



LUPUS
EUROPE

**UNITING PEOPLE WITH LUPUS
THROUGHOUT EUROPE**



**Advocating
patient-led research**
*By Kirsten Lerstrøm,
Chair*



Disclaimer

LUPUS EUROPE is a patient led umbrella organization of national lupus patient groups.

LUPUS EUROPE is a UK Charity No 803768

LUPUS EUROPE operates on funds from membership fees, donations, project partnerships, pharmaceutical sponsorships and other such support for general operations and specific projects.

Industry sponsors for operations and initiatives are GSK, UCB, Merck, Lilly and other smaller grants fx for annual convention.

LUPUS EUROPE Board of Trustees are elected to office and serve on a voluntary basis and do so without personal honorarium.

LUPUS EUROPE



Established in 1989

24 national lupus groups:

Between 10- 6,000 members each

Total membership of +30,000

Approx 500,000 diagnosed with lupus in Europe*

Complex and complicated: Autoimmune, connective tissue +



Could You Have Lupus?

Lupus is a chronic autoimmune disease that causes inflammation in various parts of the body. The disease can range from mild to life-threatening. Ninety percent (90%) of people with lupus are women, and eighty percent (80%) of them develop lupus between ages 15 and 44. Lupus is very hard to diagnose because symptoms vary from person to person, can come and go over a long period of time, and can mimic symptoms of other illnesses. It is important to know the symptoms of lupus and to know if you are at risk for this disease. Here is a simple test to help you. Read each question and answer it in terms of your current AND past health status.

- Brain and Nervous System**
 - Have you ever had a seizure or convulsion or become confused for no known reason?
 - Have you had unexplained fever higher than 102°F / 39°C for more than a few days?
- Heart or Lungs**
 - Have you felt chest pain while taking deep breaths?
- Kidneys**
 - Have you ever been told you have protein in your urine?
 - Have you ever had swelling in your legs and ankles on both sides at the same time?
- Blood and Circulatory System**
 - Have you ever been told you have anemia, low white cell count, or low platelet count?
 - Do your fingers and/or toes become pale or red or blue and numb or painful in the cold?
 - Have you ever had blood clotting problems or a miscarriage?
- Eyes, Nose, and Mouth**
 - Have you had sores in your mouth or nose that lasted for more than a week?
 - Have you developed irritation or dryness in your eyes or mouth for more than a few weeks?
- Stomach and Intestines**
 - Have you had unexplained weight loss or abdominal pain that is worse when you breathe?
- Muscles and Joints**
 - Have you had stiff, tender, and swollen joints that are worse in the morning?
 - Have you felt extremely tired, weak, or achy for days or weeks, even after plenty of sleep?
- Skin**
 - Has your skin ever broken out after being in the sun, but it's not a sunburn?
 - Have you ever had redness or rash across your nose and cheeks in the shape of a butterfly?
 - Has your hair fallen out for no reason?

If you can answer "yes" to three or more of these questions, talk to your doctor about lupus. Early diagnosis and proper medical treatment can often keep lupus under control.

Please turn over this page for more information.

LUPUS
Foundation of America, Inc.

Multifaceted, multidimensional

Almost all organs and body systems

Anchored in Rheumatology, but also other specialties could be involved

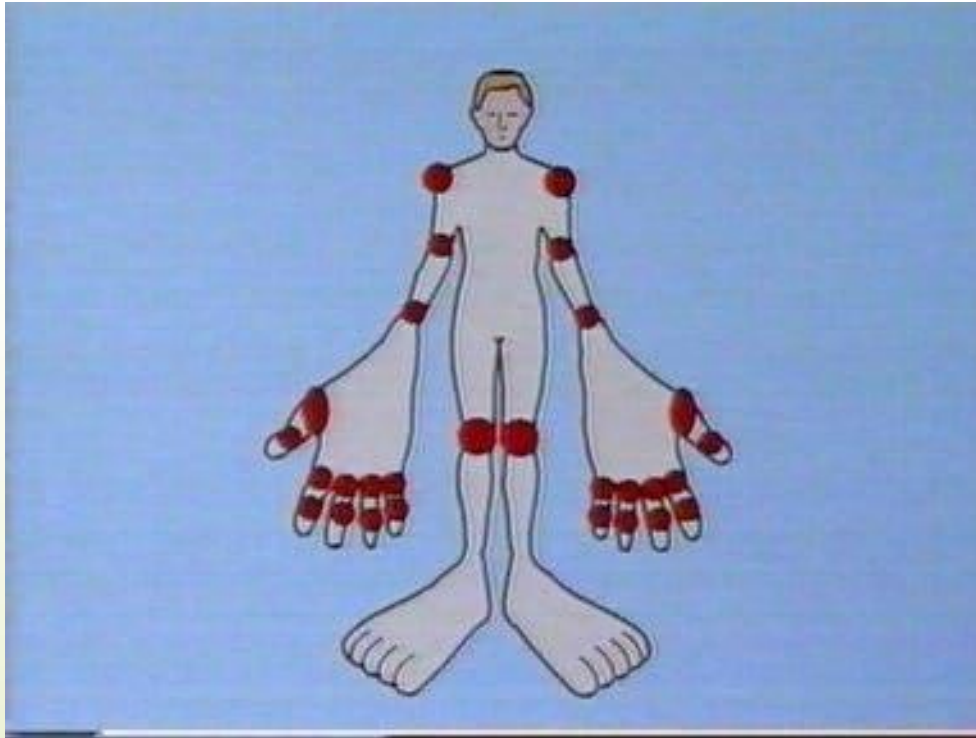
Average diagnosis age: 37 years

Time to diagnosis: 7 years*

9 out of 10 is female*

- at the time of creating career and establishing family!

DAS28 – disease activity score 28 joints



<http://www.rheumatology.org/Practice-Quality/Clinical-Support/Quality-Measurement/Disease-Activity-Functional-Status-Assessments>

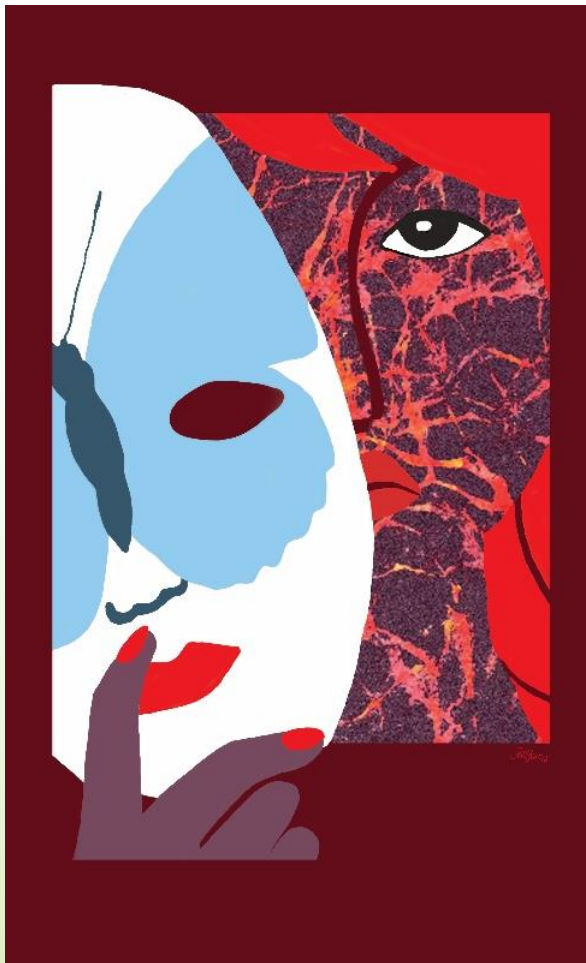
Only one compound in 60 years!



1955 Antimalarias approved
for treatment of lupus
1959 Prednisolone approved
for lupus treatment
2011-12 Belimumab approved
by FDA and EMA*

More than 100 open lupus
trials on clinicaltrials.gov, but
so far only belimumab has
passed phase III

Treatment not good enough



Almost half out of employment within a few years of diagnosis*

For the majority of those remaining in employment, it is on considerably reduced terms*

We NEED to do better

Living with Lupus – Next Move

WHY DID WE DO THIS?????

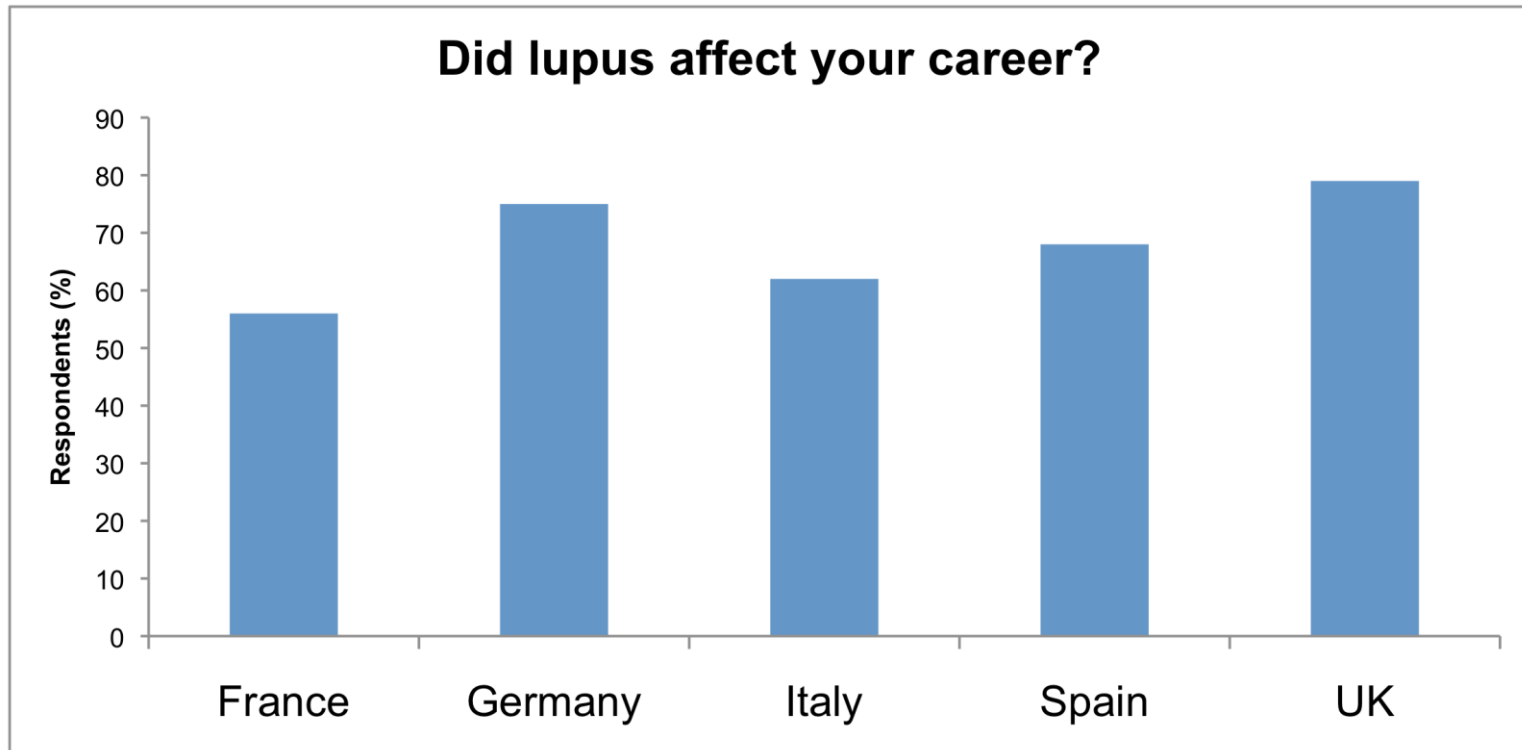


“... But after reading the questions again, I realized that this most certainly concerns me. Again I was reminded how different my career could have turned out if Lupus had not interfered.

Thank you „someone“ for having the interest in and bothering to collect this information about us with Lupus. ”

From a comment on one of the social networks when Survey II Living with Lupus was launched

Effect on patients' careers



In total, 27.7% (310/1121) patients (mean age 36 years) had to change their career within 1 year of diagnosis

Structure



Demographics



Fatigue Severity
Scale (FSS)



Work Productivity
Impairment (WPAI)



Lupus Quality of
Life (LupusQoL)

Organization

Clinical Advisory Committee

Counseling
Analysis
supervision
Presentation

Co-ordination

Planning
Programming
Communication
Administration
Facilitation

Language Contacts

Part 1 –
Design & Translation
Testing
Distribution
Follow-up



Organization

Clinical Advisory Committee

Prof. **David Isenberg**,
Univ. College London, UK
Prof. **Caroline Gordon**,
Univ. Birmingham, UK
Prof. **Matthias Schneider**,
Heinrich-Heine-University
Düsseldorf, Germany

Co-ordination

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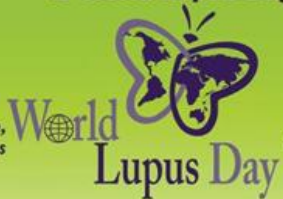
Common campaign for World Lupus Day

From LUPUS EUROPE international contact to fellow colleagues in member groups

Make LUPUS Work

10th May
is World Lupus Day

- The Lupus European On-line – LEO – Survey gave the following statements – part of the previously untold story – having lupus is life changing
- 9 out of 10 diagnosed are women
- 7 out of 10 reported having lupus had impact on career
- For those having had career change, 28% came within 1 year of diagnosis
- 52% are still in paid employment



- Those in employment reported on average: 13% missed work time due to lupus
- 39% reduction of productivity while working
- 42% of overall work impairment due to lupus
- 56% daily activity impairment due to lupus i.e. shopping, exercise, childcare etc.

References: (FR10243) IMPACT OF LUPUS ON FATIGUE, HEALTH-RELATED QUALITY OF LIFE AND WORK PRODUCTIVITY: RESULTS FROM THE LUPUS EUROPEAN ONLINE (LEO) SURVEY, EULAR 2011
Session: Epidemiology, health services and outcome research

(OP0277-PARE) LUPUS EUROPEAN ONLINE (LEO) SURVEY: A PATIENT-DRIVEN SURVEY TO EXAMINE THE IMPACT OF LUPUS, EULAR 2011 Abstract
Session: From abstract to concrete the variety of PARE organisations.

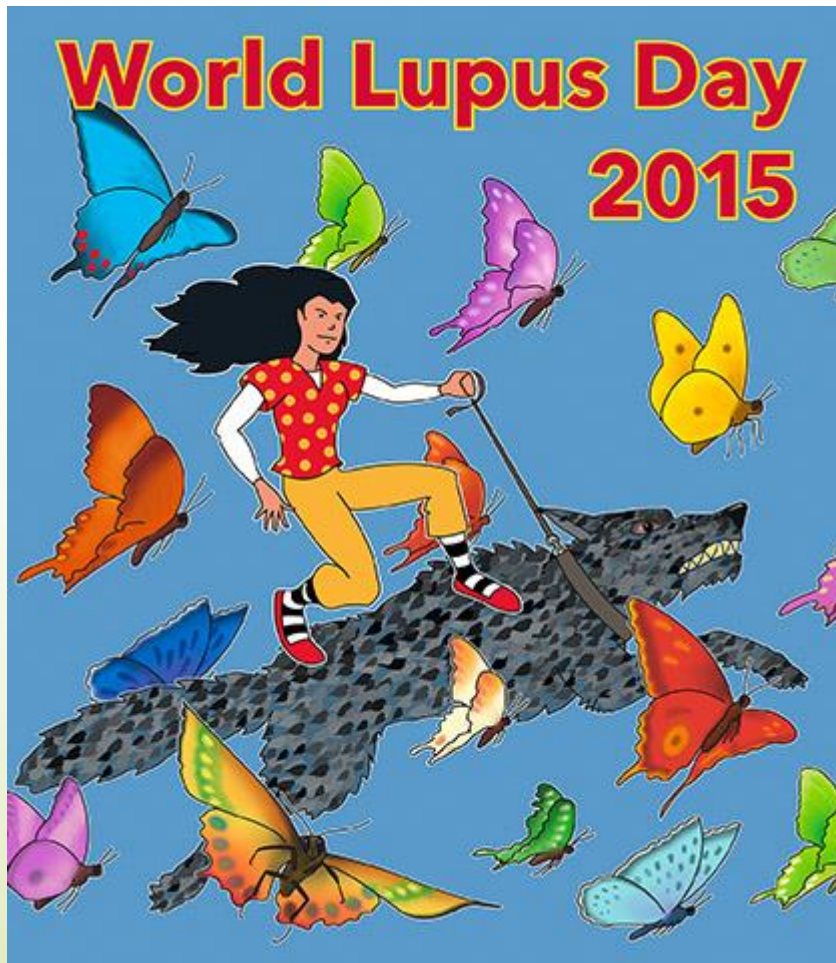
For further information about lupus and member countries/ Groups of LUPUS EUROPE please contact the address below:

**Lupus DK
Gigtforeningen
Gentoftegade 118
DK-2820 Gentofte, Denmark
Tel: +45-39-77 80 00**

The Lupus European Online - LEO - Survey supported by UCB © 2012 LUPUS EUROPE. All rights reserved



Tame your wolf – tame your lupus



It is the firm belief of LUPUS EUROPE that:

- Being involved in one's own disease
- Adherence to treatment
- Having the patient's voice heard in projects and trials

- *will help improve the situation for people living with lupus*

Tame your wolf – tame lupus is the theme for the campaign World Lupus Day 2015



LUPUS EUROPE – engagements, f.x.:

- EULAR Recommendations
 - Comorbidities
 - Lactation on RA and SLE treatment
 - Womens Health Issues
- European applications
 - FOREUM
 - *REFRACT, DORIS, "When the wolf bites its offspring"*
 - EU Horizon 2020
 - *United, iManage*
- International Initiatives
 - *T2T, DORIS, Uniting World Lupus Groups*



Who are we representing patients

- Patients = diagnosed with lupus
- EULAR trained Patient Research Partners
- Trained from other sources
 - LSE, EURORDIS, EUPATI and more

Lupus specific training is wanted



Thank you