



**LUPUS  
EUROPE**

UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

# NEWSFLASH

The Newsletter of LUPUS EUROPE

29-04-2011



***So this is Lupus***, sung by Lupus specialists

Dear Friends,

This month we were in Porto to attend the European Lupus Meeting and present LUPUS EUROPE. We heard a lot, spoke with doctors, nurses, other patients and very nice Portuguese people in Porto. In this NewsFlash you will find a few highlights to give you an idea about our stay.

We wish you pleasant reading.

Trustees of LUPUS EUROPE

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

**\*\*\* 8<sup>th</sup> European Lupus Meeting, Porto, Portugal, April 6-9<sup>th</sup> \*\*\***

Our chair Yvonne Norton spoke at the opening session on Wednesday. 'So, This is Lupus – from the Patients' point of View'.



When I was first invited to speak at the Opening Session of the 8<sup>th</sup> European Lupus Meeting in Porto, I thought what an honour it was to be asked, especially to follow Prof Graham Hughes, and what an opportunity to speak to upwards of 700 medics and tell them what having lupus is like for the patient, also, at that time, 6<sup>th</sup> April seemed a long way off!

As April drew nearer, I started to think how I would present my talk and, on mentioning it to Prof George Kitas, he said 'Well, why don't you tell the audience that they will have heard the clinical facts from Prof Hughes but now you will tell them what lupus really is?' So, that is what I set out to do.

Before I could do this, though, a big obstacle was to overcome. When I went into the large auditorium where the Opening Session was to take place – a rather high stage with no access for my wheelchair! The young 'sound' man went off to find two ramps, a headset (I could not reach the microphone) and a low table to place a glass of water and, with help

from three young men and Peter, I was able to take my place on the stage and my presentation began....

Firstly, I thanked the organising committee for giving me the opportunity to say what lupus is like from 'the Patient's Point of View' and then I thanked Prof Hughes as without his help and medical skills I would not be alive now. Then came the 'real business'.

I showed a few slides which depicted what a day in my life is like, from struggling to get out of bed in the morning (feeling as tired as though I had not been to sleep at all) to the difficulties in showering and getting dressed. I had slides showing the many medications I take every day and the effects that some of the medication has on me – excessive sweating, multiple food allergies, difficulty in walking etc. I underlined that, in over thirty years, the diagnosis time for lupus has not improved and that it is still taking up to seven or eight years for a lot of patients to have their diagnosis and this really is not good enough and needs to get better! Then I asked questions of the doctors 'When a lupus patient comes to you, what do you really see? Do you see how she/he has struggled to get up, shower, dress and get to the consulting room? Do you see how tired your patient is following examination, going to the x-ray department, pharmacy etc? Do you realise that when your patient gets back home all she/he may be able to do is go to bed for the rest of the day?'

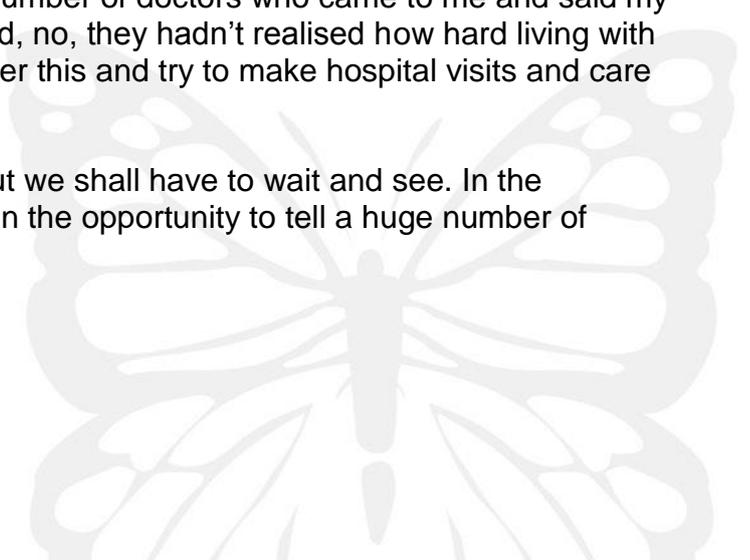
I followed through with suggestions of how consultants can help lupus patients – teach their students not only the facts of lupus but to consider the patient, the struggle she/he may have to get through the day, the continual terrible fatigue she/he has etc.

I suggested that doctors check if there is a Lupus Support Group in their country and, if there is, that they should take part by giving talks and writing for Group newsletters. If there is not, I suggested that they help set up a Group and reach out to patients in this way.

I then asked how many people in the room know the significance of 10<sup>th</sup> May and explained that this is World Lupus Day and I gave a challenge to the medics that, on 10<sup>th</sup> May, they text, e-mail or tell 10 people (who do not have lupus) that this is World Lupus Day and ask them to inform a further 10 people. If enough people do this we have the capacity to spread the message world-wide. My closing remark was: 'Doctors, it's over to you.....!'

Will my talk have any effect? At the reception following the Opening Session and during the next three days, I was amazed at the number of doctors who came to me and said my remarks had made them stop and think and, no, they hadn't realised how hard living with lupus can be but, in future, they will consider this and try to make hospital visits and care plans easier for their lupus patients.

Will they do this? I would like to think so but we shall have to wait and see. In the meantime, I have had my chance and taken the opportunity to tell a huge number of medics what lupus really is!



*At the opening session we were pleasantly surprised with a song especially written for the occasion and sung by a young doctor Raquel Faria.*

So this is Lupus  
May you never heard  
Sure it's not contagious  
No cancer, not a bug  
*And so this is Lupus*  
*It can be in your skin*  
*It can be in your kidney*  
*It can be all way in*  
**Don't give up on you**  
**Fight with all your strength**  
**Be sure tha'f'u really want**  
**You can change your own fate**  
So this is Lupus  
With it thousands faces  
More women and young  
Escaping no races.  
*And so this is Lupus*  
*It can be so smooth*  
*That people think you're lazy*  
*When you're dying for thruth*  
**So this is Lupus**  
**We still haven't reached**  
**The mystery beneath it**  
**That's why we're here to meet.....**

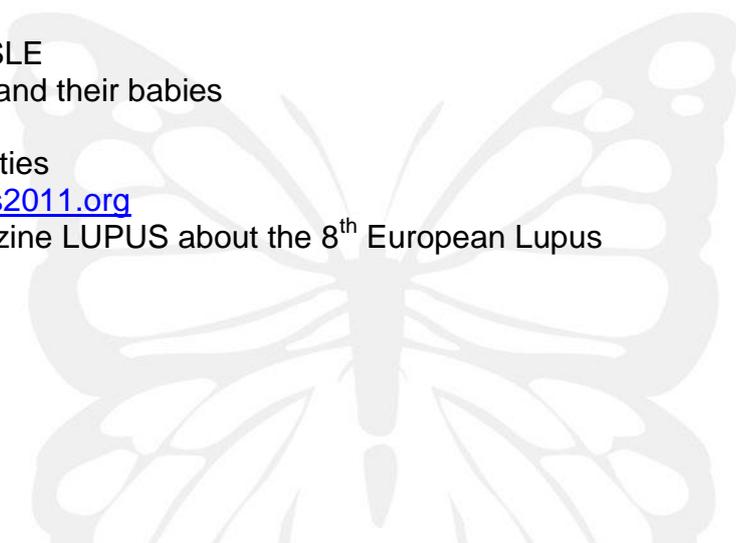
Carlos Vasconcelos / Raquel Faria  
8<sup>th</sup> European Lupus Meeting  
2011, Porto, Portugal

**On John Lennon's music "So this is Christmas"**

### **Some topics at the Porto Lupus Meeting**

- \* Towards an European network of centres of excellence. Doctor Dimitrios Boumpas, one of the medical advisors of LUPUS EUROPE, spoke about the EULAR Task Force on SLE
- \* EULAR recommendations for good clinical practice
- \* Skin & lupus: What's new?
- \* Lupus patients in clinical practice
- \* Managing difficult organ involvement in SLE
- \* Management of pregnant lupus patients and their babies
- \* Off-label drugs in lupus
- \* Children and adolescent lupus particularities
- \* all topics can still be found on [www.lupus2011.org](http://www.lupus2011.org)

We will take the special issue of the magazine LUPUS about the 8<sup>th</sup> European Lupus Meeting with us to Kopenhagen.



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

Please e-mail news of WLD activities planned in your country or by your Group to Simone Müller-Pretis for inclusion on LUPUS EUROPE website and to Sophie Yan for inclusion on the Lupus Foundation of America (LFA) World Lupus Day website:

Simone Müller-Pretis: [webmaster@lupus-europe.org](mailto:webmaster@lupus-europe.org)

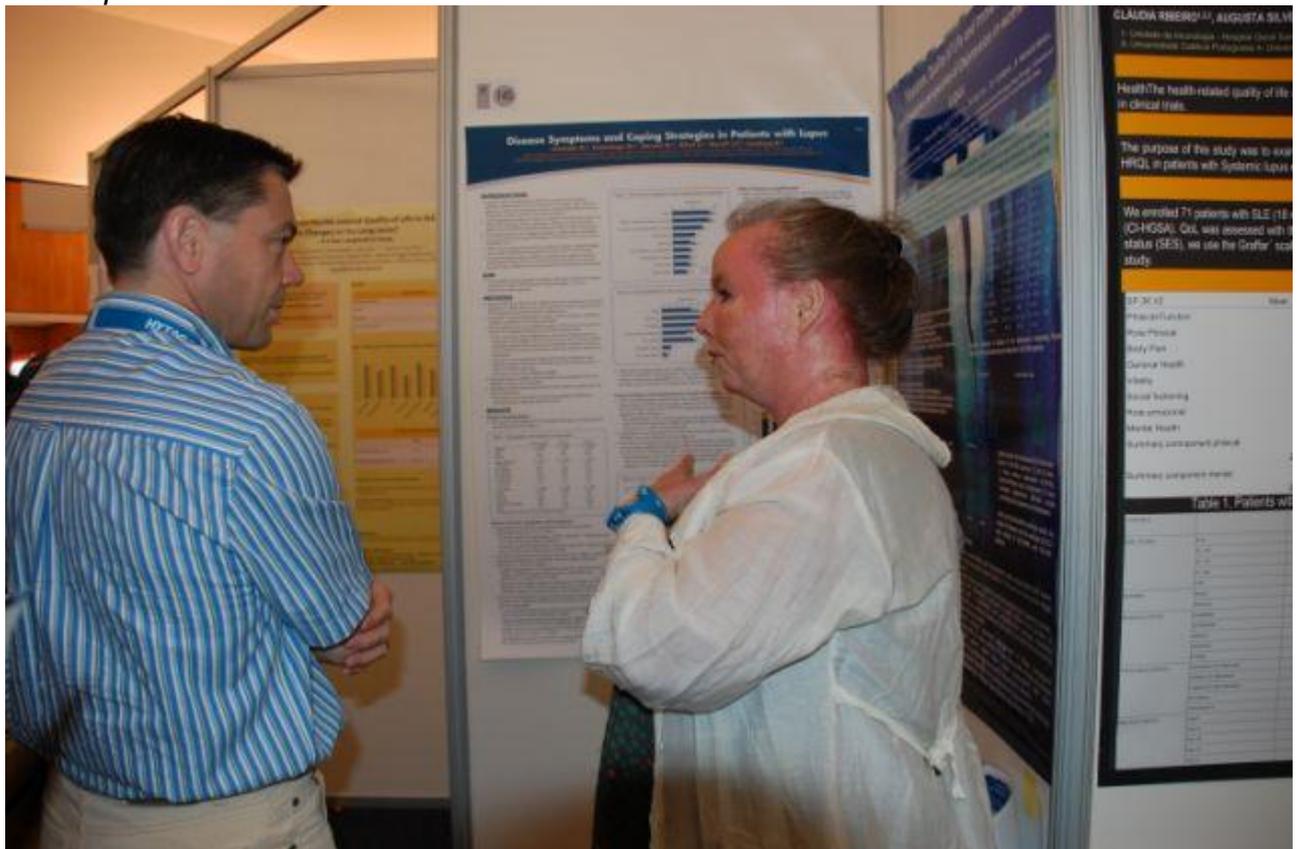
Sophie Yan: [yan@lupus.org](mailto:yan@lupus.org)

### \*\*\* Survey “Living with Lupus” Abstracts submitted \*\*\*

Four abstracts have been filed:

1. “Disease symptoms and coping strategies in patients with lupus”  
8<sup>th</sup> European Lupus Meeting, Porto – Apr 7-9 2011  
(based on the combined European and US results of the 2009 survey) Accepted for poster presentation.

*The poster presentation was given by Vice Chair Kirsten Lerstrøm. The abstract will be published in LUPUS*



Presenting a poster is rather fun as you get to meet many people with interest in the work presented or in the activities of our patient organization. It was a very busy

spot during the poster tour. Here (on the picture) the talk is about another patient organization doing studies among their patients about Fatigue.

A hand-out of the poster was made and we have kept a stack to be distributed during our convention in September.

A PDF of this subject will be posted on the website later.

2. "Disease symptoms, treatment satisfaction and coping strategies in patients with lupus "  
International Society of Pharmacoeconomics and Outcomes Research – ISPOR – 16<sup>th</sup> International Meeting, Baltimore, MD – May 21-25 2011  
*Accepted for poster presentation on May 23<sup>rd</sup> by co-author Mary Crimmings, Lupus Foundation of America.*
3. "Impact of lupus on fatigue, health-related Quality of life and work productivity"  
Medical and research professionals, EULAR Congress 2011, May 25-28 2011  
Accepted for poster presentation.
4. "Developing a patient-driven survey to examine the impact of lupus"  
PARE, EULAR Congress 2011, May 25-28 2011. **Accepted for Scientific Abstracts Oral Presentations** during the Abstract Session: From abstract to concrete – the variety of PARE organizations. The presentation will be for ten minutes on May 27<sup>th</sup>. *Further information on these abstracts contact Kirsten Lerstrøm [vicechair@lupus-europe.org](mailto:vicechair@lupus-europe.org)*

### \*\*\* EULAR Congress 2011, London \*\*\*

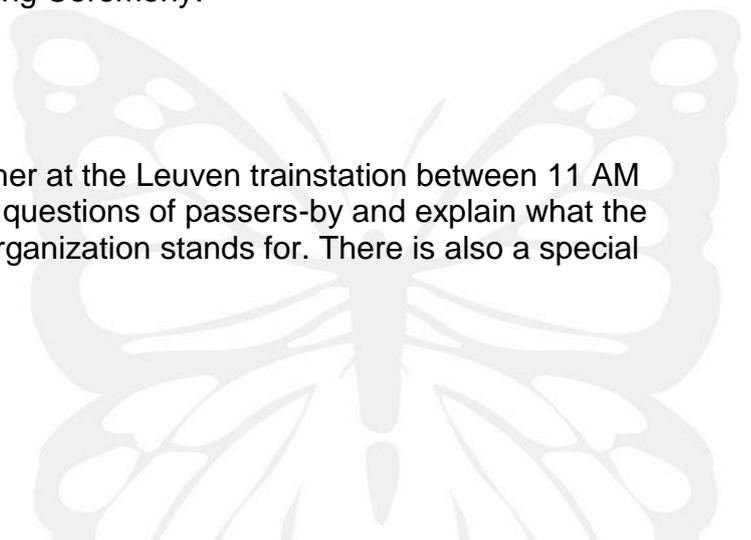
LUPUS UK and LUPUS EUROPE will share the stand this year in the EULAR Village at EULAR Congress 2011 May 25-28 in London. The venue is on Canary Wharf in the East End of London. Registration fee for patients is EUR 35 for the whole congress. *If you attend the congress please inform Chair Yvonne Norton [chair@lupus-europe.org](mailto:chair@lupus-europe.org) Please check [www.eular.org](http://www.eular.org) for details on the congress*

### \*\*\* The Edgar Stene Prize – Fatima Lavoll is Member of the jury \*\*\*

Fatima Lavoll has been appointed by the Norwegian Rheumatism Association to sit as jury member on the Edgar Stene Prize. In 2011 the Edgar Stene Prize will be awarded for the essay topic "How Exercise Improves my Life with a Rheumatic Disease". The winner will be announced at EULAR during the Opening Ceremony.

### \*\*\* World Lupus Day Activities \*\*\*

In Belgium/Flanders lupuspatients will gather at the Leuven trainstation between 11 AM and 5 PM at a informationstand to answer questions of passers-by and explain what the CIB-Liga: the Belgium/Flanders patients organization stands for. There is also a special



poster printed for World Lupus day, to be given to doctors, pharmacists and others. Hopefully this year the whole of Flanders will know about World Lupus Day.

**\*\*\* EPF and Patients' Rights Day \*\*\***

Katharine Wheeler represented LUPUS EUROPE in Brussels at the Annual Meeting of the European Patients' Forum. The first day of this Annual Meeting 11th April was the 5<sup>th</sup> European Patients' Rights Day. In another NewsFlash you will find more information about the EPF Meeting.

29<sup>th</sup> April 2011  
Marja Kruithof  
Secretary LUPUS EUROPE



**Ready for the Gala Dinner in Porto,  
Palácio da Bolsa**

