



**LUPUS
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

NEWSFLASH

The Newsletter of LUPUS EUROPE

June 2014

Dear Friends and Colleagues,

On 10th May and during the month of May we have celebrated World Lupus Day in many countries. It was a great year with fantastic and creative initiatives.

In a few days the EULAR 2014 will take place in Paris on 11-14 June. As per tradition we welcome all to visit our stand H06 in the EULAR Village. Also as usual the program for us is packed with meetings and events. We very much look forward to the Congress.

We can also look back at some really important events like the Global Patients' Congress, the Autoimmunity Congress, Midterm of EUPATI, the European Lupus Meeting and the AGM of European Patients' Forum. Detailed reports with links and notes will be available on our new web site.

Besides all these activities we have also been very much engaged in developing a new LUPUS EUROPE web site which will be launched by the end of this month. With this new platform we aim to be able to easily communicate any topics, events and projects in order to accommodate the great wish to have up-to-date info and discussions for members, to have better ways of sharing between us, and to improve the communication to our growing group of interested contacts within and outside Europe.

We are so pleased to announce that Susanna Palkonen (Chief Executive Officer at the European Federation of Allergy and Airways Diseases Patients Associations) will be the key speaker at the Convention 2014, addressing the main theme "A Better Life with Lupus" with the key issues of "Access" through our "Treatment, Knowledge and Empowerment" sessions during the convention program.

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

EULAR 2014, 11-14 June 2014, Paris, France

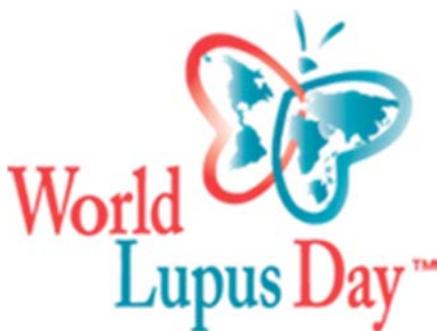


Please come to visit our stand H06 in the EULAR Village! During the four days of The Eular Congress, Bernadette van Leeuw, Kirsten Lerstrøm and our Patient Partners in Research: Davide Mazzoni and Mette Toft, will be attending the event.

We will be meeting with key patient group representatives such as the Lupus Foundation of America, sponsors, various projects and task forces.

LUPUS EUROPE News

World Lupus Day, 10 May



Many, many activities, campaigns and national events took place in member countries this year. One initiative that stood out was the short film Butterfly Tattoo launched on YouTube bringing the personal story of Myra from Germany and supported by the Lupus Foundation of Germany.

Butterfly Tattoo, German short film by German Star

Myra is a German singer and producer with Filipino roots, who was diagnosed with lupus after a severe flare of the disease. For the Lupus Foundation Germany, she describes her fight to accept and cope with a life-threatening disease with touching words and pictures, in a short film, "Butterfly Tattoo." Her work was supported by the German Foundation for Lupus Research.



Please click on one of the links below to view the entire German campaign – “Butterfly Tattoo”:

- English Version: www.bit.do/ButterflyTattooShortFilm
- Deutsche Fassung: www.bit.do/ButterflyTattooKurzfilm



**LUPUS EUROPE Convention 2014 - “A Better Life for Lupus”
September 19-23 2014, Helsinki, Finland**

There are no straight paths in lupus. In addition to the prominent speakers from the hosting country, Finland, we are so very pleased to announce that Susanna Palkonnen (Vice-Chair of European Patients Forum and CEO of the European Allergy and Airways Diseases Patients Associations) will deliver the keynote speech on “Access” to care, with an emphasis on our three subgroups “Treatment, Knowledge and Empowerment”.

This year we will also have the special opportunity to have our newly trained Patient Partners in Research with us, and will give a special training session on the Monday morning on the projects, the experience and prospects.

T2T SLE? - > T2T SLE!

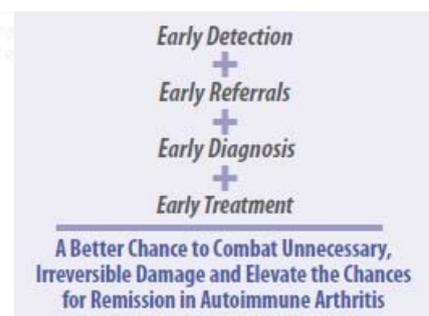
Recommendation: Treat-to-target in systemic lupus erythematosus.

Recommendations from an international task force Ann Rheum Dis doi: 10.1136/annrheumdis-2013-205139

The principle of treating-to-target has been successfully applied to many diseases outside rheumatology and more recently to rheumatoid arthritis. Identifying appropriate therapeutic targets and pursuing these systematically has led to improved care for patients with these diseases and useful guidance for healthcare providers and administrators. Thus, an initiative to evaluate possible therapeutic targets and develop treat-to-target guidance was believed to be highly appropriate in the management of systemic lupus erythematosus (SLE) patients as well. Specialists in rheumatology, nephrology, dermatology, internal medicine and clinical immunology, and a patient representative, contributed to this initiative: 11 recommendations with four overarching principles were agreed upon. Prominent features of these recommendations are targeting remission, preventing damage and improving quality of life: <http://ard.bmj.com/content/early/2014/04/16/annrheumdis-2013-205139.full>

Early Symptoms of Autoimmune Arthritis Study

The International Foundation for Autoimmune Arthritis has teamed up with the Sjögren's Syndrome Foundation, Spondylitis Association of America, Lupus UK, and the International Still's Disease Foundation to lead a patient-centered research study that will analyze early symptoms, as reported by the patient, for the following six core Autoimmune Arthritis diseases: Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA),



Ankylosing Spondylitis (AS), Sjogren's Syndrome (SS), Adult Onset Still's Disease (AOSD), and Systemic Lupus Erythematosus (SLE). If you are a patient diagnosed with one (or more) of these diseases, you can help to combat delay in diagnosis.

This study will investigate current improper identification of early symptoms that may correlate with a delay in diagnosis. With a vast majority of patients affected, early symptoms that accompany a primary Autoimmune Arthritis disease are often comprised of extensive joint involvement, systemic features and other complications. This non-profit team has identified that current published symptoms of the primary Autoimmune Arthritis diseases, which are used for detection, referral, and diagnosis, are inconsistent and fail to include some of the most common early symptoms identified in patient self-reports of their individual early disease experience.

Using results from the patient-reported early symptoms collected in this study, a comprehensive and consistent Early Symptom Patient Model (ESPM) will be developed for both the above mentioned individual Autoimmune Arthritis diseases and for the group as a whole. In addition to these core objectives, a secondary focus will be to evaluate the pervasiveness of "Undifferentiated Autoimmune Disease" in patients which later progress to a confirmed diagnosis of Autoimmune Arthritis.

30 minutes of your time can change millions of lives. You may qualify if:

- A patient who was diagnosed with one or more of the following diseases: Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA), Ankylosing Spondylitis (AS), Sjogren's Syndrome (SS), Adult Onset Still's Disease (AOSD), or Systemic Lupus Erythematosus (SLE)
- Onset age 18 years or after (adult onset)
- Diagnosed after 1995

If you qualify to participate, please use this personalized invitation link:

<http://fluidsurveys.com/s/early-symptoms-autoimmune-arthritis-study/?code=nk2rzsnpk>

If you are not a patient and know someone who you feel would be interested in this study, you may invite them to participate with this direct link: <http://fluidsurveys.com/s/early-symptoms-autoimmune-arthritis-study/>

The survey takes approximately 30-40 minutes to complete and can be saved and revisited to complete. All responses are due by June 30th, 2014.

VISION 2043



Campaign for World Arthritis Day

Looking to the future, what one change would you make to transform the lives of people with RMDs? Having a rheumatic or musculoskeletal disease (RMD) can put limitations on the way people live their lives. The Vision 2043 competition asks you to show us one idea to help improve the lives of people with RMDs by the year 2043.

You can play a significant role in encouraging people in your country to participate in Vision 2043. Enter your idea of how to make the day-to-day lives of people with RMDs easier, in the Vision 2043 gallery by 18 July 2014.

To find more information about the Vision 2043 competition and prizes visit the website: www.worldarthritisday.org/vision2043/enter

World Autoimmune Arthritis Day 2014

"WAAD" was a Virtual Event on May 20th. To accommodate all people, the "virtual doors" opened at 6am ET/USA May 19th and closed 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

PRE-REGISTER TODAY!!!

World Autoimmune Arthritis Day 14

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

World Autoimmune Arthritis Day 2014
Awareness Wellness Education Support It's Time!

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 19th 6am ET/USA and close May 21st 5am ET/USA (or for the duration of May 20th 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 21st 5am ET/USA-May 31st and download all the resources from the booths and resource centers!

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

The Lupus Foundation of Northern California has recently launched the WORLD LUPUS GOOGLE MAP

The Californian chapter of Lupus Foundation of America (LFA) has invited all our members to post activities on a Global Google map. Please find further information through this link: www.lfnc.org/1mforlupus.html

Past events



EUPATI – midterm status, April 2014, Warsaw, Poland

EUPATI = Patients' Academy – European Patients' Training in the three levels: the High Level Expert training will begin this Fall; the Patient Representative Level, of interest to all our members, will be launched next year, and the Portal for 100.000 + people involved in advocacy will be open at the end of the project in 2016-2017.



IAPO Global Patients' Congress, April 2014, London, UK

“Better access, better health: A patient-centered approach to universal health coverage”
Katharine Wheeler took part in this event on our behalf. Katharine has written a summary report and provided more detailed notes from the discussions. The Congress was about

Access to Health Care. The discussions helped to identify a good definition of what is access, and what is global health care and health care systems in general.

European Lupus Meeting 2014, 23-26 April 2014, Athens, Greece

Over 60 people attended the Greek session for people interested in lupus in Greece. They expressed their enthusiasm and gratitude for its organization. All the presentations, given by distinguished Greek Scientists, were extremely interesting and informative, giving the audience a great opportunity to acquire broad, practical and valuable knowledge regarding the lupus disease and related issues such as diagnosis, symptoms, treatments, co-morbidities, cognitive disorder, psychological implications, life choices, etc.

This event resulted in with a big discussion on how best to accommodate the needs and interests of lupus patients in the Eastern Mediterranean region.

Representatives from national lupus group, rheumatism associations, arthritis foundations and other organizations participated in the event's scientific meetings.



We learned that the new “Treat to Target” can pave the way for better treatment results, involving active engagement from patients.

Several updates on social media platforms were posted during the event. Various reports, articles and other souvenirs will be uploaded on the new LUPUS EUROPE web site soon.

European Patients' Forum Annual General Meeting, May 2014, Brussels, Belgium

Katharine Wheeler also took part in this event on our behalf, and wrote an event report, encouraging us to be involved in the Work Group initiative on defining Patients' organizations. She suggests us to use the link below to get to the official reports.



For more information please visit the link: www.eu-patient.eu/News/News/Report-of-our-Annual-General-Meeting/

PRECISESADS... New IMI Project to deliver a molecular map to guide therapy in systemic autoimmune diseases



The €22.7 million 5 year project will see several large pharmaceutical companies work together with universities, small and medium-sized enterprises, patient groups and regulators with the aim to delivering new treatments for systemic autoimmune diseases.

Inflammatory autoimmune diseases such as rheumatoid arthritis and lupus affect 1-3% of the population, and while treatments exist, these are costly and have a number of serious side effects. There is growing evidence that many of these conditions may be incorrectly classified. The PRECISESADS project will study 2,500 people with various autoimmune diseases, gathering data on the molecular causes of their disease as well as their clinical symptoms. Using this information, they will pave the way for a new classification of these diseases, something that will allow doctors to offer patients more personalised treatments at an earlier stage of their disease.

Vice-Chair Blanca Rubio will participate on behalf of LUPUS EUROPE.