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MPs meet for a cross-party Seminar on Lyme disease

A cross-party seminar, entitled 'Lyme disease; Evidence for Change', held in the Grand Committee Room of the House of Commons this week tackled the many controversial issues that surround this tick-borne disease.

MPs, Lords, doctors and patients present heard presentations from speakers who represent the varying views on this disease, its prevalence, diagnosis and treatment in the UK.

Whilst clinicians and patients from all sides of this divided field expressed their viewpoints, there was opportunity for the undecided members of the audience to ask searching questions. Satisfactory resolution of all the issues surrounding diagnosis and treatment of Lyme disease does seem some way off, however, patients were pleased with the supportive running of the meeting and recognition of their problems by MPs present.

Champion archer, Mel Clarke, of Taverham in Norfolk, spoke of her experiences. Mel contracted Lyme just before competing in the 2003 World Archery Championships. When she started to compete she suffered a sudden, severe collapse. US doctors were puzzled until Lyme disease was diagnosed. Her Dad was told she only had 24 hours to live. Mel has sustained paralysis and permanent damage to her eyesight from the disease. When she returned home with her diagnosis she was shocked to find that UK doctors knew little about it. Luckily Mel is stable in health and can now compete again, she recently won the bronze medal at the 2008 Beijing Paralympic Games.

Fellow patient, Stella Huyshe-Shires, an IT specialist from Devon, had to take early retirement owing to Lyme disease. Speaking from her own experiences, and from the many other cases that Stella contacts in her work for the Lyme Disease Action charity, one must conclude that UK patients are still subject to widespread medical ignorance about Lyme. It is known that early and sufficient treatment maximises a patient's chances of good recovery, but this cannot come about if a doctor does not know about the disease or has nowhere to refer the patient.

Dr. David Owen, a GP with a special interest in Lyme, from Cardiff presented a comparison between the two commonly used clinical guidelines on Lyme disease. These are termed the IDSA Guidelines (Infectious Diseases Society of America guidelines) and the ILADS Guidelines (International Lyme and Associated Diseases Society guidelines). He concluded that there are many profound differences in the recommendations made by the two documents that remain to be resolved.

Professor Sarah Randolph spoke about the possible biological changes which underpin the rise in Lyme disease cases in the UK. Putting aside human factors such as improved awareness of the diagnosis, Professor Randolph discussed what is known about tick numbers and whether the apparent rise is having an impact on human case numbers. The relationship between tick numbers in the countryside and human disease is a complex one and milder winters are probably only one aspect of tick survival.

Dr. Sue O'Connell who is Head of the Lyme Reference Unit of the Health Protection Agency, defended the HPA's current position on Lyme disease. The HPA continue to advocate that UK doctors follow the IDSA guidelines with regard to diagnosis and treatment. The HPA remain unconvinced by continuing patient preference for more consideration to be given to a patient's rate of response to treatment and that no arbitrary treatment limits be imposed.

The floor was thrown open for contributions. All sides agree on the need for greater awareness and early prevention measures. However, instances were given of these laudable aims actually failing to deliver so far. Ample evidence of the need for change in current practice was presented.

Notes to Editors:

1. Speakers include: Mel Clarke, champion archer; Stella Huyshe-Shires, Lyme patient, Dr. David Owen, GP with special interest in Lyme, Professor Sarah Randolph, Professor of Parasite Ecology and Dr. Sue O'Connell, Head of the Lyme Reference Unit in the Health Protection Agency (HPA). The meeting was chaired by Hugo Swire MP. Additional speaker notes are at item 5.

2. Lyme disease, which is an emerging tick-borne infection, is endemic in virtually the whole of the UK and in Europe – it is not just an American problem. Lyme disease has different variants in many parts of the world. The variants that occur in the UK and Europe are often different from the US ones. The variants can differ in clinical presentation and that is why Lyme Disease Action is currently calling upon the Department of Health to put in place Clinical Guidelines for UK doctors that are specific to the UK.

3. Early symptoms include feeling unwell and may include a spreading, bull's eye rash. Symptoms typically shown in later cases include: feeling unwell, flu-like symptoms, extreme tiredness, muscle pain, muscle weakness, joint pain, upset digestive system, headache, heart involvement, sight and hearing problems, involvement of the nervous system including the brain, and a great variety of other symptoms.

4. Lyme disease is caused by the bite of a tick infected with *Borrelia* bacteria that are injected into the bloodstream. Lyme disease can be difficult to diagnose and consequently many people with Lyme disease are not being recognised as having the disease. Lyme Disease Action is aware of many cases where debilitating symptoms force patients to take long-term sick leave that would not have been necessary had their illness been recognised.

5. Additional notes on Speakers.

*Mel Clarke: Mel, of Taverham in Norfolk, contracted Lyme disease from an infected tick bite in 2003 whilst competing in the World Archery Championships in America in 2003. The disease has left Mel paralysed from the waist down and blind in one eye. She currently holds 20 county records, 10 national able-bodied records and 8 world records. Mel recently won the bronze medal at 2008 Beijing Paralympics.

*Stella Huyshe-Shires: Stella, a constituent of Hugo Swire MP, worked in IT for the NHS for many years until she had to take early retirement on the grounds of ill-health because of her Lyme disease. She is now an active participant in Lyme Disease Action, a charity aiming for an improvement in the diagnosis and treatment of Lyme disease in the UK.

*Dr. David Owen: Dr Owen qualified in Molecular Biology at the University of Edinburgh in 1978 and in Medicine at the University Hospital of Wales in 1984. He currently works in the fields of General Practice, Emergency Medicine and Lyme disease. In recent years Dr. Owen has attended and presented at annual Lyme disease conferences in the USA and UK. He is Medical Adviser to the charity Lyme Disease Action (LDA) which aims to increase awareness and treatment of tick-borne diseases.

*Professor Sarah Randolph: Sarah Randolph is Professor of Parasite Ecology in the Department of Zoology, University of Oxford. She is also Tutorial Fellow in Biological Sciences at Christ Church, one of the principal colleges of the University. Her career has been supported by successive research fellowships. She has studied tick ecology as a fundamental basis for understanding the epidemiology of tick-borne diseases since 1970. She is now exploring the causes for the massive upsurge in incidence of Lyme borreliosis over the past two decades – artefact, environment or a complex nexus of biological and non-biological (human socio-economic) factors?

*Dr. Sue O'Connell: The Health Protection Agency's role is to provide an integrated approach to protecting UK public health through the provision of support and advice to the NHS, local authorities, emergency services, other Arms Length bodies, the Department of Health and the Devolved Administrations. The Agency was established as a special health authority (SpHA) in 2003. Dr. Sue O'Connell is Head of the Lyme Borreliosis Unit, at the Health Protection Agency.

6. Cases of Lyme disease with a mild, uncomplicated primary infection, if treated in time, have a good prognosis. The majority of these people return to good health.

7. There are various infections that can co-exist with *Borrelia* bacteria within a tick, and these are referred to as co-infections. Several are recorded as occurring in the UK. The public health laboratories rarely test for these diseases. It is hard therefore to assess how common these attendant diseases are in the UK population.

8. The known incidence of the Lyme disease has been increasing in recent years. Ticks and the diseases they carry are becoming increasingly widespread in the UK. Official figures for numbers of laboratory-confirmed cases of Lyme disease in England and Wales were 500 in 2004; 595 in 2005, 768 in 2006 and 797 in 2007. If figures for Scotland are added, this takes the total over 1000 in 2007. The Health Protection Agency (HPA) acknowledges that these numbers do not equate to actual numbers of cases, which they estimate could be up to 3000 per annum. Lyme Disease Action has evidence that even these

figures may be an under-estimate.

9. There is a current Early Day Motion in Parliament calling for the following measures:

Early Day Motion 958.
Lyme Disease 19.02.2008
Goldsworthy, Julia

That this House acknowledges that Lyme disease, also known as Lyme borreliosis, is a serious and potentially chronic disease which is becoming more widespread across the United Kingdom; notes the growing body of evidence which suggests patients with the disease are frequently subject to misdiagnosis and under-treatment; is concerned that the disease appears to be under-reported and inadequately investigated; and calls upon the Government to put in place a national strategy for reducing the growing toll of ill-health caused by this disease, including the development of clinical guidelines specific to the UK for the use of all medical practitioners dealing with patients with this disease.

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=35151&SESSION=891>
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10. Spokespeople are available, please contact Stephanie Woodcock on 0783 362 3713 or 01326 375419, Denzil Searle on 01209 716656 or 0778 093 3207 or Katy Weston on 0208 279 0378.

Or email contact can be made through LDA Lobby team: lobby@lymediseaseaction.org.uk

11. Lyme Disease Action – Striving for prevention and treatment of Lyme disease and associated tick-borne diseases. <http://www.lymediseaseaction.org.uk>

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