



Lyme Disease Action
www.LymeDiseaseAction.org.uk

October 2022 Webinar What are Researchers Thinking?

11.00 LDA introduction

11.20 Q&A with Lucy Delaney, Research Fellow University of Liverpool

12.00 10 minute break

12.10 Pick up where we left off

13.00 Formal webinar ends

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In the early days.....

22nd **ECCMID** London, United Kingdom
31 March – 3 April 2012

European Congress of
Clinical Microbiology and
Infectious Diseases



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10 years ago we had been running our own LDA conferences for some years. By 2012 we had our JLA project underway to clarify what things were uncertain in diagnosis & treatment of Lyme disease. Because doctors wouldn't come to **our** conferences, we decided to take information to **their** conferences. All these conferences have an exhibition hall where companies can have stands.

We heard ECCMID was going to be in London in 2012, so we decided to take an exhibition stand so we could talk to doctors. The photo is Sandra and Stella setting up the stand the evening before. We expected UK doctors, but only saw overseas doctors & researchers – some diehards and some really interested.

After that, we decided to take the exhibition stand to UK medical conferences, to talk to UK doctors, and did that every year until COVID lockdown. We took the stand, leaflets and also some ticks, because most doctors had no idea how small these are and how easy to miss.

We also decided to go as delegates to the overseas conferences – where we could meet researchers dealing with tick-borne diseases.



Then as delegates

ECCMID, Berlin 2013
ECCMID, Barcelona 2014
NorVect, Oslo 2014
NordTick, Stavanger 2014
ICLB Vienna 2015
AAAS, Washington 2015
Lyme Disease Assn, Rhode Island 2015
NordTick 2016, Sweden
NordTick, Norway 2017
ITPD, Vienna 2017
NordTick, Sweden 2018



International Symposium on
Tick-Borne Pathogens and Disease
ITPD 2017 Vienna, Austria
24 to 26 September 2017



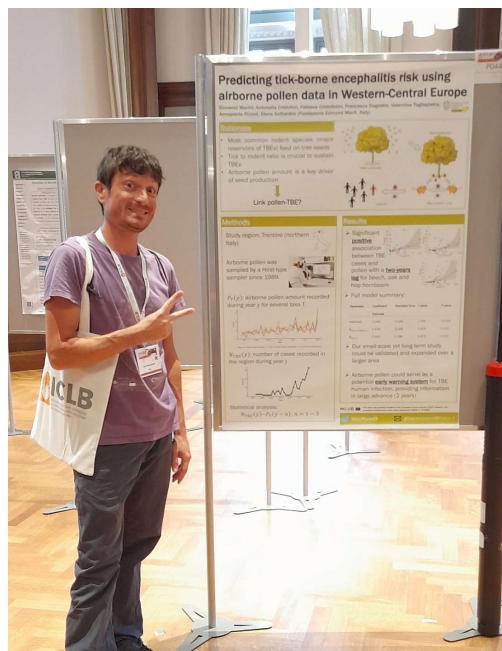
From 2013 through to 2018 – every year. Mostly Sandra. Sometimes Stella. These are just the International conferences; there have also been UK research conferences, including one during lockdown when Sandra gave a remote presentation to microbiologists..

At many of these it was LDA representing the UK, but there was the odd UK researcher – mainly the scientists from the English and Scottish Lyme disease reference laboratories. It was very useful, not just learning but hearing from the researchers – standing in the coffee queues and talking to people. Exchanging views – “What do you think about...??” The photo is Sandra back in 2015 talking to Monica Embers.

COVID lock down brought a pause to international conferences and this year as things were starting up again, we wondered what to do. We decided on a new approach - it would be useful to support a UK researcher to go and report back.



A new approach



With this important conference in September, we asked Lucy Delaney, who is working on the UK Lyme cohort study at the University of Liverpool. You heard from her at our webinar last year. Lucy didn't have it in her budget to attend this year, but was happy to go on our behalf. LDA paid for her airfare, accommodation and delegate fee. (your donations) and Lucy put in her time and effort.

It might seem like a jaunt, but I can assure you, it is very hard work. You concentrate on the talks, taking notes, sometimes photographing the slides to help you remember important points. You queue for coffee, lunch and tea – the meals are usually great, but you need to find someone both useful and compatible to sit with at meals. You do not want to get stuck with someone you definitely disagree with or someone who doesn't want to talk.

You need to get round the poster hall, where researchers have posters explaining their work. Some of these are young researchers, and very useful to make contact with. Each evening you try to write up what you've learnt & who you've talked to.



How do you find people?!



You need to network and introduce yourself to other researchers – build relationships for the future.

All these potentially useful people – and this is just those who were left at the end and happy to go out for the group photo!



Lyme Core Outcome Set

A flyer for the Lyme Core Outcome Set (LymeCOS) study. The flyer has a green and yellow color scheme with a background image of reeds. It includes the following text: 'LYME COS', 'A Core Outcome Set for Lyme Borreliosis', 'The measurement of different outcomes in Lyme borreliosis research is a problem.', 'We reviewed 134 studies and they measured 289 different outcomes.', 'Using different outcomes impacts on the ability of a study to contribute to meta analysis and effective treatments may take longer to be available to patients.', 'You can help us solve this problem by taking part in the Lyme-COS study to agree a set of core outcomes for use, as a minimum, in future research for Lyme borreliosis.', 'This study is for Health professionals, Researchers, and People who have had/have Lyme borreliosis. You can help agree the most important outcomes for Lyme borreliosis.', 'For more information and to get notified when the study launches visit www.lymecos.org'. Logos for the University of Liverpool, COMET Initiative, and LDA are at the bottom.

Lucy also had with her a bundle of flyers about the COS study LDA is funding. You heard Nicola Harman talk about this at our last webinar. You'll hear more in the near future because we need the input. Of patients, researchers and doctors.

Europe has more Lyme disease than the UK and has had it for longer, so we need to get people from other countries involved. Hence Lucy taking out some flyers about the project. It is not easy to thrust these into people's hands. They might think you are selling them something... Who are you anyhow?!

Look at this slide & **make a note of the website – LymeCOS.org**. Go there and register your interest so the researchers can tell you when the surveys launch. They've found that studies in the past have measured over 200 outcomes and so we really need to agree what are the important ones that every study should mention. You'll see more about this on our website shortly.



Organizing committee - Conference chairs

Joppe W.R. Hovius, Amsterdam UMC, The Netherlands

Hein Sprong, Wageningen University, Wageningen, The Netherlands



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

The Lancet Regional Health - Europe

journal homepage: www.elsevier.com/lanep

Research paper

Prevalence of persistent symptoms after treatment for lyme borreliosis: A prospective observational cohort study

“Interpretation: In treated LB patients, persistent symptoms were significantly more prevalent and symptoms were more severe than in individuals without LB, although the background prevalence was substantial. This suggests an association, either direct or indirect, between persistent symptoms and LB in a relatively small subset of patients.”

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Who chose the speakers at this ICLB conference? All conferences are organised by a committee. The opinions of that committee determine the range of speakers they invite, and those to whom they grant a speaking slot. ICLB is biennial – every 2 years in a different country. This one was in the Netherlands and organised by people who have done a lot of good, sound research and who talk to the patients and public.

Last year they published an important paper discussing some very thorough research.

Up to that point, most research papers have concluded that normal, healthy people have just as many symptoms as those who have had Lyme disease. Many have fatigue, many have pain.

This research discovered otherwise. So at last it cannot be denied that some people have persisting symptoms following Lyme disease. This now allows people to talk about persisting symptoms without being thought of as cranks. And it encourages research – there is a problem that needs investigating



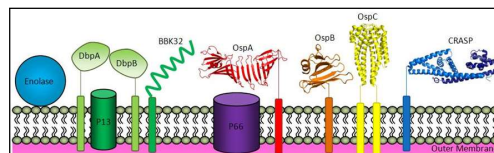
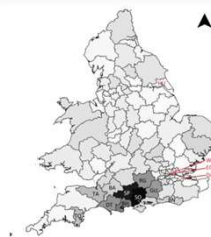
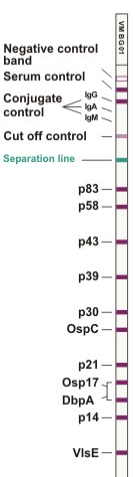
ICLB Programme

Sunday
Keynote speeches

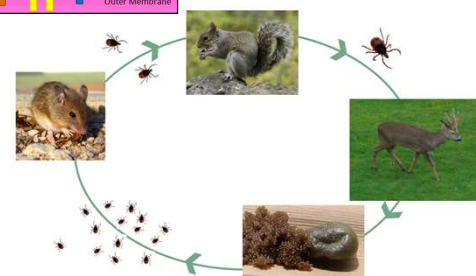
Monday
New and Hot
Epidemiology
Clinical Aspects
Young & Wild (early career researchers)

Tuesday
Pathogenesis
Ecology
Tick Biology
Lyme in the Lymelight

Wednesday
Diagnostics
Preventative measures



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On Sunday afternoon it started with some keynote speeches which were setting the scene

Monday, then had

- New and Hot – some recent developments
- Epidemiology –Where are the TBDs, who gets them?
- Clinical Aspects – symptoms, treatment etc
- Young & Wild - early career researchers

For each topic in the conference there was a small sub-committee deciding who the speakers would be. Looking at these sub-committees, we can see that some of these are hard-liners (have talked about Lyme anti-science & believe diagnosis and treatment of Lyme disease is straightforward) but, this being the Netherlands, some of them are not, so there was a variety of talks.

... Tuesday & Wednesday continued on next page. ...

Tuesday

- Pathogenesis – development of Lyme disease; how it progresses and what *Borrelia* do
- Ecology – where *Borrelia* live – the hosts eg mice etc - & how these influence the spread of disease
- Tick Biology – the interaction of Ticks with the diseases
- Lyme in the Lymelight – Dedicated to topics that are controversial and have been the subject of debate. This is where the Netherlands organizing committee gets people to listen to what they might not want to. – both patients and doctors.

Wednesday

- Diagnostics – How good are the tests & where are the problems
- Preventative measures

So there was a lot of ground to cover.

Lucy discussed key talks on each of these days.