

We had hoped to manage a re-start of our quarterly newsletters and the last two came out of our keyboards as scheduled. The next was due in August, but somehow, what with one thing and another, the month passed, and here we are at the end of September.

News from LDA

First, the Bad News

Sandra Pearson, our hugely valued Medical Director, is stepping down.

Sandra has been working with us since 2010 and was appointed trustee and medical director in 2011. She has given us at least half her life ever since. She is battle weary and says *"As an NHS Consultant whose husband had Lyme disease, I thought, probably naively, that my fellow UK professionals would listen to me, as a carer and as a professional. That has not been the case and I have found it increasingly difficult to maintain my enthusiasm in the face of apparent disinterest, whilst also continuing to support my husband with his ongoing illness."*

LDA believes that Sandra knows more about Lyme disease than any UK doctor - just look at the selection of images further down this newsletter. Although GPs have been very grateful for her information, consultants don't seem to want to listen.

Dispiriting; and you can all, whatever your background, understand that after 10 years of this she feels as if she has run out of steam.

Recent news from PHE that a case of Babesia has been diagnosed in Devon (see further on) has stirred the feelings of frustration. In 2009, with her husband very ill, they travelled to "the experts" at University College London, to be told that "he is too ill to have Lyme" and the UCLH

positive test result for Babesia "doesn't mean active infection".

If, like Sandra, you were a doctor who had read numerous papers not only about Lyme disease, but also Babesia, just think what you would feel.

Back in 2012, Sandra and Stella went for a first meeting at the PHE Rare & Imported Pathogens Laboratory (RIPL) when it took over the testing for Lyme disease from the Southampton laboratory.

RIPL was just starting to learn about Lyme disease and the folder on the desk, presumably containing briefing notes, was mis-labelled "**Lyme's** Disease". LDA understood that much of the science on this disease would be new to the RIPL team. But the RIPL team at that point did not seem to value LDA's knowledge.

Relationships have now moved forward for some of us, but not really for Sandra.

Stella says *"I half expect, as a patient, to be patronised and dismissed, but Sandra didn't. Although some of us get to at least help tick the "patient participation" box, Sandra needs to be able to converse on the same level as doctors. Many consultants have refused to do this."*



European Study Group for Lyme Borreliosis, Berlin 2013. Spot the one from the UK bang in the middle



RCGP conference 2012



Primary Care 2014



With Brian Fallon March 2015



With Monica Embers Nov 2015



NordTick 2016



MSD Veterinary conference 2016



BBC 2016



Primary Care conference 2017



BBC 2017



Primary Care conference 2018



Primary Care Dermatology Society 2018



Clinic workshop 2019



RCGP Spotlight podcast 2019

Our huge thanks to Sandra for all of this. For the discussions with health professionals, input to the help desk, PubMed searches, medical explanations to trustees and volunteers and much, much more!

So where now for LDA?

Sandra enabled us to communicate with GPs and although they cannot now ask her about difficult cases via our help desk for medics, they do have the RCGP on-line module and the Spotlight Toolkit in which Sandra played critical roles. These products are kept under review.

Our Research Team is getting established, and Sandra is contributing as a volunteer, so her knowledge is not lost to us! We are now starting to have some conversations with universities and Public Health England as their Covid-19 related work is easing off to some extent.

What has happened in the UK recently?

Much talk about Covid-19

There are discussions about the difficulties of testing for Covid-19 - speculation that some positive tests may just be due to fragments of destroyed virus, and that antibodies do not always develop. Differences of opinion between groups of doctors, scientists and politicians on what should or should not be done. Ring any bells?

You will probably have noticed **Long Covid**. This is not just acknowledged, but it is studied, and there are clinics for the patients! This is partly because no-one can deny the numbers involved, but also because many health professionals are experiencing it.

It is probably difficult for a doctor to tell a fellow doctor "it's all in your head".

To be fair, it is probably also the presence of enough objective symptoms, such as measurably reduced lung capacity and cardiac issues. But who has actually studied the Long Lyme patients? *Properly*; using outcome measures that matter to patients. Are there too few of us to be worth it? Do we even know how many UK Lyme disease patients genuinely suffer long term effects of Lyme disease? See the diagram and discussion at the end of this newsletter from a European review of Lyme disease for some possible statistics.

The [proposed definition](#) of Long Covid is diverse symptoms beyond 4 weeks of symptom onset, but a proper clinical definition has yet to be agreed. How long has it taken to get an agreed definition of Post-treatment Lyme Disease Syndrome, and has it been defined by patients or by doctors?

It is noteworthy that some doctors and researchers are including patients as co-authors in papers about Long Covid. When they have actually been a patient, they realise the importance of true patient participation in studies - it is not just a trivial tick-box exercise.

For Lyme disease, there is a planned cohort study of UK patients to start later this year. Let us hope that it will occur to those designing this study to do the long term follow up of cases that is needed and to involve patients in the design of the study.

It is possible that some of the insights and discussions around Covid-19 will open up discussions on Lyme disease. Maybe even make people more receptive to a specialist Lyme disease clinic.

Babesiosis in the UK

In July Public Health England issued a news release announcing the first reported case of human babesiosis in England.

Those of you who came to our [2014 conference](#) will remember all those hundreds of ticks, collected by volunteers in Bath, Devon and Norfolk, being presented to Martin Andersson. Martin had come over from Sweden to give a talk on a new pathogen he was working on, and had said beforehand that he'd love some UK tick samples to test for that bacterium.

Martin reported back saying that the Bath sample had approximately 3% infected with *Babesia venatorum* which causes human babesiosis. The Norfolk and Devon ticks did not test positive for Babesia.

The Big Tick project at Bristol University, analysing ticks collected from dogs, found the Babesia parasite in ticks from right across the country, from Cornwall to Norfolk to Scotland. Given this prevalence of the parasite in UK ticks, why so few reported UK cases?



Evidence from mainland Europe indicates that a lot of people have been exposed to Babesia, though there have been few cases reported. So it seems likely that most people who contract babesiosis recover without treatment and probably without even consulting a doctor.

The people it seriously affects are usually (but not always) immunocompromised and in those people it can be very serious; a few deaths have been reported in Europe. These seriously ill cases are the ones likely to be tested and to receive a diagnosis. The others simply go under the radar. There may have been other cases in the UK.

We have put a more [detailed discussion on our website](#), covering what Babesia is, the symptoms, diagnosis and what we know about it in the UK.

Publications on UK studies

Although only published in the last few months, these were papers being worked on long before the Covid-19 pandemic struck.

This study of Southampton Hospital data, for the 8 years 2010-2017, looked at how children under 18 with a facial palsy coming in to the emergency dept. or Paediatric unit had been diagnosed and treated.

In a word - inconsistently!



These cases were all before the NICE guideline was published and the study found "some children appearing to receive no treatment, and others receiving antibiotics, steroids and

antivirals.” The title of the paper points out that a lot of the facial palsies were due to Lyme disease. Because of the findings, the authors suggest that areas with endemic Lyme Disease should consider local guidelines for paediatric facial nerve palsy, including empiric treatment.

The study also recommends that “all children presenting with facial nerve palsy in endemic areas should have Lyme serology performed.”

Reading this paper in detail there are several interesting points and we have explored these in [a separate news item](#). It’s all a bit more complicated than many people think!

1. When does a Lyme disease blood test result count as “positive” from a treatment decision point of view?
2. Infection rate of Borrelia in ticks - the paper says “up to 30%” but it depends on what you count!
3. Outcome following treatment for Lyme disease - is it really as “excellent” as this paper says?

Read our [comments on the website](#).

Ever wondered what GPs type on the computer when they diagnose Lyme disease?



When a GP sees a patient, they record their consultation by capturing symptoms, diagnoses and therapies. These can be recorded as structured codes on the GP database.

In this study run by University of Liverpool, the process by which GPs code their cases when presented with Lyme disease symptoms was investigated. The GPs were informed this was a study to understand the general coding decision-making process but were not told these were Lyme disease cases.

Eleven cases were presented, based on real Lyme disease cases, which consisted of symptoms that could have a variety of other causes. The study was conducted by interviewing participating GPs and asking them to expand on their reasoning.

The study found that only two out of the eleven were given a diagnostic code for Lyme disease, although a further five recorded Lyme disease as possible. The conclusion was that GPs were reluctant to code with specific diagnostic codes when they were presented with patients with vague or unfamiliar symptomology.

This helps to show why it is so difficult to find out how many UK patients contract Lyme disease. Although positive blood tests are reported centrally, clinical diagnoses (e.g. because of a typical rash) are not and can only be discovered by searching large numbers of GP records.

We have [a fuller explanation](#) of this study on our website.

What has happened elsewhere?

There have been quite a lot of publications, and we have uploaded many to our on-line reference library - thanks mainly to an MSc student who is doing the searching for us. Here are a few items of interest. We'll pick up on some more in another newsletter.

Antibiotic prophylaxis after a tick bite?



A study in the Netherlands recruited people with a tick bite. Some of them were given a single dose of doxycycline and some no treatment.

2.9% of those receiving no treatment developed Lyme disease, but only 0.96% of those receiving prophylaxis.

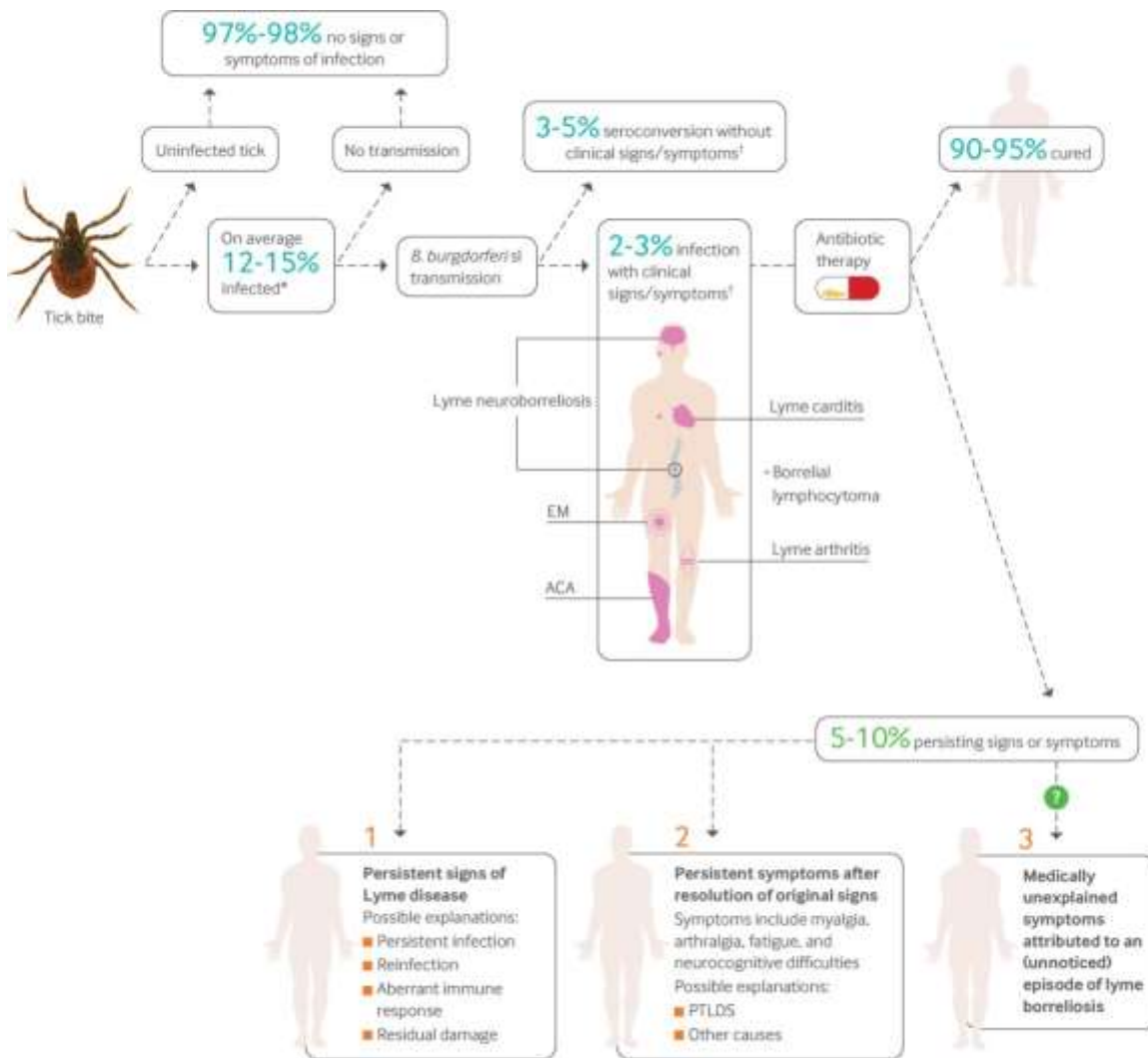
So in an area with a high percentage of infected ticks, single dose prophylaxis might be worth it; particularly for people with reduced immunity, older people, and those removing engorged ticks. But for the gardener, forester or farmer who removes more than one tick a week, and does it promptly, it is probably not worth the potential harm from the antibiotics.

The participants were recruited through the Dutch website [Tek Radar](#) which allows citizens to log their tick bites, producing a good pool of data. We discussed with Public Health England the possibility of a similar website for the UK following a series of cases around Nottingham in 2015, but nothing came of it. Discussions about UK tick surveys have been re-awakened though, following the Babesiosis discovery.

A "State of the Art Review" from the Netherlands

This is [an interesting review](#) by researchers in the Netherlands. It is open access and you can read the three responses - two long ones from the USA and one from Italy about rickettsiosis.

The article includes the diagram on the next page, which illustrates well the current *documented* evidence about the potential course of Lyme disease following a tick bite.



The text in the review notes that published studies show persisting symptoms:

- for 30 months in 40-50% of Lyme neuroborreliosis patients
- for 6-12 months in Lyme arthritis

Following this, 5-10% have persistent signs (ie measurable, observable signs) or symptoms (ie subjective pain and fatigue etc). If a doctor can measure it, then it could be due to infection or neurological/immune damage. If only the patient can measure it, then it is post-treatment Lyme disease syndrome, something else or "all in your head".

So is the outcome from treated Lyme disease "excellent"?

Maybe studies of Long Covid will open research ideas and shed some badly needed light on persistent symptoms of, or after, Lyme disease.

Access the past newsletters



You will find them in the ["What we are doing"](#) section, you can see all past newsletters, with an index of what's where.

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