



# LUPUS

## Incidence within the Community



## THE LUPUS UK RANGE OF FACT SHEETS

Further fact sheets are available as follows:

- LUPUS A Guide for Patients
- LUPUS The Symptoms and Diagnosis
- LUPUS The Heart and Lungs
- LUPUS and the Brain
- LUPUS and the Kidneys
- LUPUS The Joints and Muscles
- LUPUS The Skin and Hair
- LUPUS The Mouth, Nose and Eyes
- LUPUS and the Feet
- LUPUS Fatigue and your Lifestyle
- LUPUS and Men
- LUPUS and Light Sensitivity
- LUPUS and Pregnancy
- LUPUS and Blood Disorders
- LUPUS and Medication
- LUPUS and Associated Conditions

LUPUS UK is the registered national charity caring for people with presently incurable lupus and has some 7,000 members who are supported by over 30 Regional Groups.

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Please contact our National Office should you require further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

### LUPUS UK

ST JAMES HOUSE, EASTERN ROAD  
ROMFORD, ESSEX RM1 3NH  
TEL: 01708 731251 FAX: 01708 731252  
[www.lupusuk.org.uk](http://www.lupusuk.org.uk)

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## Are there cases of lupus in the community which have not been recognised?

Lupus can be difficult to recognise because the symptoms overlap with those of other conditions. Although the typical sun-induced rashes are often picked up by GPs and hospital doctors, some of the other manifestations may not be recognised unless they all occur at the same time and the appropriate blood tests are done to help confirm the diagnosis (see fact sheet on Lupus The Symptoms and Diagnosis). In Birmingham, a study was done to look for undiagnosed cases that were not picked up in the survey mentioned above. A questionnaire looking for lupus symptoms was sent to a group of women and those with a certain number of positive answers were asked to have a blood test (the ANA test). If it was positive, the people were asked to attend for a clinical assessment by a specialist doctor and more blood tests. In this way three new cases of lupus, out of 3,000 adult women sent the questionnaire, were identified. If the results of this small study were repeated on a larger scale, it could mean that up to 1 in 500 adult women (not 1 in 3,500) has lupus. This is probably an overestimate, but it is quite possible that there are a number of undiagnosed cases in the community.



## What should I do if I think I have got SLE?

If you think you have lupus after reading LUPUS UK fact sheets, you should see your GP and discuss why you think you have SLE and show the GP the fact sheets if necessary. If the GP agrees that lupus is possible, the GP may arrange the blood tests or may ask for a second opinion from a doctor at the local hospital. If the initial blood results support the diagnosis, a specialist opinion on the need for further tests and treatment is recommended, as lupus is a complex and variable disease. Most people do well with appropriate treatment but there is presently no cure, and lifelong follow-up of the disease is required.



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Systemic lupus erythematosus (SLE or lupus) is a multisystem disease which can affect people of all ages and has been found worldwide, although some groups of people are at greater risk of developing the disease than others (see below). The clinical features of the disease and the tests used to diagnose it are discussed in other factsheets. This one covers studies estimating the incidence of the disease (how many people develop the disease) and the prevalence of the disease (how many people have the disease) at a particular time. In other words, it covers “who gets the disease”. “Why they get the disease” is harder to answer but will be discussed briefly.

### How common is lupus?

Until a few years ago there was very little information on how common lupus is in the UK. It was generally considered a rare disease, most general practitioners (GPs) only having one or two patients on their lists. However, studies done in the late 1980s and early 1990s have shown that lupus is more common than was realised, particularly in women. Results from the largest UK study in Birmingham showed that in a population of 1.2 million, there were 242 adult people known to have lupus and 33 new cases of lupus diagnosed in one year (1991; children were not studied). From these figures the prevalence and incidence rates for lupus, corrected for the age of the population, were calculated. The prevalence was 28 per 100,000, that is about one person in 3,500 has lupus. The incidence (new cases per year) was 3.8 per 100,000, that is about one person in 26,300 developed the disease that year. The previous results from the smaller cities of Nottingham and Leicester were very similar.

### What groups of people are most at risk of lupus?

Many studies have shown that women are about 10 times more likely to have or to develop lupus than men. In Birmingham, the figures showed that lupus occurred in almost exactly one in 2,500 adult women; which shows that lupus is not a rare disease in women. It is however rare in men, occurring in approximately 1 in 25,000 adult men. Although the disease can start at any age, the first signs of the disease in women usually appear during the reproductive years (after the onset of menstrual periods and before the menopause). The disease is most commonly diagnosed in women between the ages of 20 and 40, and it appears to be milder in those in whom the disease starts after the menopause (when the monthly periods stop). There is no particular age pattern in men with lupus.

It is also well recognised that people from different ethnic and racial backgrounds are at different risks of developing lupus. People of Afro-Caribbean origin are particularly likely to develop the disease, even when they are born and live in North America or the UK. Surprisingly, people of West African origin (from which the Afro-Caribbean populations were descended) are at low risk of developing lupus. Studies have suggested that up to 1 in 250 women in Jamaica develop lupus. In Birmingham, 1 in 500 women of Afro-Caribbean background have lupus, compared with about 1 in 1000 women from India and Pakistan, and about 1 in 2,500 white European Caucasians. Other studies have shown that people of Chinese and Polynesian backgrounds are also at increased risk of developing lupus, compared with white Caucasians.

### Why do people get lupus?

These observations on the different risks of developing lupus in different populations have suggested that genetic factors (which people are

born with), play an important role in the development of the disease. This does not rule out a role for environmental factors which may also be shared by people from particular backgrounds. There is no single gene which puts people at risk of developing lupus (unlike haemophilia and cystic fibrosis). It seems most likely that between 20 and 80 genes contribute to the risk of lupus and that the genes set the scene and environmental factors contribute to whether or not the disease develops and when. The “environmental” factors include exposure to UV light (sun-exposure), various infections, possibly chemicals in the environment, factors related to stress (not well-identified) and female hormonal activity (for example the oestrogen-containing contraceptive pill or pregnancy). These factors combine together to influence the immune system in such a way that immune abnormalities result which cause the disease to develop (or recur).

### Will children of people with lupus get lupus?

Because so many genes are involved in the development of the disease (only half of which are inherited by a child from one parent with lupus), and because environmental triggers have to occur during the life of the individual to make the disease appear, it is not common for the children of people with lupus to have lupus. Most studies have shown that about 1 in 20 people with lupus will have a close relative (mother, aunt, sister, brother; less often father or uncle) with lupus. Occasionally the baby of a mother with lupus will be born with a special form of lupus called neonatal lupus syndrome, due to the passage of certain antibodies (anti-ro and/or anti-la) from the mother to the baby during pregnancy. This form of lupus only lasts a few months, as the baby destroys the antibodies from the mother and does not make any more itself. It does not predispose to lupus in the future in that child.