Newsletter August 2010

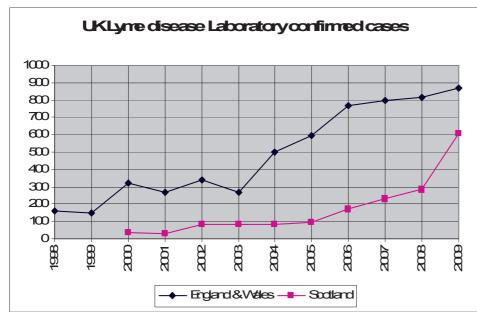
www.LymeDiseaseAction.org.uk



The picture tells a story

The Health Protection Agency (HPA) and Health Protection Scotland (HPS) have announced their Lyme disease figures for 2009. These are normally published in May but this year have been delayed. The HPA figures for England and Wales have still not arrived on the Lyme Disease Epidemiology pages of the HPA website, but are disclosed in a more general Zoonoses report.

Laboratory confirmed cases (ie positive blood tests) have risen in England and Wales by a modest 6.6%. In Scotland, however, **cases have doubled** and one is led to wonder why.



Whilst it is known that the terrain in Scotland has a greater abundance of tick habitat this has always been the case. Awareness in the whole of the UK has been rising because of increased press coverage but this is not exclusive to Scotland. Could the rise be down to better testing in Scotland?

The western blot blood test, used throughout the UK, records patterns of different bands produced by antibodies reacting to specific antigens of the bacterium *Borrelia burgdorferi*. In Scotland this test has been

considerably developed by the National Scottish Lyme borreliosis Testing Laboratory at Raigmore Hospital and now incorporates two local strains.

The most recent paper by Roger Evans et al just published in the Journal of Clinical Pathology explains that differences between strains "are considered to contribute to some of the difficulties experienced in the accurate serodiagnosis of Lyme borreliosis." The authors' conclusion is that 3 additional bands (20, 28 and 48 kDa) should be regarded as specific to Lyme borreliosis in addition to the 11 already used in the Raigmore in-house western blot. This paper highlights not only the importance of tailoring the test but also **the need to improve testing:** something LDA has been highlighting for years.

The 2009 figures from both the HPA and HPS are "provisional", so until we know the figures are comparable (ie based on positive blood tests only) and until they have been confirmed - we can only speculate on the differences.

More

HPA report: http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Zoonoses/EpidemiologicalData/zooepiDataEnglandandWales/

HPS report: http://www.documents.hps.scot.nhs.uk/giz/10-year-tables/lyme.pdf

JCP paper: More specific bands in the IgG western blot in sera from Scottish patients with suspected Lyme borreliosis. Evans et al. J Clin Pathol. 2010 Aug;63(8):719-21. Epub 2010 Jun 30



MP to LDA conference

Charlotte Leslie, the local MP for Bristol NW, will be attending part of the conference at Bristol University this year and will thus be able to hear first hand of the problems facing patients with Lyme disease.

LDA conferences in the past have included medical presentations about different aspects of Lyme disease in an attempt to provide information to doctors. This year is different in that we shall be concentrating on patients, many of whom will have read far more widely than most doctors on the subject. So the presentations will be on topics indirectly related to Lyme disease and the focus will be on sharing ideas and forging a way forward. This is what we need to do - move forward.

In a series of workshops we will collect evidence of the hurdles that delegates have faced and assess the priorities that we need to address over the next year. One workshop will explore constructive approaches to making a complaint and discover what resources LDA could provide to help the process.

There will be a couple of important announcements during the day. We hope that this conference will be a landmark, and not only because an MP is prepared to sit and listen to us. **September 3rd - don't miss it!**

More

Conference details & booking: http://www.lymediseaseaction.org.uk/conference.htm

BBC Doctors

This daytime soap is incorporating a storyline on Lyme disease over the next month. Over this weekend "Julia" the Practice Manager will have a few days away and be bitten by a tick.

The story develops over the next few weeks with expected resolution at the end of September. To retain the interest of readers in this particular sub-plot, the story has to develop rather faster than might happen in real life but we have hopes that it will illustrate some important points.

The programme is shown on weekdays on BBC1 at 13.45 and repeated at 18.30 on BBC HD.

The NHS: all change

The focus of the White Paper is putting patients at the heart of the NHS. The paper, and the related report on Arms Length Bodies, will have a huge impact on the NHS and has the potential to change things for the better for Lyme disease patients. But it will not happen overnight.

The Health Protection Agency will be abolished and its functions transferred to the new Public Health Service, directly under the Secretary of State for Health. Details will be announced later this year.

The National Institute for Health and Clinical Excellence (NICE) will "rapidly expand".

HealthWatch England will be created within the Care Quality Commission, to strengthen the collective voice of patients and to build on existing complaints handling structures.

Choice will be extended: the right to choose to register with any GP; choice for diagnostic testing; choice of named consultant-led team. So far of course these are just words, but if we can stimulate innovation in laboratories (see p 1) and have the support of politicians (see this page) then maybe we can also help foster some knowledgeable GPs and consultants. Then it really would all change!