Dear Friends,

At the end of May all Trustees of LUPUS EUROPE, together with co-opted Tony Bonello were in London to attend EULAR and present LUPUS EUROPE. In this NewsFlash we also inform you on a Conference in Madrid, January 2012, and the Convention in Copenhagen.

We wish you pleasant reading.

Trustees of LUPUS EUROPE
EULAR, the Annual European Congress of Rheumatology, is an important platform of scientific and clinical information in Europe. During the Congress there is interaction between medical doctors, scientists, people with arthritis/rheumatism, health professionals and representatives of the pharmaceutical industry worldwide. This year there were 16106 participants, only a small number of them were patients.

LUPUS UK and LUPUS EUROPE shared a stand in the EULAR Village. Tony Bonello, as representative of LUPUS EUROPE welcomed a lot of visitors, one of them the former Secretary of LUPUS EUROPE Nele Caeyers. We hope that the contacts with these visitors will lead to new plans and are happy that there was such interest in lupus.
Jane Robinson, from LUPUS UK, was also in the stand. You see her on the picture together with our Chair.

On Thursday we attended the UCB Satellite Symposium

“Chasing the Butterfly – where are we in SLE?”

*Introduction: Where are we in SLE? Graham Hughes (UK)*
- Today’s symposium “Chasing the Butterfly: where are we in SLE?” brings together leading clinical lupus experts from North America and Europe to talk about important developments in our understanding of SLE.

*The immunology of SLE and its disease pathogenesis Jennifer Anolik (US)*
- SLE is a complex autoimmune disease with considerable heterogeneity in clinical manifestations and disease course, characterised by pathogenic autoantibody formation, immune complex deposition and organ damage. The continuing need for more effective therapies with less toxic side effects has led to an interest in targeted biologic therapies.

*Optimal care for the lupus patient with existing therapies Ronald van Vollenhoven (Sweden)*
- Treatment of patients with SLE remains a major challenge for the practicing rheumatologist. Depending on the manifestations of SLE (mild, moderate or severe) treatment will vary. For many patients SLE is a chronic, smouldering disease, and for such patients, corticosteroids should be minimised, and disease
control must be sought using antimalarials and immunosuppressives. In addition, the clinician must actively pursue prevention of long-term consequences of the disease, including cardiovascular disease and osteoporosis. Some biologicals are being used in the treatment of SLE.

*What do current SLE clinical trials mean for the future? Bevra Hahn (US)*

- Recent clinical trials in SLE, both successful and unsuccessful, have given an indication of strategies for further trials. Future studies must address statistical power, homogenation of study populations, effects of race, attention to dosage with the desired biologic effect, and inclusion of measures of quality of life and fatigue.

*Current and future role of health technology assessment (HTA) in chronic conditions, such as lupus Steve Palmer (UK)*

- While clinical effectiveness remains the most important consideration in HTA, assessments of cost-effectiveness are becoming increasingly used as an input into decisions regarding which technologies also represent good value at the level of the health care system.

*followed by Panel discussion.*

During breaks we had time to visit other stands like the stand of the American APS
Kirsten Lerstrøm gave an oral presentation on the methodology of the survey Living with Lupus: Career/Work situation about the onset, organisation, structure and designing the questionnaire. The findings of this survey is now presented as the Lupus European Online (LEO) study.
Poster presentation on the top results from the survey and each of the four individual parts. LUPUS EUROPE Medical Advisor Professor Matthias Schneider presented the poster.

If you want more information on the abstracts [www.abstracts2view.com/eular](http://www.abstracts2view.com/eular) Submit at the bottom of the page and the list of abstracts EULAR 2011 is shown. Click on Abstract Session: From abstract to concrete the variety of PARE organisations OPO277-PARE Lupus European Online (LEO) Survey, a patient-driven survey to examine the impact of lupus.
LUPUS EUROPE attended the Meeting of the Standing Committee of People with Arthritis/Rheumatism in Europe, PARE

- LUPUS EUROPE has applied to become a co-opted member in order to become entitled to be present with more than one representative at meetings, have a right to vote, and have a basis to promote lupus among other rheumatism associations.

- At the meeting the results from the events in the past year under Belgian rule were presented. Attention for Muscoskeletal diseases will be asked from the EU Parliament and the EU Commission.

- New ideas and important issues for 2012 were presented, for instance the issue of Cross Border Health Care.

- A suggestion is to have a special PARE session at next year’s congress about umbrella organisations like LUPUS EUROPE.
Friday morning LUPUS EUROPE had been invited to take part in the EULAR Task Force on SLE. The meeting was about research trends, for instance the invitation to Lupus Centres to get involved in different research projects. It was about complexity of research in lupus, learning from research on other diseases where complexity and special knowledge is required (Alzheimer, Multiple Sclerosis). The aim is to place lupus higher on the priority list of EULAR and to work together in research on lupus in Europe as much as possible. Our chair Yvonne Norton and co-chair Kirsten Lerstrøm have been invited to be part of this new project.

In EULAR Village was a garden where during breaks people could meet and have lunch.
The days were long. If you want to know more about EULAR [www.eular.org/eular2011](http://www.eular.org/eular2011)
During EULAR was a meeting on a Conference next year in January in Madrid. This year the first Excellence in Rheumatology Conference was in Istanbul. Next year there will also be a patients programme.

***ADVANCE NOTICE Excellence in Rheumatology ***

The second Excellence in Rheumatology Conference will take place in Madrid, 25-28 January 2012.

The Conference will boast a number of innovative ideas including a Patient Programme designed by a ‘Patient Committee’ focusing on two distinct disease areas, Lupus and Rheumatoid Arthritis (RA). The three members of the 'Patient Committee' working on the Lupus Programme are from LUPUS EUROPE - Yvonne Norton (Chair), Peter Norton (Treasurer) and Marja Kruithof (Secretary).

For the first time ever, bursaries will be available for patients to attend a scientific Conference. A total of 50 bursaries will be shared by Lupus and RA, 25 each. The Lupus bursaries will be offered to all member countries/Groups, with 1 delegate from each Group being able to attend the Conference at no cost to themselves except for the time and commitment to fully participate and to disseminate what they have learnt to a wider patient audience in their home country.

Preference will be given to patients who have not previously had the opportunity to attend international Conferences and who will be prepared to share information with other patients on their return. A good understanding of English is essential.
Also at the Conference:
- Expert patients manning stations that health professionals can visit during breaks
- ‘Hot Spots’ where patients can discuss issues with health professionals
- Patient delegates will have open access to scientific sessions

Application forms will be mailed to all member Groups with the closing date for return being 15th October 2011.

Bursaries will include:
- Economy class tickets from country of origin to Madrid
- 3 nights’ accommodation in Madrid for the duration of the Patients’ Meeting and EiR
- Registration to attend the Patients’ Meeting and EiR

Please visit [www.excellence-in-rheumatology.org](http://www.excellence-in-rheumatology.org) to discover more about the Conference and the list of Speakers and Facilitators for the exciting Patient Programme and watch out for the mail that will deliver the Application form.

Further information if needed from: Yvonne Norton – [chair@lupus-europe.org](mailto:chair@lupus-europe.org)

***Convention in Copenhagen 21 – 24 September 2011***

We are happy with the Registration Forms that we already received.
The final date to register for the Convention is 21st August.
The Trustee Election Nomination Form must be completed and returned by August 6th.

25th July 2011

Marja Kruithof

Secretary LUPUS EUROPE