



St Thomas' Lupus Trust

What is Lupus?

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What is lupus?

The basic problem is an alteration in the immune system. The normal immune system, which produces antibodies to fight against foreign invaders, such as bacteria, goes into 'overdrive' and produces too many antibodies. This in turn can affect any organ in the body.

The cause is not known. There is a definite genetic tendency but despite years of research, no virus or infectious cause can be identified. Neither is there evidence of an environmental cause.

The current figure for estimated sufferers is 1 in 750 Caucasian females and as high as 1 in 250 amongst ethnic minority females. Although the cause is not known, research suggests that hereditary factors play a role. Advances in genetics have dramatically improved the pace of research for discovering the genes that contribute to lupus susceptibility, severity and mortality. The identification of these genes will provide a framework for understanding the basis of this illness.

General features:

Lupus patients suffer from a wide variety of symptoms some of which are described below.

Fatigue:

The most common feature of lupus is fatigue. It is a major symptom in some patients, and can be extremely distressing. The cause of this fatigue is still poorly understood, but generally, energy levels seem to improve once the disease is brought under control.

Skin Rashes:

These can affect any part of the body, the most well-known being the so called "butterfly rash" over the cheeks and the bridge of the nose. In many

patients the rash is made worse by exposure to ultra-violet light e.g. sunlight.

Hair Loss:

Hair loss is an important feature of lupus and is often the first sign of a disease flare. In the majority of patients the hair grows back completely once the disease is brought under control.

Joint Aches and Pains:

Flu like symptoms are common in lupus patients and are a major feature of the disease. Sometimes joint pains can be severe, mimicking early rheumatoid arthritis but normally the joints are not damaged and this clearly differentiates lupus from rheumatoid arthritis.

Dry (scratchy) eyes:

Many patients with lupus also have "Sjögren's Syndrome" with poor tear secretion. This results in irritation of the eyes and in some patients quite marked dryness. This is usually helped by artificial tears (e.g. hypromellose eye-drops).

Inflammation of Tissues covering internal organs:

The thin "sausage-skin" covering internal organs such as the heart (pericardium) and lungs (pleura) can be inflamed leading to painful symptoms such as pleurisy.

Depression:

This is a major feature of lupus and very common indeed. It often requires both treatment of the lupus itself as well as the depression.

Kidney Problems:

The kidney is the "silent" organ and often patients do not know that the kidney is involved; it is common practice in our unit to teach patients to test their own urine (using "dip sticks" or "albusix sticks"). Urine testing is essential in lupus patients for the early

detection of kidney involvement, for which treatment must be prompt.

How is lupus diagnosed and monitored?

During the past thirty years, more sensitive blood tests have allowed us to recognise that for every patient with severe lupus, there are many more with subtle forms of the disease who are undiagnosed. Blood tests are used both for confirmation as well as for monitoring the progress of the illness. The ANA (antinuclear antibody) test, if positive, should be followed by other more specific tests to pinpoint more accurately the extent and type of the disease.

Because there are such a variety of symptoms, we would recommend consulting a dedicated lupus text.

Main tests in lupus:

- Anti-nuclear antibodies ("screening test")
- Anti-DNA antibody ("specific" for lupus)
- Anti-cardiolipin (clotting tendency)
- (ESR) Erythrocyte sedimentation rate
- (CRP) C-reactive protein
- Routine blood count and chemistry
- Platelet count
- Complement
- Urine

Many patients, when first told they have lupus find information scarce and often full of gloom. Until recent years, lupus was widely regarded by doctors as a rare disease - sometimes as a dire disease, involving kidney damage and a fatality rate. They may have advised their patients against pregnancy at all cost and issued other alarming warnings.

However, the real prognosis is good, indeed in the majority of patients, the disease can be brought under control and many patients are able to come off all medication.

Fund-raising Office:

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www.lupus.org.uk

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If you would like to learn more about lupus, we have a number of excellent lupus books and guides available:

Lupus - A Guide for Patients - £3

Lupus: The Facts - £10

Lupus - A Guide for Nurses - £3

The Big 3 (GP Booklet) - £2

Talking About Lupus - £10

Please contact the fundraising office to pay by credit or debit card.