

LUPUS

Incidence within the Community



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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 factsheet 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?

Lupus is still considered a rare disease by many people, and most general practitioners (GPs) have only one or two patients on their lists. However, studies done in the last 20 years have shown that lupus, particularly in women, is more common than many people realise. A study in Birmingham in the early 1990s showed that, there were 242 adult people known to have lupus and 33 new cases of lupus diagnosed in a population of 1.2 million. The prevalence was 28 per 100,000, that is about one person in 3,500 had lupus. The incidence (new cases per year) was 3.8 per 100,000, that is about one person in 26,300 developed the disease in 1991. A study published in 2007 based on the UK General Practice Research Database, which covers approximately 5% of the UK population, estimated that lupus incidence rates in the UK during all of the 1990s was 4.7 per 100,000 per year; with 7.9 out of 100,000 females and 1.5 out of 100,000 males developing the disease each year.

The two most recent and largest US studies from Michigan and Georgia undertaken in 2002-4 showed higher rates still, with age-adjusted incidence rates of about 5.5 per 100,000. There were with 5 times more new cases in females than males (about 9.3 per 100,000; that is nearly 1 in 10,000 females developed lupus per year but less than 2 in 100,000 males were diagnosed each year). These US studies also found higher prevalence rates, with 73 per 100,000 living with lupus and about 1 in 800 females were affected. Lupus had been diagnosed in nearly 9 times more females than males in the population studied (128 versus 15 per 100,000).



What groups of people are most at risk of lupus?

Although the disease can start at any age including childhood in males and females, the first signs of the disease usually appear in females during the reproductive years (after the onset of menstrual periods and before the menopause). The UK GP database study found that incidence was highest at age 50-54 years for females and 70-74 years for males. Some studies have suggested that up to 20% of cases develop lupus in childhood and have estimated that the incidence of lupus is 0.36-0.9 per 100,000 children per year. Prior to puberty and after the reproductive years, the disease is much rarer than during the reproductive years and there is less evidence of it being more common in females, highlighting the role of female hormones in the development of the disease in some patients. In the recent US studies, lupus was most common in females aged 30-59 years and in Michigan the average age at diagnosis of lupus in all new cases was 39 years. The disease appears to be milder in women in whom the disease starts after the menopause (when the monthly periods stop).

It is well recognised that people from different ethnic and racial backgrounds are at different risks of developing lupus. People of African origin are particularly likely to develop the disease, even when they are born and live in the UK or North America. Other studies have shown that people of Chinese and Polynesian backgrounds are also at increased risk of developing lupus, compared with white European Caucasians. Studies have suggested that up to 1 in 250 women in Jamaica develop lupus. In Birmingham, 1 in 500 adult 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 Europeans. The results from the recent US studies have confirmed the UK data from Birmingham that people of Black African origin are about 3 times more likely to suffer from the disease, and that they develop lupus younger especially females aged 20-49.

These US studies also found that people of Black African origin were more severely affected than those of white European origin with increased rates of kidney involvement, as was observed previously in a study from North West England published in 2007. In Georgia kidney failure in lupus patients was 7-fold more likely among black than white patients, emphasising the importance of testing for kidney disease in lupus patients. In the study of lupus kidney disease in North West England the highest rates were seen in people of Chinese origin with a prevalence of biopsy proven kidney involvement in 110 per 100,000 population compared

with 99 per 100,000 in Afro-Caribbeans, 21 per 100,000 in Indo-Asians (Asians from the Indian subcontinent), and 6 per 100,000 in white patients.



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 that 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.



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 factsheet 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 have further blood tests. In this way three previously undiagnosed cases of lupus, out of 3,000 adult women sent the questionnaire, were identified in addition to a number of women who had already been diagnosed with the condition. If the results of this small study were repeated on a larger scale, it could mean that 1 in 500 adult women (not 1 in 3,500) has lupus in the UK. 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 factsheets, you should see your GP and discuss why you think you have SLE and show the GP the factsheets 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.

The LUPUS UK Range of Factsheets

A range of factsheets are available as follows:

1. LUPUS Incidence within the Community
2. LUPUS A Guide for Patients
3. LUPUS The Symptoms and Diagnosis
4. LUPUS The Joints and Muscles
5. LUPUS The Skin and Hair
6. LUPUS Fatigue and your Lifestyle
7. LUPUS and Pregnancy
8. LUPUS and Blood Disorders
9. LUPUS and Medication
10. LUPUS and the Kidneys
11. LUPUS and Associated Conditions
12. LUPUS and the Brain
13. LUPUS The Heart and Lungs
14. LUPUS The Mouth, Nose and Eyes
15. LUPUS and Light Sensitivity
16. LUPUS and the Feet
17. LUPUS and Men
18. LUPUS and Mixed Connective Tissue Disease

LUPUS UK is the registered national charity caring for people with lupus and has over 5,500 members who are supported by the Regional Groups.

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Please contact National Office should you require further information on the sources used in the production of this factsheet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

LUPUS UK is certified under the requirements of the Information Standard.



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