**LymeResearchUk - newsletter 2018**

**Introduction**

To summarise the recent developments in the UK regarding Lyme disease: clearly there have been a lot of new events and developments of interest to patients or those at risk of Lyme disease or other tick borne infections - including open meetings by Public health England for clinicians and patients; a discussion in the House of Lords; new events put on by VisAVis symposium (lectures from clinicians and researchers) and cheap low-cost seminars from the Academy of nutritional medicine (AONM) (which are often linked to some of the issues related to chronic illness) - as well as the usual array of events and work already being done.

**New Lyme disease organisations and groups**

I have provided a time a list of organisations, and key documents, and links to these in an **Appendix A**. For example it catalogues the key professional organisations, statutory agencies, and international agencies - that have ‘contributed’ to policy and practice on Lyme disease which affected the UK. It also provides information on key activities organised by the state, such as the Public Health England (PHE) open meetings etc.

New Lyme disease groups have developed in the UK include, **Justice for Lyme; Time for Lyme; Vector-borne Infection Research Analysis Strategy (VIRAS, 2015); Caudwell LymeCo charity (2015); Lyme Disease UK (LDUK, 2014); LymeAid (2014) and Fight Lyme Now** - alongside the existing and first group, **Lyme Disease action**. Not all have a website some are only putting information out via social media.

Some of these focus on similar issues, sometimes in different ways, but there’s often an overlap between them - mostly they share a commitment to improving testing, and also trying to raise awareness.

**The guidelines development**

[**https://www.nice.org.uk/guidance/indevelopment/gid-ng10007**](https://www.nice.org.uk/guidance/indevelopment/gid-ng10007)

The major events that have taken place recently all that in September 2016 **the National Institute for clinical excellence (NICE)** started a process of guidelines development - and all national Lyme groups were allowed to register as stakeholders. The ones that did so were Lyme disease action, Lyme research UK, Lyme disease UK, Viras, and possibly a couple of others. Individuals or nonregistered stakeholders could submit evidence - but this would not be placed on the website, and would receive no commentary from the committee, and process.

It is noticeable, that if you look at the first stage of consultation (which is basically on the scoping document) produced by NICE - this was entirely based on existing British infection Association guidelines. It mirrored those existing 2011 guidelines almost exactly.

The comments from groups contributed varied and extensive - however in terms of the scope of the guidelines development many groups wanted co-infections, and prevention to be included. They declined to do this, saying that it was only possible to focus on Lyme disease specifically - and that prevention lay outside of the guidelines process. In actual fact NICE do have a separate process for public health advice – which would arguably would cover prevention exclusively. Having said that they did include a focus on the ‘Information needs of people with suspected or confirmed Lyme disease’ as a topic .

Bear in mind but NICE ***already had*** guidelines prior to this, in its ‘clinical knowledge summary’ section.

<https://cks.nice.org.uk/lyme-disease>

**The 1st stage consultation with NICE**

The consultation process at this stage was quite difficult. Lyme research UK was able to mount its own small team of respondents, which were aimed at bringing together people specifically knowledge of science, technology, and research. We also were able to raise awareness of how the NICE committee process worked, and work with some other groups coordinating discussions, sharing of information, and ideas about what should be submitted to the committee. This was quite a useful and process to share information in this way.

Unfortunately the committee failed to comment on any of the comments raised by Lyme groups, (presumably because they were quite complex and detailed). They referred all the issues back to the committee - so that no response was made to any of the points raised on the scoping document. The final scoping document was, as far as can be ascertained, is exactly the same as the first.

Three lay members representing personal experience of Lyme disease were appointed, and one of these was the CEO of Lyme disease John Caldwell’s Lyme charity who therefore was unable to contribute to the guidelines as a stakeholder.

**The 2nd stage consultaion**

The second stage of consultation was recently in the last few months, and this was on the draft guidelines which were very extensive. There were about 20 documents some of which were several hundred pages long - particularly that which explained the evidence that they used and how they reviewed the evidence and research.

We only had one month to respond to this - and this was quite an arduous exercise. However we managed to complete and submit a response which is attached. Some of the other groups submitted very long and detailed responses, up to 90 pages long! We are awaiting the outcome of our responses which are expected in April - when the final guidelines will be produced.

**The new APPG in parliament**

The second major event this recent time period, was the construction setting up and launch of an all-party Parliamentary group by Michelle Donelan and Simon Hoare who have been joined by a number of MPs including Caroline Lucas of the Green party. The aims and process of this investigation are as yet unclear. However they have said they will be launching an inquiry of some kind. The funding of this exercise is also under debate, but it looks as if some element of this process will be crowd funded, probably for the role of the secretariat.

Lyme research UK have provided documentation (in the form of summaries) of the aims of 12 different APPG’s (related to health) as ‘examples of the aims’ of these types of activities – to help Lyme groups understand what the APPG process is like. We also interviewed two people (playing the role of secretariat) to show what the role of doing that involves on how these things are organised, aimed, and the activities were justified etc. Often this work done by other charities on other health topics is collaborative (with the APPG in parliament) and rests heavily on previous work and the resources of the charity NORMALLY holding the ‘secretariat role’.

Is difficult to say at the current time what role LymeresearchUK could play in this process - it is not clear what MPs would like us to….. However they have been offered help in an advisory capacity related to social research.

**The DOH sponsored review**

The other exercise that we have been involved in recently is the University College London review of evidence - that took place and preliminary documents from this have been made available.

<https://eppi.ioe.ac.uk/cms/Default.aspx?tabid=3701>

Many Lyme groups and individual Lyme patients were consulted by this group of researchers and this consultation took place in two stages. Firstly they interviewed us around key issues that came up in research, and then secondly they reflected back what their ‘final results of the published evidence’ to discuss that a second time. So this work was based on what currently existed in terms of knowledge (in published research) around themes which were prevention; experience of diagnosis (including testing); knowledge of Lyme in doctors and patients, etc.

The final results were quite extensive and the first five reports, and are going to be published academically in more detail in published papers. We have not yet reviewed this information - but the headline is that research evidence was lacking in many areas, and this made it difficult for them to come to solid conclusions at times. They made a number of recommendations where this knowledge was lacking, and I think this may prove to be quite useful in the future.

Kate Bloor LymeresearchUK February 2018

**Appendix A: major events in the Lyme disease policy timeline in the UK**

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| **ORGANISATIONS ;** | **WEBSITE** | **KEY DOCUMENTS POLICY PUBLICATIONS AND EVENTS ETC** |
| **ILADS – The International Lyme and   Associated Diseases Society; see other publications?** | http://www.ilads.org/ | First version 2004 **(has a comparison with IDSA as table), Ilads, T., & Group, W. (n.d.). Lyme and Associated Diseases Society Evidence-based guidelines for the management of Lyme disease. Comparative and General Pharmacology.** Latest version   guidance – Burascano, J (2008) (16th edition). **Advanced topics in Lyme Disease Diagnostic Hints and  Treatment Guidelines for Lyme and other Tick-borne illnesses** |
| **Grade research summary : Cameron, D. J., Johnson, L. B., & Maloney, E.2014** | <http://informahealthcare.com/doi/abs/10.1586/14787210.2014.940900> | Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease. |
| **IDSA – Infectious Diseases Society of   America ;** | <http://www.idsociety.org/Index.aspx> | First   version 2000, Latest version: IDSA, 2006, **The Clinical Assessment, Treatment,   and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and   Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society   of America**, Gary P. Wormser, et al, Clin Infect Dis. 43 (9): 1089-1134. doi:   10.1086/508667 |
| **The IDSA Review Panel was not charged with updating or rewriting the 2006 Lyme Guidelines substantially** | <http://cid.oxfordjournals.org/content/51/1/1.full> | IDSA review : IDSA undertook a review of it’s own   guidelines, Lantos  et al (2010). **Final  report of the Lyme disease review panel of the Infectious Diseases Society of   America. Clinical infectious diseases: an official publication of the   Infectious Diseases Society of America,** 51(1), 1–5. |
| **European guidance on neuroborreliosis 2010** | doi:10.1111/j.1468-1331.2009.02862.x;  <http://www.ncbi.nlm.nih.gov/pubmed/19930447> |  |
| **Guidelines for lyme disease or other TBI's** |  | <http://www.lymediseaseaction.org.uk/resources/guidelines> |
| **BIA** | doi:10.1016/j.jinf.2011.03.006 http://www.ncbi.nlm.nih.gov/pubmed/21421007 | British Infection Association. (2011). The epidemiology, prevention, investigation and treatment of Lyme borreliosis in United Kingdom patients: A position statement by the British Infection Association. The Journal of Infection, 62(5), 329–38. |
| **Map of medicine** |  | A flow chart type guide to dealing with lyme disease : **removed from website ? 2012** |
| **NICE** | <http://cks.nice.org.uk/lyme-disease#!topicsummary> | clinical knowledge summaries CKS - Basis for recommendation - *based on expert opinion in a guideline from Public Health England Prevention of Lyme borreliosis[PHE, 2012] and the British Infection Association's position statement …... 2011].* |
| **MEDIA TV RADIO FILMS** |  |  |
| **America** |  | Under Our Skin (One) ; http://www.underourskin.com/film/ |
|  |  | Under our skin (Two) |
| **French** |  | <https://vimeo.com/95647143> |
| **Australia** |  | <http://www.lymebook.com/australia-dvd-invisibly-ill-bec-mills> |
| **GOVERNMENT /NHS AGENCIES** |  |  |
| **Requested by CEO of HPA –working group set up** | Unorthodox Clinical and Laboratory Practices Related to Lyme borreliosis. Retrieved from http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\_C/1204013002855 | Professor B Duerden: Independent   Appraisal and Review of ILADS 2004 ‘Evidence-based guidelines for the management of Lyme disease’. |
| **Health Protection Agency** | [http://webarchive.nationalarchives.gov.uk/20140714084352/http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\_C/1195733835074](http://webarchive.nationalarchives.gov.uk/20140714084352/http:/www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1195733835074) | Set up 2003/ HPA Act 2004   – 2012 (as a separate organisation accountable to the secretary of state for health)- **review of ILADS guide filename: HPA review of ILADS guide.** Tim Brooks the HPA lab director has given talks at conferences including one to the LDA which outlines the RIPL/HPA positions. Now HPA has been subsumed into the PHE (public health England) |
| **Public Health England** - Public Health England (PHE) is an executive agency of the Department of Health which formed on 1 April 2013. | Set up 2013 <https://www.gov.uk/government/organisations/public-health-england>  <https://www.gov.uk/government/organisations/public-health-england/about#responsibilities> | Two open meetings with public and lyme patients etc so far -training module online (done with LDA). Has a lot of downloadable files and information on Lyme disease including a referral and treatment pathway. |
| **PHE - Open days on Lyme disease first October 2013 + 2015** | <https://publichealthmatters.blog.gov.uk/2013/10/15/conference-wrap-up-lyme-disease/> | This year, for the first time, we hosted the PHE Lyme Conference in London, speakers such as Dr Matthew Dryden, a consultant microbiologist at Winchester's Royal Hampshire County Hospital (who worked with PHE to set up the UK’s first Lyme clinic in September 2012 or thereabouts which was swiftly closed down about one year later), as well as representatives from Lyme disease support groups.PHE conducted an open day on 25th March 2015, |
| **OTHER GROUPS OR NETWORKS / PROFESSIONAL** |  |  |
| **British society for Immunology** |  | Contributed to the 2015 HOL debate sumbmitted evidence to it. |
| **European Society of Clinical   Microbiology and Infectious Diseases?** | http://www.ncbi.nlm.nih.gov/pubmed/15606643 | Latest (general) European guidance published |
| **House of Lords debate 2015** | <http://www.publications.parliament.uk/pa/ld201516/ldhansrd/text/151022-gc0001.htm> | lyme debate on 22nd Oct 2015 at House of Lords lead by Lord Greaves |
| **HOC debate and conf. Lyme disease patient Demetrious Loukas  19th January, 2015** | <http://lymediseaseuk.com/2014/12/30/patient-led-lyme-disease-conference-19th-january-2015/> | Attended by: Ruth Parry, Scientific Policy Manager, Department of Health (Micro-biologist, Virologist);Dr Tim Brooks, Head of Rare and Imported Pathogens Laboratory, Public Health England; Amanda Semper, Scientific Program Manager, Rare and Imported Pathogens Laboratory, Public Health England (TBC). |
| **European Union Concerted Action on   Risk Assessment in Lyme Borreliosis (EUCALB)-**  This website was established in 1997; role to make research information available to professionals and students etc **NO LONGER AVAILABLE** | <http://www.eucalb.com/> | O’Connell S (Eurosurveillance 1996);   Stanek G, O’Connell S et al, 1996, European Union Concerted Action on Risk   Assessment in Lyme Borreliosis: clinical case definitions for Lyme Borreliosis.   Wiener Klinische Wochenschrift (Vol. 108, pp. 741-747) |
| **German Borreliosis society** | <http://www.borreliose-gesellschaft.de/Texte/guidelines.pdf> | Borreliose-gesellschaft, D. (2008). Diagnosis and Treatment of Lyme borreliosis Guidelines, (April). |
| **PROFESSIONAL INTEREST GROUPS** |  |  |
| **British Infection Society** | <http://www.ncbi.nlm.nih.gov/pubmed/21421007> | British Infection Association. (2011). The epidemiology, prevention, investigation and treatment of Lyme borreliosis in United Kingdom patients: A position statement by the British Infection Association. The Journal of Infection, 62(5), 329–38. doi:10.1016/j.jinf.2011.03.006 |
| **LABORATORIES** |  |  |
| **Southampton reference laboratory** | 2003 - 2012 | Ms O'Connell (lab director) published widely often with IDSA key members or authors. eg Poster presentation: ‘*Recommendations for diagnosis and   treatment of Lyme borreliosis: guidelines and consensus papers from   specialist societies and expert groups in Europe and North America’,* unpublished; various publications in peer reviewed journals |
| **Rare and Imported Pathogens Laboratory   (RIPL)** | 2012 (1/6/2012) | Guidelines for the laboratory available. |
| **CHARITIES** |  | **Please note this does not include the more recent new groups and charities since 2012** |
| **Lyme Disease Action (UK)-** full list of different guidelines with comments on their website page | [http://www.lymediseaseaction.org.uk/about-lyme/tests/ ; http://www.lymediseaseaction.org.uk/resources/guidelines/](http://www.lymediseaseaction.org.uk/about-lyme/tests/) | Lyme Disease Action. (2011). Comment   on the British Infection Association’s Position Statement on Lyme borreliosis   June 2011. First issued to the BIA 14/ 6/ 2011. Journal of Infection, 5(5). There are numerous documents from them including newsletters, statements, articles etc. Recently there have been several papers published by the chair and medical advisor published in professional or academic journals. Video on historical perspective <https://www.youtube.com/watch?v=uXyHYQVoa84&feature=youtube>  - epetitions were also sent via the HOC system about uk guidelines etc but some time ago. |
| **James Lind Alliance project** | 2012 approx | Project set up and paid for initially by Lyme   Disease Action, a UK charity.[ii]HPA and DOH, are involved in   examining ‘known uncertainties’ with respect to diagnosis (and treatment) for Lyme disease.  The project outcomes are   expected to include potential funding of research based on a review of   ‘uncertainties’, and a ‘priority setting’ process, that includes clinicians,   patients, and the charity. |
| **BADA -website** | <http://www.bada-uk.org/> | ‘To achieve our aims, we endeavour to widely disseminate evidence-based and up-to-date information’. Now closed down. |
| **Tick Talk Ireland** | <http://www.ticktalkireland.org/> | Very active group based in southern Ireland (Eire) and have held conferences, talks, support group, and various interactions with Irish government health bodies and also other agencies. |