



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

Formerly European Lupus Erythematosus Federation (ELEF)

MEDIA RELEASE

LUPUS EUROPE LEADS THE WAY

Survey II – Living with Lupus – Career/Work situation

WORLD LUPUS DAY – 10th MAY – saw the launch of a special on-line survey promoted by LUPUS EUROPE in conjunction with UCB pharma SA.

LUPUS EUROPE is the umbrella organisation of 20 countries - Belgium, Cyprus, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Israel, Italy, Malta, The Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland and United Kingdom.

The survey is in five languages, English, French, German, Italian and Spanish, the five most spoken languages in the member countries.

An on-line survey carried out during 2009 highlighted Career/Work as a major problem for lupus patients throughout Europe with a large number being unable to work due to their illness or having to reduce working hours. In many cases, patients had to make a change of career.

This on-line survey looks at the reasons for change of career/reduction of working hours and also at the problems of young people who find having lupus interferes with their study and the difficulties in finding employment, often due to a major symptom of lupus – fatigue.

There have been many previous validated surveys looking into the problems caused by lupus but this is the first survey to look specifically at the Career/ Work issue.

It is hoped that a minimum of 1000 responses will be made to the survey throughout Europe and that the answers will give important data for future projects aimed at helping lupus patients, giving the medical profession better information that may help with treatment and advising companies who are employing, or considering employing, people with lupus.

LUPUS EUROPE IS LEADING THE WAY IN UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

Notes for Editors overleaf

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Notes for Editors

WHAT IS LUPUS?

Lupus, or SLE (systemic lupus erythematosus) is an illness of the immune system whereby the antibodies that usually help fight infection and disease are overproduced, causing inflammation almost anywhere within the body. **Lupus is a complex disease** often varying within the individual over months or years and quite frequently manifesting itself differently from patient to patient.

HOW DOES LUPUS DEVELOP?

LUPUS is neither infectious nor contagious, and is triggered by a number of factors including viral infection, sunlight, trauma or strong medication. However, **the principal trigger is hormonal activity and change**, resulting in 9 sufferers out of 10 being female, usually between the ages of 15 and 55. It is also possible that a weak genetic predisposition may contribute.

WHO HAS LUPUS?

It is estimated that 1 in 750 women in Europe have the disease, many of them still to be diagnosed due to the mix of symptoms and lack of awareness within the medical profession. **GPs seem unwilling or unable to look for the signs of lupus** and a long delay in diagnosis invariably has a depressing effect on the patient who is struggling to establish what is wrong.

Lupus is incurable - it may strike at puberty, after childbirth or at the menopause and whilst principally suffered by women can also affect men and children. Sadly, patients do die due to lupus, despite the best efforts of specialists, doctors and nursing staff.

HOW DOES LUPUS AFFECT THE PATIENT?

Extreme tiredness and joint/muscle pain are invariably present - rashes, hair loss, anaemia, feverishness, mouth ulcers, depression and other symptoms can also be in evidence. **One patient in three is likely to have a form of kidney involvement** and the heart, lungs or brain can also be affected. Miscarriage, often recurrent, may be a possibility. Lupus can too easily be life-threatening for some patients and damaging in the long-term for very many.

AND THE PROGNOSIS?

Lupus is for life, and over 90% of patients remain on continuous medication, often steroids, which in turn can bring side-effects. Partners, family members and friends are, therefore, all co-sufferers of lupus.

Better awareness by the general public and above all by the medical profession will be the only way to help towards speedier diagnosis and proper management of this ongoing, debilitating condition.

LUPUS EUROPE aims to make lupus more widely known throughout Europe.

Someone you know may have LUPUS.....