

Newsletter

No 7 November 2011

www.LymeDiseaseAction.org.uk



A busy 9 months

A lot of water has passed under the bridge since the last newsletter. Back in February, we reported that the James Lind Alliance Priority Setting Partnership was rolling and we were inviting clinicians to awareness days. These days were very successful in Scotland, but less so in England where clinicians seem to be much more affected by the attitude of the Department of Health. Have a look at the [conference](#) transcripts for our report on attendances at these awareness days.

The next pages of this Newsletter have a fuller report on the JLA PSP - this has occupied a lot of our time and effort, and we know yours too.

The new LDA website was launched with significant changes to layout and with a Resource section for patients, clinicians and employers bringing pertinent facts to the attention of each group.

The [guidelines page](#) lists (with links and comments) all the main English Language guidelines on Lyme disease. Unlike the HPA, LDA does not believe in presenting a selected subset of these, so they are all there. Read and compare.

*JLA Priority Sharing Partnership
Website
Facebook
Response to the BIA
LDA Conference 2011*

The website is updated fairly frequently with news and reports, so keep your eye on it. [Facebook](#) provides for very fast dissemination of news - you do not have to have a Facebook account - just click on the Facebook logo on our website homepage. We have also just started to make use of a [YouTube channel](#) to post some videos and in particular to provide a verbal comment on the HPA's decision to ban a speaker from attending the LDA conference.

Position paper from the British Infection Association

As a statement from the major professional association in Britain concerned with Lyme disease, this started off as a disaster. That they felt they could say they consulted widely with their members (infectious diseases consultants and microbiologists) and still came up with such a biased, uncritical, misleading account of Lyme disease diagnosis and treatment simply destroys any confidence we may have had in those consulted. However, maybe only a few responded to the consultation; we don't know and we can only hope that that was the case.

However, what started off as a disaster turned into something useful. The President of the BIA **listened to LDA's concerns** about the position paper, and asked for our comments in writing so she could present them to the BIA council. You can read the BIA Position Paper and the LDA [detailed comment](#) on the [Guidelines page](#) of the LDA website, and review the evidence yourself.

As a direct result of this dialogue the BIA is supporting the James Lind Alliance Priority Setting Partnership (PSP) as a sound and transparent way of documenting the uncertainties in the diagnosis and treatment of Lyme disease, and we have a BIA member on the steering group.

JLA PSP - meet the steering group

LDA is investing significant funds in this Priority Setting Partnership over 2011 and 2012. With the help of the BIA, we managed to put together a very useful steering group:

Lester Firkins, JLA, who chairs this PSP. His role is to ensure that we keep within the straight and narrow, and that clinicians and patients have an equal voice. As he has absolutely no medical knowledge he is able to keep his head above any biased waters.

Stella Huyshe-Shires, current chair of LDA, is representing patients.

Dave Ashcroft, is a GP from Aberfeldy, on the edge of the Scottish Highlands. Having conducted an audit at his practice, and responded to increased awareness in the area, Dave is aware of the probable number of cases missing the vital early diagnosis. See the [slides he presented](#) to the JLA Awareness day in Edinburgh for the view from Tayside.

Caroline Rayment, is both a GP in Yorkshire and a patient who had a long battle obtaining thorough treatment for Lyme disease which she caught on sabbatical in Eastern Europe. This provided her with an unexpected, and unwelcome, insight into the difficulties of both patients and clinicians and into the lack of UK research and knowledge.

Jean Walker, worked as a GP in Scotland for 4 years, has worked in microbiology, completed an Msc in health inequalities and public policy and is now a public health trainee in Inverness working in Health Protection.

Alastair Miller, is an infectious diseases consultant in Liverpool and is also clinical lead for the chronic fatigue syndrome (CFS/ME) service. He runs a neurological infection clinic and so has seen patients with suspected neurological Lyme disease and also some with suspected primary LD. He has a keen interest in research and chairs the Specialist Advisory Committee on Infectious Disease at the Royal College of Physicians.

Mark Fenton works for NICE and is Editor of UK DUETs. He is on the PSP to contribute to the identifying of uncertainties, and the searches undertaken to identify systematic reviews which might address any submissions.

Matthew Hall is the biomedical information specialist on the team. He has been a medical librarian on one of the NHS Evidence Specialist Collections and has therefore database searching experience. He is currently undertaking a PhD in Infectious Disease Epidemiology.

The steering group holds monthly teleconferences and will have a face to face meeting in February to go through the final set of sorted uncertainties submitted through the survey.

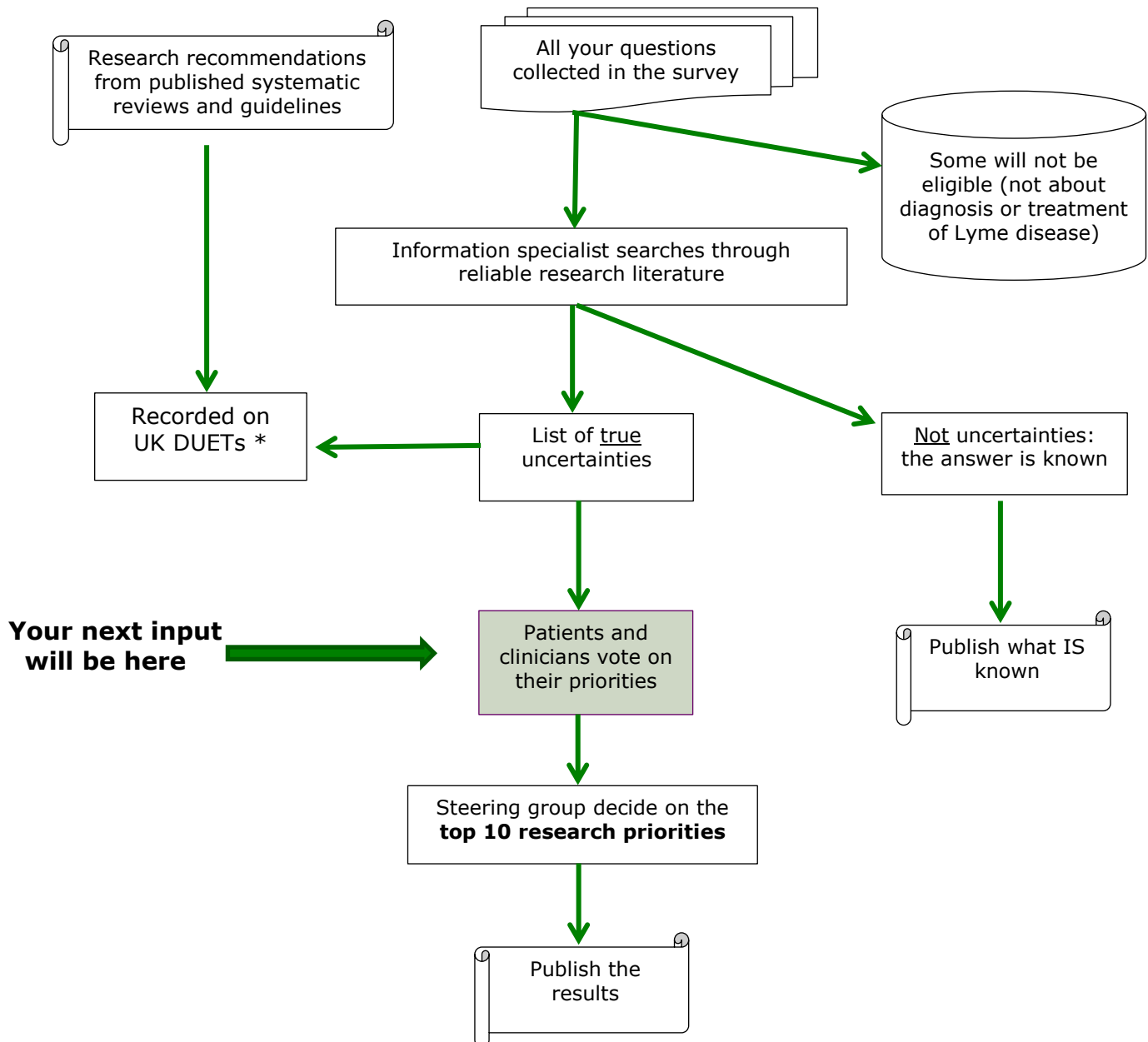
Happening now:

- Review of existing guidelines and systematic reviews for uncertainties that have already been identified.
- Sorting YOUR submitted questions to the now closed survey.

Happening next:

- Discussion of the long, sorted, grouped list of discovered uncertainties

JLA PSP: the process



* The **UK Database of Uncertainties about the Effects of Treatments (UK DUETs)** has been established to publish uncertainties about the effects of treatments which cannot currently be answered by referring to relevant and reliable up-to-date systematic reviews of existing research evidence.

Look at the [DUETs web site](#) and you will find on the right hand side the outcomes from other JLA PSPs. This is where those from the Lyme disease PSP will sit: on an official NHS Evidence web site.

LDA shop & fundraising

We have added some items to the shop recently, all of which might be useful for Christmas.



This "**Snowy Lime Tree**" is exclusive to LDA. You might notice that ticks are still around in winter - see the bottom right hand corner.
Dimensions: 11.6 x 16 cm (the card, not the tick)

We also have "**Dove over Bethlehem**"
Dimensions: 8.4 x 18.5 cm

Both cards come in cellophane wrapped packs of 10 with envelopes, and have the inside greeting:
With Best Wishes for Christmas and the New Year

On the back is the LDA logo and charity details.



Both cards are £5 per pack of 10, including p&p and are available from the LDA [website on line shop](#).

If family members have run out of ideas for you, a **polo shirt** might come in handy as a suggestion, and **tick removers** make great, if unusual, stocking fillers!

We are also offering a **Double DVD** containing a full record of the talks given at the International Lyme and Associated Diseases Society (ILADS) conference in London on 12th June 2010.

LDA was not involved in organising this doctors' conference and cannot be held responsible for the DVD contents. We agreed to pay for recording of the talks but please note that some aspects of this conference were outside the charity's remit and thus the charity either declines to comment upon them or does not endorse them. Full details of the DVD contents are on the [website shop page](#). Price : £15.00, including P&P

If you prefer to pay by cheque, send your payment to

LDA Shop
Sand
Sidbury
Sidmouth
EX10 0QN

| | |
|------------------|-------------------|
| Christmas cards | £5 per pack of 10 |
| ILADS DVD | £15 |
| Polo shirt | £19.99 |
| Trix Tick Lasso | £7.99 |
| O'Tom Tick Hooks | £4.99 |

Don't forget to state exactly what you are ordering. All these prices include postage and packing within the UK.



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