

# Newsletter

No 19 November 2014

[www.LymeDiseaseAction.org.uk](http://www.LymeDiseaseAction.org.uk)

## LDA Conference 2015 - Cambridge

The 2015 LDA conference venue has just been finalised:

Date: Saturday September 12<sup>th</sup> 2015

Venue: Murray Edwards College, University of Cambridge

We shall be using the purpose built [Buckingham House Conference Centre](#) with its adjacent accommodation. There will be dinner on the Friday night and also the Saturday night for those who want to stay on for further networking.

We shall be focusing on treatment and already have a couple of speakers confirmed. More details will follow.


## Christmas cards

We have added a new [Christmas card to the shop](#). The drawing is by David Skidmore, a cartoonist in the USA, who produced a sketch of a decorated deer tick last Christmas. On being told, via Twitter, that in the UK our principal vector is the sheep tick, he rustled up a new drawing.



With his permission we have added a festive tick remover and the new card is the result.

We also added a discrete note in small print inside just in case recipients think the tick actually looks as depicted on the front!



The sheep tick *Ixodes ricinus* can be found across the UK in woods, gardens, fields and town parks. It lives on sheep, deer, cats, dogs, mice, birds and humans. Some ticks are infected with Lyme disease and other diseases which they can pass on. Be aware of ticks and remove them properly.  
See [www.LymeDiseaseAction.org.uk](http://www.LymeDiseaseAction.org.uk)  
Drawing courtesy of David Skidmore.

So this is an awareness leaflet as well as a Christmas Card!

## Thank you

On which note, a heartfelt thank you to all of you who take our leaflets and posters and distribute them. We have got through 10,000 "Ticks and Lyme disease" leaflets in the last 6 months. Biggest thank you to the volunteer who makes up and posts the starter packs!

## RCGP e-learning module

We were delighted to have been asked to collaborate with the Royal College of General Practitioners to develop an [elearning module](#) for Lyme disease.

The course was written by LDA and a team in the RCGP to ensure it was produced according to their standards and processes, including quality peer review. The RCGP built the module and are hosting it on their website. LDA funded this to the tune of approximately £10,000 and we hope it will prove to be a good investment. As well as enhancing the education of GPs, we gain collaboration with the RCGP and the public validation of the other information we provide to GPs via their patients and our Help Desk.

After several drafts and teleconferences this was finally launched in September. Several doctors have circulated details, including Dr John Gillies, the President of RCGP Scotland.

The course takes 30 minutes and starts with a pre-course questionnaire which can be re-taken at the end of the course.

Because of the limited evidence base on treatment, this was not an easy course to write, but the panel agreed that it was important to highlight areas of uncertainty. There are some good, varied pictures of rashes and a number of myths are knocked on the head. No-one can be left in any doubt that Lyme disease can occur throughout the UK and that early treatment is important.

**In the first month of release**, the statistics show:

<b>Unique users:</b>	<b>221</b> (though some merely browse)	
<b>Pre-course assessment</b>	<b>Post-course assessment</b>	
attempts: 204	attempts: 144	
average score: 78.04%	average score: 95.35%	

So it seems reasonably successful!

The pre and post course questions are as follows-

1. Lyme disease can only be contracted in the countryside T/F
2. 90% of patients present with a rash? T/F
3. The rash can present several weeks after someone is bitten? T/F
4. The rash always appears at the site of the tick bite? T/F
5. It is important to always do a blood test for Lyme serology before starting treatment? T/F
6. Facial Palsy is NOT a recognised presentation of Lyme disease? T/F
7. The treatment for early Lyme disease is 1 weeks Penicillin V 250mg qds? T/F
8. Patients can initially get worse on treatment? T/F
9. The current UK tests have a high sensitivity and specificity. T/F
10. Late Lyme disease has a good prognosis? T/F

That should give you False - 8, True - 2.

## In the press

LDA's medical director, Dr Sandra Pearson, was commissioned to write a review article for the Nursing Standard. ["Recognising and understanding Lyme disease"](#) was published in September.

The article highlights the important role nurses may play in raising awareness and disease recognition. Advice on prevention and correct tick removal are covered. Key areas of uncertainty in diagnosis, testing procedures, treatment and the nature of persisting symptoms are discussed. The article has received positive feedback from nurses via social media.

## RCGP exhibition

For the third year running LDA booked a stand at the RCGP annual conference and exhibition. The picture shows our stand at a quiet time while all delegates were in conference, so you can see the big stand with facts and a rolling presentation on the screen which included pictures of rashes and ticks.



We were joined for the first time by a couple of volunteers and the four of us were kept busy most of the time during the two full days.

The table had leaflets and other printed information and a couple of containers of ticks - one container of dead ticks (some of them engorged) and one with 3 live ticks in. Surprisingly it wasn't the engorged ticks that drew most attention but the **live** ones.

Most people had never seen one and being able to watch it walking (once your eyes have spotted it) helps to bring home how small the nymphs are. We opened the container every so often to breathe on them and keep them active!

All doctors, trainees and medical students we spoke to were interested and grateful for the information. One young doctor came to thank us - she had talked to us last year and as a result she was able to recognise her first case this summer. Her colleagues were apparently most impressed!

The cost of attending the exhibition was £2,200, and well worth it. It has proved to be a very good way of getting good quality information to the GPs.

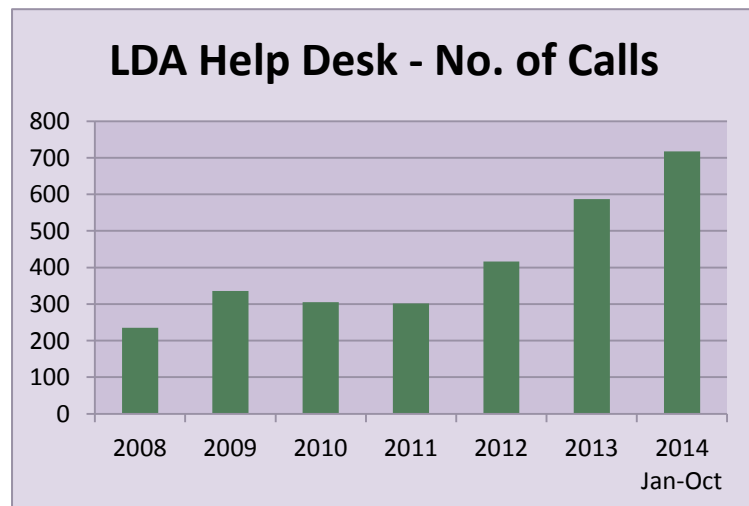
LDA trustees have agreed to continue exhibiting at both this annual conference (next year to return to the SECC in Glasgow) and also the Primary Care conference held each year at the NEC in May.



*Three did you say?!*

## A window on a problem

The number of people contacting our help desk has been rising considerably. This is probably due to the wide publicity given to Lyme disease from various sources. The graph shows the number of individual callers, but most queries generate multiple emails in which volunteers try to get to the bottom of the problem.



There is a perception in the Health Service that "the problem" is that many people read information on the internet and believe incorrectly that their illness must be Lyme disease.

The experience documented by our Help Desk is otherwise.

Yes, there are some people who ask for information about Lyme disease in case it may explain their symptoms but the

biggest problem that we can see is the lack of awareness and lack of knowledge in primary and secondary care which leaves many undiagnosed and untreated.

Just last week a consultant is reported to have said to a patient

- early antibiotics would not have affected the blood test result
- he didn't know what a Herxheimer reaction was but discounted it anyway
- the patient definitely could not have Lyme disease
- he would not suggest another course of doxycycline without testing her **bone marrow**.

Every month someone is told *You could not have got Lyme disease in Milton Keynes / London / Cornwall*. Numerous people given early inadequate treatment for "a rash" are denied treatment when they get to secondary care and their blood test is negative. Many people are given half the recommended dose of doxycycline or amoxicillin, or the wrong antibiotic entirely.

The role of the Help Desk is to answer direct questions and to provide additional supportive evidence based information for people to show to doctors to aid communication and decision-making about particular issues. We can discover the clinical information that the doctor didn't know to ask about and the lab wasn't told. We act as a bridge between patient, doctor and laboratory. Discussing test results with RIPL we have been able to turn cases around. This is a free service to the NHS and it works.

Out in cyberspace on .GOV.UK is a very useful [Suggested Referral Pathway for Lyme disease](#) produced by Public Health England. It would save a great deal of grief and expense if this could be more widely circulated within the NHS.

It may now be possible to collate the data emerging via the helpdesk on its new platform to provide a useful insight into the general systemic difficulties which continue to plague Lyme disease diagnosis and treatment in the UK.