

3rd October, 2012

Press Release

Royal National Hospital for Rheumatic Diseases Supporting Lupus Awareness Month

The Royal National Hospital for Rheumatic Diseases NHS Foundation Trust (RNHRD), known locally as the 'Min', will be helping to raise awareness of lupus during October 2012.

Lupus is an illness of the immune system, where the body's defence mechanism begins to attack itself, leading to inflammation and sometimes pain in different parts of the body. Worldwide, Lupus is more common than leukemia, muscular dystrophy and multiple sclerosis but the disease is often very difficult to diagnose.

Sue Brown, Consultant Nurse and member of the Connective Tissue Diseases (CTD) service at the RNHRD said: "Lupus is a complex condition and the severity and frequency of symptoms can vary considerably from person to person. Symptoms can include skin rashes, joint pain, excessive fatigue, migraines, hair loss and breathlessness."

Sue continues: "Lupus came to many people's attention through the TV series 'House', where 'It's not lupus, it's never lupus' became something of a catchphrase. Dr House often had to correct his diagnostic team who had mistaken other conditions for lupus."

"In real life, it's quite the opposite - with its many possible symptoms which can vary widely and come and go unpredictably, identifying lupus can be very difficult and some people may have experienced months or even years of uncertainty before their diagnosis."

Linda Rumbles, Chairperson of the Western Lupus Group said: "Having lupus I sometimes feel isolated and misunderstood by those around who do not fully understand exactly what living with lupus is like. The support I receive from the RNHRD, the Western Lupus Group and the National Charity Lupus U.K. is very important to me.

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It enables me to talk to others with lupus who know and understand how I feel, giving me a chance to ask questions, and pick up hints on self help, but above all it makes me feel I am not alone'

The RNRHD CTD team provides a multi-disciplinary approach to diagnosis, treatment and management of lupus and other auto-immune diseases.

Sue explains: "Treatment of lupus varies according to the individual patient; it is currently incurable but treatable and manageable, especially if diagnosed early. As well as providing intensive treatment and therapy we offer people with lupus the opportunity to learn new coping skills and techniques which could help them gain more control over symptoms and energy levels."

"Our group education programme also provides a valuable opportunity for those with lupus to meet with others with the same condition; it can feel quite daunting when you are first diagnosed and discussing your feelings, worries and concerns can really help."

"It isn't easy living with lupus – it can take time for medications to take effect and for you to learn how to balance the demands of the illness without it overwhelming you. You have to make adjustments in your life and change some of your activities, but it doesn't mean the end of everything."

The Western Lupus Group will be manning a stall at the RNHRD every Thursday in October providing more information about the work of Lupus UK, the national charity which supports those with the disease. Starting treatment as soon as possible will enable those with lupus to have better control of their life and help to prevent any complications developing.

OPPORTUNITY FOR INTERVIEWS

- **Patients available for further comment/interview if required**
- **Consultant nurse Sue Brown available for further comment/interview if required**

ENDS

Enc: Lupus Awareness Poster

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The RNHRD NHS FT is a national specialist rehabilitation and rheumatology hospital based in Bath.

Offering services to adults, children and young people, the trust has expertise in general and complex:

- Rheumatological and musculoskeletal conditions
 - Neurological rehabilitation
 - Chronic pain management
 - Fatigue Management
 - www.rnhrd.nhs.uk
-
- Western Lupus Group <http://westernlupus.org.uk/>

More information about Lupus

Lupus UK is the only national registered charity supporting people with systemic lupus and discoid lupus and assisting those approaching diagnosis. We presently have over 5500 Members and a number of Regional Groups around the UK who arrange medical talks, publish local newsletters, set up local occasions and organise fundraising events. Lupus UK also produces an informative national magazine with lupus articles, letters, reports, and photographs, and operates a strong Grant Programme for research purposes and welfare.

<http://www.lupusuk.org.uk>

- Systemic Lupus Erythematosus (Lupus) is an auto immune disease where the immune system does not work properly. In Lupus, the body produces 'auto-antibodies' which causes the body to fight itself and leads to inflammation and sometimes pain in different parts of the body.
- Lupus is a worldwide condition, and more common in Afro-Caribbean, Asian and Eastern races.
- Around 50,000 are people are now thought to have lupus in the UK.
- Lupus is not infectious or contagious.
- Lupus is 10-20 times more common in women than in men.
- Lupus is more likely to occur between the ages of 15 and 55.
- Lupus has a wide range of symptoms including joint and muscle pain, extreme tiredness, rashes, depression, anaemia, feverishness, headaches, possible hair loss and mouth ulcers.
- People with lupus can differ greatly in their symptoms and how the illness can affect them.

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- Most experts think that lupus has more than one cause and that there may be a number of genetic factors that make people more susceptible – it also takes one or more environmental factors to trigger lupus in those who are genetically susceptible. Environmental factors may include hormonal changes such as those experienced during puberty or pregnancy, sunlight and some medications.
- Although currently incurable, lupus is a treatable and manageable long term health condition which responds to medication in the majority of cases.
- Non medication measures, such as ensuring adequate sleep, reducing stress, avoiding factors that could provoke the condition (sun, excessive heat, fatigue, certain medications and infections) and being aware of early symptoms are also important in helping to manage the condition.