order to be able to present material of value to be included in future research. A large number of responses will show that LUPUS EUROPE members carry an important voice to be counted on when looking at the European picture of lupus.

This will be better proved by a good representation from all parts of the region, from all socio- economic levels and from all aspects with importance to handling our disease. Please do your best to promote this survey among your networks, web sites and best venues of contact to people with lupus.

**Deadline is August 15th 2010!**

English version: <http://www.surveymonkey.com/s/VNR5XPM>

French version: <http://www.surveymonkey.com/s/ZYS5NZS>

German version: <http://www.surveymonkey.com/s/2VCLY2Q>

Spanish version: <http://www.surveymonkey.com/s/M8Y8MS3>

Italian version: <http://www.surveymonkey.com/s/YFX2BBY>

For further informations please contact Kirsten Lerstrøm at [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org)  
Or check out our web site : <http://www.lupus-europe.org/>

**\*\*\* LUPUS EUROPE Annual Convention, Budapest, Hungary, September 22-26 \*\*\***

In May Convention Manager Fatima Lavoll sent to all members the Convention booking details, programme and attached the draft for our Work Plan 2011 as information. Bookings details in the Registration Form should be mailed .....

Trustee elections will take place during Council sessions. The posts for nomination this year, will be: Chair (1 year), Vice-Chair (3 years), Treasurer (2 years), Secretary (1 year) and Trustee II (2 years). The nominations form will be sent separately very soon.

The Treasurer wishes to remind all national groups that annual subscriptions should be paid prior to the Convention - "no payment, no vote".

More information about the Annual Convention will be provided in the July NewFlash.

**\*\*\* Trustee Meeting \*\*\***

Next meeting of Trustees will take place in London from 8th - 10th August 200. It will naturally be focusing on the experience from the participation in the two main events EULAR and International Congress in Vancouver, planning our coming Convention in Budapest and conducting elections for our board at this same occasion. As always Minutes from the meeting will be sent to all members.

**\*\*\* Caring & Sharing \*\*\***

CARING AND SHARING, LUPUS EUROPE's magazine, will be published by the middle of December 2010. National groups who have material in the form of articles/notices/photographs for this year's edition are urged to send them to the Editor at [secretary@lupus-europe.org](mailto:secretary@lupus-europe.org) by the middle of October 2010.

*June 2010  
Ferial Bouabida  
Co-opted secretary  
LUPUS EUROPE*

