



**LUPUS  
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

# NEWSFLASH

The Newsletter of LUPUS EUROPE

April 2014

Dear Friends and Colleagues,

Spring with some really great events has kept us very busy the past months.

A few weeks ago it was the Autoimmunity Congress in Nice, then followed by the Trustees meeting in Amsterdam and now we are looking forward to the European Lupus Meeting in Athens. Soon World Lupus Day will be celebrated in many member countries, highlighting the awareness and campaigning activities from member groups and sister organizations around the world. In June we meet again in Paris for the EULAR Congress and meeting of fellows from People with Arthritis and Rheumatism in Europe.

We also participated in the IAPO Global Patients Congress in London, Lupus Europe being represented by Katharine Wheeler. It is now midway through the EUPATI project developing a Patients Academy, and a workshop on engaging patients took place in Warsaw. New interesting research groups have been established to define remission in SLE, drugs used while breastfeeding and women-specific matters in pregnancy, maternity and menopause with SLE or APS and more. This is surely exciting times for us with great opportunities.

LUPUS EUROPE is currently working on developing a new website which will be launched soon where you will find reports, photos and links from these events, projects and many more.

**Please enjoy reading!**

***Kirsten Lerstrøm, Chair LUPUS EUROPE***

UK CHARITY COMMISSION REGISTERED ADDRESS:

St. James House, Eastern Road, Romford, Essex RM1 3NH, United Kingdom | Registered Charity No. 803768

MEMBER COUNTRIES: Belgium, Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Israel, Italy, Malta  
The Netherlands, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, The United Kingdom

## Upcoming events

---



### **European Lupus Meeting 2014, April 23-26**

An exciting programme awaits and we really look forward to meet many people with lupus from Greece as well as from elsewhere in Europe. Please note the special session Saturday afternoon from April 16-18th, where patients attending the congress had an opportunity to meet and discuss news from congress and what the lupus groups can do to improve the situation for lupus.

### **World Lupus Day, May 10 2014**



World Lupus Day activities will continue to be showcased on the World Lupus Day Web site through the local activities map. Please send us your World Lupus Day activities to Sophie Yan at [yan@lupus.org](mailto:yan@lupus.org) so we can post them as soon as possible. Please include in your email the name, date, time, and location of your event(s), as well as any contact information (website and email, phone numbers, etc).

In addition, feel free to include fliers, photos, or any other attachments you may like to share with the public through [worldlupusday.org](http://worldlupusday.org).

## World Autoimmune Arthritis Day 2014

"WAAD" is a Virtual Event held annually on May 20th. To accommodate all people, the "virtual doors" open at 6am ET/USA May 19th & close on May 21st at 5am ET/USA, allowing all people to participate in live events during May 20th in their own time zone.



Learn ALL ABOUT WAAD14 at [www.WorldAutoimmuneArthritisDay.org](http://www.WorldAutoimmuneArthritisDay.org)

**PRE-REGISTER TODAY!!!**

World Autoimmune Arthritis Day 14

2014 Theme: "A Day in the Life of an Autoimmune Patient"

Join us LIVE for 47 continuous hours ONLINE at the WAAD14 Virtual Convention. The virtual doors open on May 19<sup>th</sup> 6am ET/USA and close May 21<sup>st</sup> 5am ET/USA (or for the duration of May 20<sup>th</sup> in every time zone globally). Live event entry fee is \$5 USD if pre-registered & \$7 USD once the event has started. OR, visit the site for FREE AFTER the live event, May 21<sup>st</sup> 5am ET/USA-May 31<sup>st</sup> and download all the resources from the booths and resource centers!

REGISTRATION NOW OPEN: <https://engage.vevent.com/rt/ifaa-waad14>

WHILE SUPPLIES LAST, GET A FREE LIMITED-EDITION SHOULDER BAG! (with Pre-Registration) SHIPS INTERNATIONALLY

For more information please visit the LUPUS EUROPE virtual stand on the [website](#) or contact us at [info@lupus-europe.org](mailto:info@lupus-europe.org)

## LUPUS EUROPE News

---

### Survey on the value of services in the home to support independent living and care for people with long-lasting illnesses or conditions

The European Commission - through its unit supporting research and innovation in technologies for ageing and integrated care - is undertaking a short survey. It aims to find out how people who are living with long-lasting illnesses or conditions think that services in the home (like mobile phones, the internet, or personal health monitors) which communicate with the doctor, nurse or other care professional could help enhance independent living and care. The views of patients and caregivers have been often overlooked in this subject area. This survey is your opportunity to make your voice heard.

- The survey is open to anybody who is living with illnesses or conditions that last many years (or even a lifetime), and to the caregivers of people living with illnesses or conditions that last many years (or even a lifetime).

- The survey is being conducted online on a specialist survey website, allowing all responses to be completely anonymous and confidential.
- The results of the survey will be made public by the European Commission's Directorate General for Communications Networks, Content and Technology (DG CONNECT) at a conference in Athens, 12th-14th May 2014.

All survey participants can have a copy of the results emailed to them, if they wish.

### **WHEN THIS SURVEY WILL CLOSE**

To share your views, please make sure you reply by **Wednesday, April 30th 2014**.

TO TAKE PART, PLEASE CLICK ON THE LINK BELOW:

[European Commission survey on how services in the home could help improve the care of illnesses and conditions and enhance independent living](#)

*In case you have any queries, please contact Alexandra Wyke of PatientView at [info@patient-view.com](mailto:info@patient-view.com)*

### **The Lupus Foundation of America & BMJ launches Lupus Science & Medicine™ - the first lupus-specific Open Access Journal**

The journal is developed in response to the need for a barrier-free forum for publication of ground breaking studies in lupus. It provides a central point for publication of basic, clinical, translational and epidemiological studies of all aspects of lupus and related diseases.

Please find out more here:

- Access the [latest content](#)
- Read more about the journal in the [introductory editorial](#)
- Read the [press release](#) issued announcing Lupus Science & Medicine

MEMBER COUNTRIES: Belgium, Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Israel, Italy, Malta, The Netherlands, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, The United Kingdom

For more information and details visit [lupus.bmj.com](http://lupus.bmj.com) to learn more

**The cost of care of systemic lupus erythematosus (SLE) in the UK: annual direct costs for adult SLE patients with active autoantibody-positive disease**

MA Khamashta, IN Bruce, C Gordon, DA Isenberg, O Ateka-Barrutia, M Gayed, C Donatti, A-L Guillermin, J Foo & A Perna. LUPUS March 2014; 23(3)

Conclusions - Improvement of the overall stability of SLE and early intervention to minimize the impact of renal disease may be two approaches to mitigate the long-term direct cost of managing SLE patients in the UK.

Recently there has been some very interesting studies investigating the cost of care in lupus and other long term chronic diseases. It is interesting to see what kind of costs has been selected and the actual societal implication because of the disease short and long term.

For more information click [here](#).

**Impact assessment of energy-efficient lighting in patients with lupus erythematosus: a pilot study**

L. Fenton, R. Dawe, S. Ibbotson, J. Ferguson, S. Silburn and H. Moseley. *British Journal of Dermatology*, Volume 170, Issue 3, March 2014

Conclusions - Compact fluorescent lamps emit UV that can induce skin erythema in both individuals with LE and healthy individuals when situated in close proximity. However, this occurs to a greater extent and is more persistent in patients with LE. EEHLs emit UVA that can induce erythema in patients with LE. LEDs provide a safer alternative light source without risk of UV exposure.

The EU Declaration on energy saving light sources for domestic use, brought discussions on what importance this would have for lupus. This study reflects the need to have more recent studies on use of new technologies.