

### **PHE Conference 2013**

Public Health England's Lyme disease Conference was, despite some initial scepticism amongst patients, a very useful day. It gave a lot of people the opportunity to listen to, and in many cases talk directly to, the people most involved in determining care for Lyme disease patients in the UK.

All presentations have been made available by PHE and these, together with some brief notes, are available on [LDA's website](#).

Our thanks go to Lady Mar, who has championed the patients' view and Kate Bloor and Michael Cook who were instrumental in involving her in the debate.

For LDA it has been the culmination of 10 years' work in trying to get doctors and the Department of Health to listen to patients and to address the genuine issues that exist.

The afternoon session was chaired by Dr Christine McCartney, Senior Advisor on Microbiology Services to the Chief Executive, PHE. She tasked Dr Tim Brooks, PHE, with drawing up an action plan from the day. This has already been drafted and meetings arranged to progress the items.

The next 6 months will demonstrate the commitment from the parties concerned to progress these action points. All participants have other jobs to do and the winter season inevitably brings demands on those in the NHS, and microbiology labs such as RIPL in particular. The Winchester Lyme disease clinic still does not have funding confirmed for 2014 and is fully booked well into the New Year. Demand for this is not in question.

#### **Joint Action plan**

1. Develop patient information.
2. Review & rewrite PHE website.
3. Produce UK guidance.
4. Establish formal procedures for LDA, RIPL & Lyme Clinic to co-operate for patients' interests.
5. Improve tests & share best practice between RIPL & Raigmore.
6. Examine feasibility of data collection on confirmed cases.
7. Apply for research funding for clinical studies & laboratory testing.

### **LDA Conference 2014**

The next conference will be held at the University of Surrey, Guildford on Saturday 5th July 2014. The current plan is to spread it over Saturday and include Sunday morning to allow more time for networking and discussion.

We are starting to invite speakers, and hope to include some international figures to talk on topics that are high in patients' minds and should be in the thoughts of all clinicians. Discussion groups will also feature, as they received very positive feedback in 2013.

RIPL will be reporting on the action plan and I am sure everyone will watch progress with interest.

## UK Guidance - at last

Following the Public Health England Lyme disease conference on October 9<sup>th</sup> in London, PHE have now confirmed a Multidisciplinary group to develop new UK Lyme disease guidance for the UK.

Published in [PHE's Health Protection Report](#) for 18<sup>th</sup> October this news item states that the "true prevalence is uncertain because of the difficulties associated with diagnosis and the non-specific nature of symptoms associated with chronic sequelae of the disease."

Reading that again, one can see how we have moved on: uncertainties in prevalence, diagnosis and chronic sequelae. Not actually recognition of chronic disease, but acknowledgement that there are limits to what we know and understand and that Lyme disease warrants further study.

This agreement comes more than **5 years after** an [Early Day Motion](#) was tabled in the House of Commons and supported by 88 MPs from all parties.

### Early Day Motion 958 February 2008

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 professionals dealing with patients with this disease.

## Stephanie Woodcock

Talking of history, many of you will know that Steph Woodcock was the founding chairman of LDA in 2003. She retired from trusteeship at our 2013 AGM last month, having in the past fulfilled the roles of chair and then treasurer. She will continue to be involved with the charity. Following more than 20 years working in a voluntary capacity first for ME patients and then, following her own diagnosis, Lyme disease patients, Steph and her closely involved husband Ken are currently on a well earned semi-sabbatical in New Zealand.

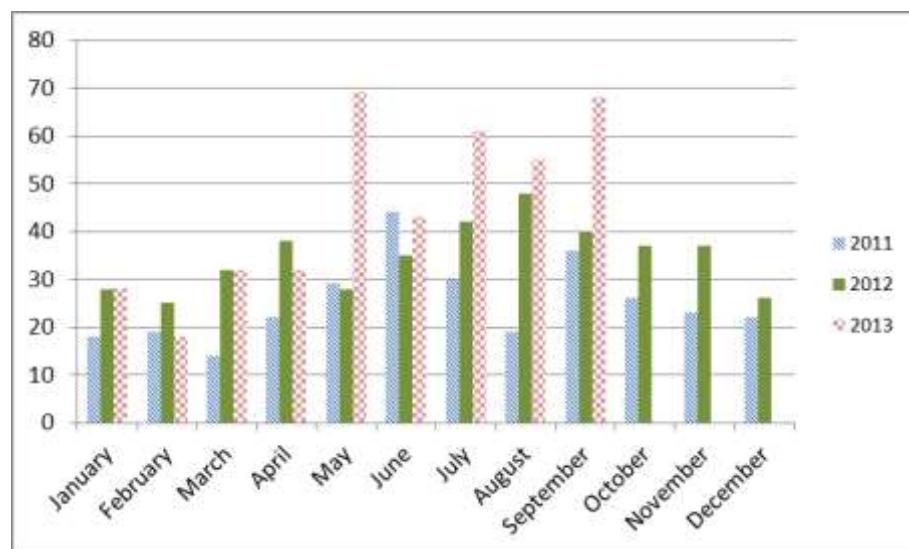


Whatever this charity achieves none of it would have been possible without Steph, and her fellow founding trustees Gill Reese, Cecylia Malenczak and Mairi Macleod. All of these have now retired, some several years ago, but LDA's progress rests on their recognition that a formal charity was needed to progress matters in the UK; and Steph's critical guidance.

And if this newsletter has any typos, it is because our best proof reader is in New Zealand!

## Patient Support

LDA has for some years run an email support line for patients. We provide accurate information about Lyme disease that patients can provide to their doctors to help inform discussions. Data on the number of requests is shown below.



No. of individual queries to LDA's Patient Support line over the last 3 years.

With permission of the patients concerned, we have recently taken a few case summaries to our regular meetings at RIPL. Our support team members know what might give rise to negative test results and also what key information to ask the patient about (travel history, rashes, medication, detailed symptom list etc). When this information has been combined with the detailed test results that RIPL have, even on negative tests, it has enabled a significant turnaround in some cases. It takes time and knowledge to draw these elements together and this has proved the value of the closer cooperation between RIPL and LDA.

It is our hope that we can continue to develop this into a more formal interaction to assist patients, RIPL and any specialist Lyme Clinics.

## Clinician Support

An important element of Patient Support has been to offer doctors, in particular GPs, contact with LDA's Medical Director. While Dr Pearson cannot make clinical recommendations for individual patients she can often provide a perspective on the difficulties facing patients and their treating clinicians and answer questions by providing evidence based, referenced information on all aspects of Lyme disease.

This has helped on a number of occasions, including one where the GP was about to refer a patient to a psychiatrist because she had reported seeing ticks in her back garden!

This support line was launched at the Royal College of General Practitioners conference in October and [a flyer is available](#) on our website.

## Twitter snapshot

Do you follow us? You don't have to tweet yourself - you can just [dip into our Twitter feed](#) occasionally by clicking on the Twitter icon at the top of the LDA website Home page.

**Tweets**



**Lyme Disease Action** @LymeAction 5 Nov

Topical azithromycin cream (not doxycycline) protects mice from #Lymedisease after tick bite. Hope for humans [ncbi.nlm.nih.gov/pubmed/24165183](http://ncbi.nlm.nih.gov/pubmed/24165183)

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**Lyme Disease Action** @LymeAction 2 Nov

RT @PearsLDA Thanks to @edyong209 Brilliant description of how ticks feed. Not a bite, or a stab, more a drill down [bit.ly/1dp7Jh1](http://bit.ly/1dp7Jh1)

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**Lyme Disease Action** @LymeAction 2 Nov

@amaranwosu @PearsLDA Info from the web "can" be assimilated by docs" but is it? We have @TheInfoStandard info for all, but who reads?

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**Sandra Pearson** @PearsLDA 1 Nov

@LymeAction @rcgp Nymph most common life-stage of tick to transmit Lyme disease to humans>'Of Ticks Mice & Men'>Fig1 [1.usa.gov/RvuqUD](http://1.usa.gov/RvuqUD)

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**Lyme Disease Action** @LymeAction 1 Nov

@PennineAcuteNHS ID doc in M'chester told patient with +ve #Lymedisease test numbness in legs & face "not Lyme related". Docs need R leaflet

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**Lyme Disease Action** @LymeAction 31 Oct

@rcgp GP just told patient not to worry as nymph tick was "too small" to transmit #Lymedisease Best to engage brain B4 making assumptions!

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**Department of Health** @DHgovuk 28 Oct

MT @depthealthpress: Report on #NHSComplaints by @TriciaHart26 and @AnnClwyd published: [bit.ly/1ccdsWf](http://bit.ly/1ccdsWf)

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Our last three tweets are always displayed at the bottom of the LDA Home page for easy reading. From there you can follow links and explore items further, whether or not you tweet yourself.