

7th Global Patients Congress

9-11 April 2016



Selsdon Park Hotel, South London, UK • www.globalpatientscongress.org #GPC2016

Patient Panel - Fertile source of inspiration for campaigns

Anne Charlet

Vice-Chair, LUPUS EUROPE



LUPUS EUROPE

Patient-led umbrella organization, since 1989

24 Lupus patient groups in 22 countries across Europe

Total membership of +30,000

500,000+ diagnosed with lupus in Europe, 80% women

Board: 8 volunteer members

Do More with Less



Anne Charlet

Vice-Chair Lupus Europe
Board of Lupus France
Daughter with lupus

Lupus Europe Patient Panel

7th Global Patients Congress



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE
Formerly European Lupus Erythematosus Patients (ELEP)

Our Message to the Medical Community.

This week, a group of European people living with Lupus gathered in Brussels to search how we can improve adherence to treatment and the quality of life of our lupus patients across the continent. We would like to share with you what we found, and where we would very much like your support.

Dear Doctor,
First and foremost, THANK YOU so much for being there and bringing the CARE, with all your knowledge, experience and commitment to help me go through my journey with lupus. Without you, many of us would simply not be here, and others would have a miserable life. Thanks to you for your dedication and giving me the best care, your participation in research programmes, your continued education to better understand and treat lupus which all help me to have access to a better life. I need to benefit from the latest standards of care, like those produced by EULAR, which continuously reflect the collective expertise of the lupus experts around the world, so please, if you are not a lupus expert, refer me to the best specialist.
INFORMATION is critical for me to feel in charge and safe. Don't hesitate to over-communicate and tell me how I am doing. Please explain my blood test results to me, and other tests or examinations you have prescribed. Please tell me what it is for, and what it will tell us both about my lupus or the treatment. I may be taking many pills that I am not sure I need. Please explain my blood test results to me, and other tests or examinations you have prescribed. Please tell me what it is for, and what it will tell us both about my lupus or the treatment. I may be taking many pills that I am not sure I need. Please explain my blood test results to me, and other tests or examinations you have prescribed. Please tell me what it is for, and what it will tell us both about my lupus or the treatment. I may be taking many pills that I am not sure I need.

Our Message

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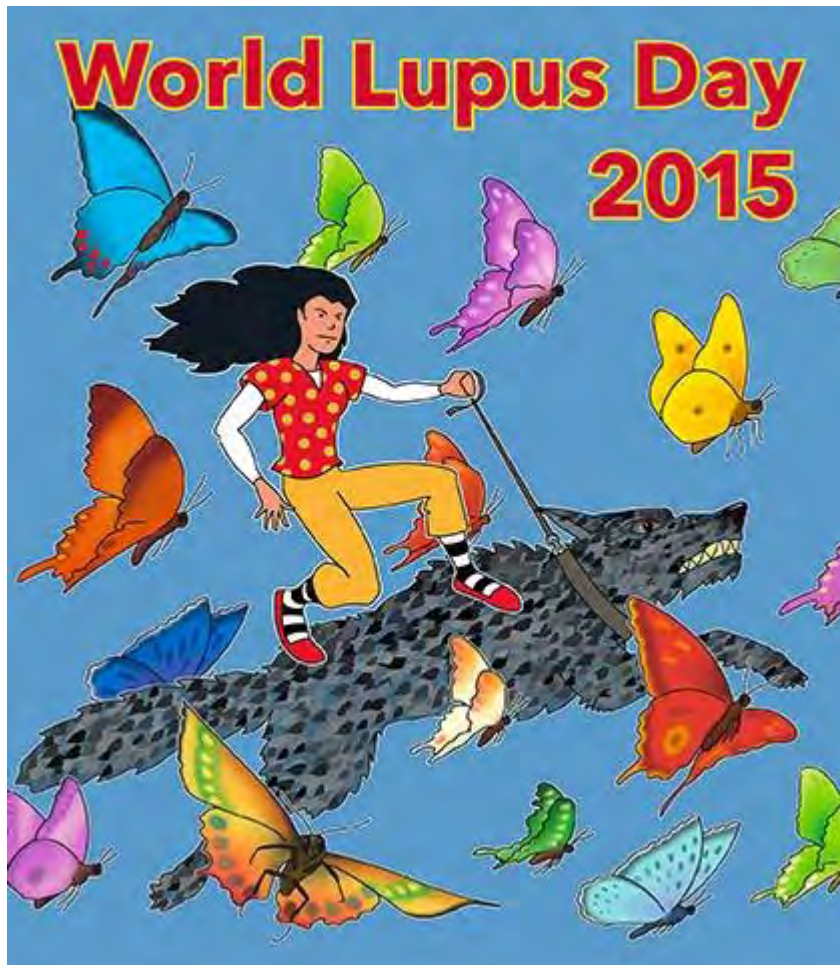
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the doctor. Explaining



LUPUS EUROPE Patient Panel on Treatment.
Jane, Jeanette, Claudine, Ana, Sander, Christine, Angela, Daniela, Davide and Bernadette
November 2014





Tame your wolf – Tame lupus
World Lupus Day 2015 theme

Key Success Factors

BY patients **FOR** patients

Psychologist experts also
had lupus

Participants took results to
their national group

Used results in several
different media

Strong organising team

Very thorough planning

Contact us:
secretariat@lupus-europe.org

Look us on web and social media to find out more:

www.lupuseurope.org

lupus-europe-blog.org



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International Alliance of
Patients' Organizations

A global voice for patients

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Thank you