

The British Infection Association (BIA) is aware of the increased publicity relating to Lyme disease. This follows the recent publication of research indicating an increase in the incidence of infection in the UK<sup>1-3</sup>. Subsequent reports in the broadcast and print media have highlighted concerns regarding the diagnosis and treatment of Lyme disease among both patients and doctors. As a body representing UK Infection specialists we share many of these concerns and support the proposals for UK-based research made by NICE and the James Lind Alliance<sup>4,5</sup>.

## **Ticks, Lyme and the scale of the problem**

Lyme disease is an infection caused by the bacteria *Borrelia burgdorferi* that may be acquired through the bite of certain infected ticks. Whilst studies have suggested a small increase in cases and an extension of the distribution within the UK, it remains a relatively uncommon condition.

There are gaps in our knowledge regarding the epidemiology of Lyme. Most infections occur in the South of England and Scottish Highlands, but occasional cases are identified across the UK and more work is needed to establish the actual incidence. Much of the research upon which we base our practice has been gathered from continental Europe and the USA where tick ecology is different and the infections they bear may vary. Screening in the UK has not identified any other major tick-borne infections in the UK to date. Continuing research is needed to improve our understanding of the epidemiology of Lyme and other tick-borne infections across the UK and develop effective strategies for prevention.

## **Diagnosis**

The BIA is supportive of initiatives that seek to increase awareness amongst the public and primary care practitioners regarding the early recognition and treatment of Lyme infection. Patients who present early on with a history of tick bite and features of the classic bullseye rash (“erythema migrans”) associated with Lyme should be treated immediately and there is no need for testing. Early treatment is effective and key to reducing the burden of chronic infection and its complications. Only more complicated presentations are likely to require discussion with, or assessment by, specialist physicians.

We appreciate that there is significant concern and confusion among both patients and medical professionals regarding the reliability of laboratory tests for Lyme disease. This has led to some electing to seek testing at private laboratories, usually overseas, at their own expense. Many of these tests have little or no published research to validate them and produce results that are difficult to interpret. We suggest caution in seeking diagnosis from laboratories that are not accredited by their national authorities, or acting on tests that have little or no research to validate them. The BIA supports the two-tier testing strategy recommended by NICE<sup>5</sup> and other international health authorities. These remain the best currently available tests to guide treatment decisions.

## **Treatment**

There are a number of well researched evidence-based treatment guidelines available in the UK and internationally. We support the regimens advised in the NICE guidelines and their recommendations for further research. It is rarely necessary to offer alternative agents or longer treatment and where thought required such decisions are best made by specialist physicians. It is widely acknowledged that symptoms can take a considerable period – sometime many months – to resolve after successful treatment.

We acknowledge that some of those who remain symptomatic following treatment for Lyme disease may have questions regarding antibiotic efficacy or the presence of persistent infection. Lyme disease is only one potential cause of chronic symptoms and it is important to keep an open mind regarding other diagnostic possibilities to avoid missing clinically significant alternatives requiring different treatment. There is a need for improved management services for those with persistent symptoms in whom tests are negative, or who do not improve with treatment. In addition there is variation in the approach to the management of such cases across UK institutions and we support the development of standardised management pathways in secondary and tertiary care centres developed with input from patient groups.

## Support

In addition to the NICE guidelines referenced above there are a number of useful resources for patients and professionals.

Guidance for GPs is available at [https://www.guidelinesinpractice.co.uk/infection/lyme-disease-when-to-suspect-and-how-to-manage/454252.article?utm\\_source=MGP%20Ltd&utm\\_medium=email&utm\\_campaign=970183420180727%20GinP%20Highlights&dm\\_i=HEZ,5RXZE,8INKGZ,MJ86F,1](https://www.guidelinesinpractice.co.uk/infection/lyme-disease-when-to-suspect-and-how-to-manage/454252.article?utm_source=MGP%20Ltd&utm_medium=email&utm_campaign=970183420180727%20GinP%20Highlights&dm_i=HEZ,5RXZE,8INKGZ,MJ86F,1)

Further information and patient support is available on the Lyme Disease Action website: <https://www.lymediseaseaction.org.uk/>

## References

1. Cairns V, Wallenhorst C et al; "Incidence of Lyme disease in the UK: a population-based cohort study"; BMJ Open. 2019 Jul 30;9(8). Available at <https://bmjopen.bmj.com/content/9/7/e025916>
2. Tulloch JSP, Semper AE et al; "The demographics and geographic distribution of laboratory-confirmed Lyme disease cases in England and Wales (2013-2016): an ecological study."; BMJ Open. 2019 Jul 30;9(8). Available at <https://bmjopen.bmj.com/content/9/7/e028064.long>
3. Tulloch JSP, Decraene V et al. Characteristics and patient pathways of Lyme disease patients: a retrospective analysis of hospital episode data in England and Wales (1998-2015). BMC Public Health. 2019 Aug 15;19(1):931. Available at <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7245-8>
4. James Lind Alliance <http://www.jla.nihr.ac.uk/priority-setting-partnerships/lyme-disease/top-10-priorities/>
5. NICE guidance NG95; Lyme disease; October 2018; Available at: <https://www.nice.org.uk/guidance/ng95> and NICE quality standard QS186; July 2019. Available at <https://www.nice.org.uk/guidance/qs186/chapter/Quality-statements>.