

Lyme Disease UK

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On 29th January 2016 *BBC North West Tonight* showed a short film documenting the experience of Emma Horlock with Lyme disease. During the programme, both Lyme Disease Action and Public Health England made comments, apparently, about the German tests with which Emma was diagnosed.

We believe that these comments, as presented in the context of the programme, were very misleading and had the effect of discrediting Ms Horlock's testimony.

The statement made by LDA was *"Some of these are not specific to Lyme Disease and may not be licensed for diagnosis. Some patients diagnosed by these may have Lyme Disease but some may not."*

From the context, LDA is commenting on the tests Ms Horlock used. The veracity of the statement depends on what is meant by "these" which is not made clear. The context leads us to believe that "these" refers to the tests used by Ms Horlock. LDA is making some very general claims and inferring they are specifically applicable to Ms Horlock's tests. They do not say which tests are or are not specific to Lyme disease, it is not clear what they mean by "licensed for diagnosis" and they suggest that "these" are unreliable. The statement is ambiguous but has the effect of casting doubt on Ms Horlock's diagnosis and foreign tests in general.

The statement made by Dr Will Welfare on behalf of PHE was also made in the context of Ms Horlock's German tests. The BBC said that PHE *"voiced concerns that private tests may not be subject to the same stringent quality control,"* presumably, as British tests. This is a general statement indicating a potential concern which makes no actual comment on Ms Horlock's tests, though the context implies one. Foreign tests are subject to a variety of quality controls and the best are up to exacting European and American standards. For statements from both American and German laboratories offering Lyme disease testing, please click [here](#). From our support group members' experience, it is pertinent to note that the thresholds and types of tests used by PHE consistently miss patients who are diagnosed abroad and improve with Lyme disease treatment, suggesting a potential issue with false negative tests from PHE rather than false positives abroad.

The second part of Dr Welfare's statement was a direct quote and said *"It is extremely important that patients are reviewed by a medical practitioner on the whole symptom complex and presentation of their illness, and not treated on the basis of a single test without supporting evidence."* We agree wholeheartedly with this statement as long as the practitioner concerned is one with an extensive understanding of Lyme disease. However, it is important to understand that the overwhelming opinion of Lyme disease patients in this country is that this is precisely what they do not experience from the NHS. A very common experience among LDUK members is to present with a history of a tick bite, history of a rash, sometimes with photos, full symptom history consistent with Lyme disease, and often supporting tests from abroad, but to have Lyme disease ruled out, even by senior Infectious Disease consultants, on the basis of a single NHS serology test. This makes Dr Welfare's comment, although true, extremely misleading. His description of appropriate Lyme diagnosis is exactly what Lyme patients are asking for, but are often currently denied.

It is not clear if the misleading nature of these comments is due to editing by the BBC or to careless or deliberate statements by PHE and LDA but the result is that the public may not have not been given an accurate picture of Ms Horlock's position and the wider situation of Lyme diagnosis in the UK.