



**LUPUS  
EUROPE**

**UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE**

# **NEWSFLASH**

The Newsletter of LUPUS EUROPE

March 2014

“Patients + Participation = Our Vote for a Healthier Europe” is the EPF campaign launched to encourage ALL in Europe to be involved in the EU elections in May. Access to healthcare is very much on the European patient political agenda as well as on the agenda at the local level. Later this year input from patients’ organizations will be important for mapping health professional competences and qualifications in respect to fulfilling the obligations to Patients’ Rights to Cross Border Healthcare. LUPUS EUROPE is presenting at the campaign launch at the European Parliament with a poster and flyer under the title “A Second Chance”.



*A Second Chance by Stefania Viscillo*

Access, involvement and engagement are all key issues this year, where we are pleased to announce “Access to a better life with lupus” at Convention in Helsinki September 19-23, “What is lupus to me” at the European Lupus Meeting in Athens, a stand at EULAR Village at EULAR in Paris and more special activities/developments to ensure our involvement as patients’ representatives.

**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

## Patients + Participation = Our Vote for a Healthier Europe

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When Stefania Viscillo's painting, "A Second Chance" was chosen as winner of the Unmasking Lupus competition, it was also a very strong signal to describe what it is to live with lupus – not just for the diagnosis, but also for the life change that followed.



So naturally this was a very good case to present, when we had the special opportunity to join the EPF launch at European Parliament. Please check our web site for the poster and flyer.

## Upcoming events

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A promotional banner for the 9th International Congress on Autoimmunity. The banner has a light blue background with a faint molecular structure. On the left is a circular logo for 'NICE 2014' featuring a globe and the text '9TH INTERNATIONAL CONGRESS ON AUTOIMMUNITY'. In the center, the text reads '9th International Congress on Autoimmunity' in large blue letters, followed by 'Nice, France | March 26-30, 2014' in orange and 'Novel Diagnostic Tools &amp; New Therapeutic Avenues in Autoimmune Diseases' in smaller blue text. On the right is a white box with a globe icon and the text 'Click here to Join Autoimmunity Network 2,000 Experts Worldwide!'. A solid red horizontal bar runs along the bottom of the banner.

### Autoimmunity Congress 2014, March 26-30, Nice

At the coming Autoimmunity Congress there will be a patients' event in French on March 29<sup>th</sup> where lupus with other autoimmune diseases will present and provide discussion on the diseases.

Nice - Acropolis 1  
Esplanade Kennedy Nice, Cedex 4  
Tele: +33 (0) 4 93 92 83 00  
Fax: +33 (0) 4 93 92 82 55  
[www.nice-acropolis.com](http://www.nice-acropolis.com)

For more information please see the program on the website or send us an [e-mail](#).

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

The scientific meeting on lupus occurs every three years: in 2014 the 9th Meeting will take place in Athens and we are happy to announce a special event for Greek lupus patients on the Saturday April 26<sup>th</sup> of the meeting with a special English session addressing key issues for lupus groups concluding the day. All patients from Europe are welcome to attend the meeting for free, yet travel and accommodation at own cost. Please confer with the web site [www.lupus2014.org](http://www.lupus2014.org) for further information or mail [info@lupus-europe.org](mailto:info@lupus-europe.org).

### **World Lupus Day – May 10<sup>th</sup>**

For World Lupus Day, LUPUS EUROPE will support the theme of “Access to a Better Life” for all people who have lupus in their lives. This will be reflected in some of the initiatives that Lupus Europe will focus on, and is the theme for this year’s convention. We know that most member countries will be staging their own events based on their own themes, so it would be most rewarding to have your announcements uploaded on our web site or on FB. Placing all events and campaigns would be fantastic. Gabor has offered to make your announcements available on [www.lupus-europe.org](http://www.lupus-europe.org).

Please send your details – texts, jpegs, icon etc to [Gabor Vargar](mailto:Gabor Vargar)

### **EULAR 2014, Paris June 11-14<sup>th</sup>**

We will have a stand at the EULAR Village this year. Being present at EULAR is always a very demanding effort from us and the national group. For the national group this is the key event to boost national issues and connections For LUPUS EUROPE the stand will provide the international anchor for lupus. This time together with Lupus France and we hope to stage a special event for lupus together with Lupus Foundation of America.

**Rosa Chaves Goncalves, former Chair of Lupus Portugal**

It is with great sadness that we have received news that Rosa Goncalves passed away on January 15<sup>th</sup> 2014.

During 2009-2012 Rosa Goncalves was the chair of and longtime delegate to LUPUS EUROPE from our member the Portuguese lupus group: Associação de Doentes com Lupus, [www.lupus.pt](http://www.lupus.pt).

It was at the LUPUS EUROPE Convention 2010 in Budapest we all met her at council the last time.



*Dr. Rosa Goncalves, Lupus Portugal*

When the European Lupus Meeting was held in Porto in 2011, Rosa worked hard at arranging the patients' forum for Portuguese lupus patients.

Rosa was a doctor by training and living with lupus. She worked very hard for more than a generation to bring awareness to the cause and improve the situation of people living with the disease in Portugal.

Rosa has made clear and deep footsteps in the ground for better understanding and clinical practice in controlling lupus for which we, her colleagues, will remain most grateful.

We will remember Rosa Goncalves with fondness and sent our most sincere regards to the members of [Associação de Doentes com Lupus](http://www.lupus.pt).



***EULAR/EUMUSC .net at European Parliament***

**EULAR/EUMUSC.net conference, October 17-18, Brussels**

Chronic diseases and health care delivery 2020: The challenge of rheumatic and musculoskeletal diseases. Findings, lessons and perspectives from the EUMUSC.net project.

The event was a great success. Not only due to the high quality of speakers and the participation of high level representatives of important organizations, but also due to the relevance of the information presented, the quality of discussions and the results achieved. The evidence collected by the eumusc.net project and presented during the conference proves that rheumatic and musculoskeletal diseases (RMDs) are one of the most burdensome chronic conditions affecting EU citizens. However, it was also shown that it is possible to reduce such a burden by developing specific policies, including the implementation of tools such as the ones developed by the eumusc.net initiative. To this end, the project and the Conference provided valuable recommendations to EU and Member States on how to implement concrete actions to reduce the burden of RMDs and hence improve the living conditions of millions of people in Europe.

The Conference report and the presentations are now available. You can find them in the following link: <https://www.dropbox.com/sh/ajz38o8ofb5jemp/FrtmRWXZ75>

## **EULAR/PARE Patient Partner in Research training, November 4-5, 2013 Brussels**

Congratulations to Mette Toft (DK), Petra Bednarova (SL), Davide Mazzoni (IT), Francesca Marchiori (IT) and Spyridoula Trivizaki (GR). Thank you for doing this training that will be important to have the lupus voice heard in research and development of new therapies!

## **EULAR/PARE Autumn Conference, November 15-17, 2013 in Reykjavik – Volunteer Engagement**

Please see the report from this conference by Bernadette van Leeuw on [our web site](#). One of the “take home messages” is the following on **volunteer engagement**:

Workshop 3: working with volunteers (*from the presentation slides!*)

1. Remember to ask (people start to be volunteer when they are asked, not after a general meeting).
2. Ask those you do not usually ask (there are people who would have agreed but were never asked)
3. Be specific when you ask (“to be present on a certain day for a stand” not only “ask questions of the members from time to time”).
4. Consider how you present tasks (an appropriate task for individuals)
5. Also ask the busy (do not think the people have no time, ask them !)
6. Go for the best for the job (write a list of the 5 “best for you” and ask them).
7. Ask at the right time (not when everybody is tired and want to leave the meeting, but when you are in a good spirit, for example...)
8. Let the right person ask (sometimes, it’s better if it is not a member of the board)
9. Say thank you (even when people have done a little effort)
10. People want to be part of a success (to say good things about the association is more attractive and creates a positive spiral).
11. Recruiting takes place all year long (not only before general meeting)
12. It is easier to find three than one (tasks may be solved by a small group rather by a single person)
13. Take the viewpoint of the person you ask.
14. Remember the question : what will it take for you to say “yes”, in order to avoid misconceptions
15. If you get definitely “no”, try someone else from the network.

## EUPATI Expert Patient Training Course

Lupus Europe would like to draw your attention to the EUPATI training course: the application period for this opened on Monday 10 March 2014 via the EUPATI website. This is an exciting and unique opportunity offering patient advocates expert training in medicines research and development, specifically tailored for them. Launching this application process is a major milestone for the EUPATI project.

Please click on the following link for more information [Expert Patient Training Course](#). In addition to the application form, you will also find a detailed guide for applicants as well as Q&A document.

Please note that the closing date for applications is **20 April 2014**.

EUPATI Workshops & Conferences c/o EFGCP Secretariat  
Square de Meeûs – Rue de l'Industrie 4  
BE-1000 Brussels, Belgium

E-mail: [eupati@efgcp.eu](mailto:eupati@efgcp.eu)  
EUPATI Website : <http://www.patientsacademy.eu>

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