



**LUPUS
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

NEWSFLASH

The Newsletter of LUPUS EUROPE

21-09-2012

Message from the Chair:

Dear Friends,

As ever, the months roll by more quickly as any of us would like and, suddenly, it is the Annual Convention again – this time in Nicosia, Cyprus.

Our Friends within Lupus Cyprus are working hard to provide a Convention that will be pleasing for everyone and they are working closely with the Trustees to set up a programme that will have a good mix of business sessions, medical presentations and social events.

During the Convention of 2008 in Palma de Mallorca, Spain, big changes were made. ELEF became LUPUS EUROPE and I was elected first Chair of the newly-named organisation. Over the past four years I have worked hard (and long hours) to bring LUPUS EUROPE to the fore of the worldwide Lupus stage and I am proud of some of the outcomes. This year we have exceptional circumstances with four Trustee places becoming vacant. I have decided to step aside and, along with Peter Norton (Treasurer) and Fatima Lavoll (Convention Manager) to make way for others to form a new Board of Trustees. The post of Secretary is also open due to Marja Kruithof stepping down during May for health reasons.

The date for Trustee nominations has been extended to 30th September. I hope that by this date there will be enough nominations to make voting for each vacant post possible and that the close of Convention will see a newly-elected Board of Trustees prepared to move onwards into 2013 to continue the work of the past four years.

I look forward to November and the Annual Convention in Cyprus.

Yvonne Norton MBE
Chair, LUPUS EUROPE

***** LUPUS EUROPE Convention 2012, 14-18 November, Cyprus *****

The Cyprus Tourism Organisation is the main sponsor for the host CYPLAR, Cyprus League Against Rheumatism and would like to attract the attention to the presentation of the beautiful country on the web site www.visitcyprus.com.

Programme and general information for registering was sent out in March, but please contact Fatima Lavoll, convention@lupus-europe.org if you have any queries.



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

***** LUPUS EUROPE Meeting of Trustees, London, September 12-14 *****

In preparation for the LUPUS EUROPE Annual Convention in Cyprus, the recent meeting of Trustees in London focussed on the Convention – attendance and elections. A special workshop was held to discuss the best way and means to use the results from the survey Living with Lupus II, which is also known under the name Lupus European Online (LEO) when the results have been used for research and presentations. The experience from MAKE LUPUS WORK – the WLD campaign from this year was part of the discussions.

***** T2T SLE – Treat to Target in Lupus – from ? to ! *****

In May this year a first meeting took place in Zurich where a group of lupologists discussed whether it is possible at all to set a target for treatment in lupus – T2T SLE ?

The meeting outcome was; YES, it is definitely worthwhile to define treatment targets in the hope to achieve the same boost in treatment outcomes as experienced in other fields like diabetes, cardiovascular diseases and rheumatoid arthritis.

A second meeting under the theme T2T SLE! took place in August where dermatologist Annegreth Kuhn and LUPUS EUROPE vice-chair Kirsten Lerstrøm were asked to join. Here it was discussed how to set a target of treatment in a disease so very complex and complicated, where even the present measurements of disease, activity and damage do not quite cover the spectrum of manifestations. The task is not as simple as experienced in the other fields, yet because of this, perhaps even more important to define. The project is set to continue the work over the coming months and to have the process documented.



T2T August 2012 from left to right – David Isenberg, Annegreth Kuhn, Anisur Rahman, Ricard Cervera, Alexandre Voskuyl, Thomas Dörner, George Bertsias, Andreas Levitsky, Ronald van Vollenhoven, Dimitrios Boumpas.

Matthias Schneider had to catch his flight and Kirsten Lerstrøm was the photographer.

***** Lupus – as I see it, an international photo competition *****

To draw attention to SLE and the challenges of living with this disease, the Hungarian Gabriella Schopper Lupus Group would like to announce an international photo competition for all to take part.



Logo for the Lupus – As I see it - competition

Send your picture(s) of how you see lupus or other rheumatoid condition to photo@lupusz.hu no later than November 15th noon. Please refer to www.lupusz.hu/photo/ for more information and registration form.

***** Unmasking Lupus – a theme and event for World Lupus Day 2013 *****

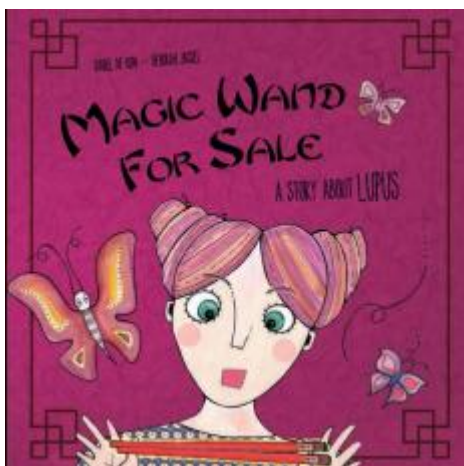
In NewsFlash July the project Unmasking Lupus was mentioned in reference to the media briefing with GlaxoSmithKline (UK) in Berlin taking place during the days of EULAR.

Unmasking Lupus will be launched at the Convention in Cyprus and will be the basis for the LUPUS EUROPE project for WLD 2013.

The aim of this campaign is to help raise awareness of lupus and its impact on people living with the disease, as well as helping de-stigmatise lupus and enhance empathy for those living with it. At the heart of the campaign will be an art competition, with creative submissions (drawings; paintings; poems or photos) invited from the lupus community (patients; carers, families and friends) to illustrate their experiences of lupus and what it means to them. A full communications campaign will support all major milestones of the project with the selected winner's illustration forming the visual representation of the resulting campaign's educational materials. LUPUS EUROPE is working with GlaxoSmithKline on this project..

For further information please contact Chair Yvonne Norton, chair@lupus-europe.org

***** Magic Wand for Sale – a childrens' book from Spain *****



Paula spends her afternoons reading the newspaper to her mother, who suffers from lupus...

Isabel de Ron wrote the book to help talk about living with this disease when children are involved. It is not presenting all there is to know about the complicated disease but rather using the story to open a dialogue about the feelings involved when lupus strikes the family.

The aim of this story is to raise the population's awareness of Lupus disease and fundraise for Lupus Associations.

When the book was first published in the region of Asturias in Spain many events, happenings and press meetings were staged at the hospitals rheumatology wards and clinics when a stock of books was provided by the Lupus Group of Asturias.

<http://sweetylondon.com/>

The book is available in English and Spanish. Isabel de Ron offers the chance to have the book printed in other languages for use in the national lupus group's awareness campaigns at printing and shipping costs. Please contact Kirsten Lerstrøm, vicechair@lupus-europe.org if interested in this.

***** German G-BA has approved belimumab after lengthy process *****

During this Summer the [G-BA, the German Federal Joint Committee](#)- Gemeinsamer Bundesausschuss, finally approved belimumab for use in treatment of SLE. The evaluation process has been long and the rheumatologists and patient group have worked very hard to prove the case that belimumab as an add-on therapy will have a considerable positive effect where traditional treatment has failed. The G-BA made a special mentioning of the importance of the involvement and good work done by the specialists and patient group.

This step is very important and an inspiration for many countries.

After this decision was made, it is now a matter of the Federal Association of Statutory Health Insurances, which is the Price Authority of Germany and the regulatory body of reimbursements to reach a pricing policy for the treatment - news on the final result is expected later this year.

***** The ATLAS study – the anti-tweak in lupus nephritis, a Phase II CTR *****

A multi-centre, randomized, double blind, placebo controlled study to evaluate the efficacy, safety, and tolerability of BIIB023 in subjects with lupus nephritis.

The study is currently open for recruitment and approx. 27 countries are participating, among those are: France, Spain, Portugal, Germany, Belgium, Poland, Russia and Israel. The aim is to reach the lupus organizations in the countries involved in the trial so patients can have the opportunity to participate.

At the moment a little more than 120 clinical trials in lupus are registered with [ClinicalTrials.Gov](#) – an institution with the US National Institutes of Health. Further on this trial can be found: <http://clinicaltrials.gov/ct2/show/NCT01499355?term=atlas&rank=1>

***** Lupus in Kenya – contacts from EULAR *****

At EULAR, Dr. Oyoo, Kenya, stopped by the LUPUS EUROPE stand a couple of times to talk about patient advocacy and creating awareness about lupus in Africa and Europe. Naturally conditions are different in the two continents, but the struggle is nevertheless for the same goal – provide peer to peer support, education and information material and discussions about treatment. Dr. Oyoo introduced Sharon Argwings-Kodhek and the amazing job she has done for lupus in Kenya. An article in [The Rheumatologist](#), March 2011 tells this inspiring story. The Regional Rheumatology Symposium takes place in Nairobi, September 26-28 with the main theme “To reduce the burden of musculoskeletal conditions”.

**Kirsten Lerstrøm
Vice-Chair,
LUPUS EUROPE**