



*"Encouraging awareness, prevention & treatment of Lyme Disease (Borreliosis) in Ireland."*

## Lyme Disease in Ireland Survey Results 2016:

Recently Tick Talk Ireland produced a survey for Irish sufferers. Detailed results can be forwarded on request; however a summary is listed below.

Text in red shows previous results for 2009-2014, text in black shows updated results for 2015/16.

**To qualify, the respondent must be a Lyme sufferer who was:**

- \* Living in Ireland - infected by Lyme here or abroad or
- \* Not living in Ireland - but infected within Irish Counties

104 people responded to the survey during the months of July 2009 to May 2014:-  
127 people replied to the survey during the months of July 2009 to end April 2016:-

When asked which country the tick-borne infection took place, 61% of our respondents were infected in Ireland and 22% in North America. The remaining 17% listed Europe as their source of infection.

When asked which country the tick-borne infection took place, 64% of our respondents were infected in Ireland and 18.5% in North America. The remaining 17.5% listed Europe as their source of infection.

It's interesting to note that our first report back in 2009 showed an even split between USA & Ireland of 43.5% each. Ireland jumped from 43.5% in 2009 to 64% in 2016 which may indicate a rise in Lyme cases, or it could indicate that more people are aware & therefore more cases are being diagnosed locally. Similarly cases in Europe (ie where infection took place) including the UK, rose from 13% in 2009 to 17.5% in 2016, which caused a drop in US cases overall. Whether more people are being infected in Europe or whether just more cases are being diagnosed it is hard to know. However we feel it important that UK & Irish consultants are made aware that it is NOT just an illness caught in the US & more needs to be done to ensure Lyme cases are not being misdiagnosed, due to lack of awareness or concern.

From those who were infected In Ireland, 13 people indicated they were infected in Kerry, 10 in Galway, 3 in: Cork, Kilkenny, Limerick, Louth, Mayo and Wicklow. The remaining counties included the Aran Islands, Donegal, Dublin, Kildare, Roscommon, Tipperary, Waterford and Westmeath.

From those who were infected In Ireland, 19 people indicated they were infected in Kerry, 13 in Galway, 5 in Cork, 4 in Mayo, 3 in: Kilkenny, Limerick, Louth, Tipperary & Wicklow. Remaining counties inc. Aran, Clare, Donegal, Dublin, Kildare, Roscommon, Waterford, Westmeath & Wexford.

Galway & Kerry continue to be the highest areas for Lyme disease – this is also reflected in our [Tick Talking](#) while you're walking surveys where more ticks are readily seen in these areas indicating a much higher risk of infection.

It's important to note from both the results above & also from our Tick Talking survey that Lyme can be prevalent in any part of the country – given that deer, mice, birds, squirrels, farm animals or pets can carry ticks it is worth considering that the risk, although smaller in less endemic areas, should still be taken seriously & [prevention methods](#) will still need to be observed (for instance regular body

checks looking for ticks on yourself, children & pets, spraying of DEET before country walks, regular use of tick repellent on pets & keeping the lawn well cut with leaves cleared to prevent ticks taking up residence in the garden!)

An overwhelming 42% of respondents said they were infected whilst out walking (in woods, along a beach, by a lake or in a park). 8% indicated they were infected in their own gardens & 7% whilst camping. Other pursuits included outdoor sports, playing, travelling, living or working in rural areas, also from pets & farming.

An overwhelming 41% of respondents said they were infected whilst out walking (in woods, along a beach, by a lake or in a park). 10% indicated they were infected in their own gardens & 6% whilst camping. Other pursuits included outdoor sports, playing, travelling, living or working in rural areas, also from pets & farming.

The results were very similar indicating a need for prevention methods whilst out walking. If a tick is spotted not all will be infected, however early removal of the tick can minimise chance of infection. Ensure that proper removal takes place ([see tips on our website](#)) by using fine tipped tweezers or tick twisters available in vets or on the web. Incorrect removal can leave the head behind causing a secondary infection. Causing any stress to the tick using incorrect methods such as burning, smothering or chemicals can cause the tick to regurgitate which can increase the chance of infection.

42% of our respondents said they were diagnosed within a year of symptoms, whereas 52% patients waited a year or more before receiving a diagnosis (the remainder stating length of time unknown). Those that were treated earlier seemed to have fewer symptoms and better recovery time. **72 out of our 104 respondents have been ill for more than a year in TOTAL** including pre & post treatment which is an alarming 69%. Nearly a QUARTER of these patients have been ill for **10 years or longer**. This supports the claim that Lyme **MUST** be treated quickly to avoid chronic and persistent infection.

43% of our respondents said they were diagnosed within a year of symptoms, whereas 52% patients waited a year or more before receiving a diagnosis (the remainder stating length of time unknown). Those that were treated earlier seemed to have fewer symptoms and better recovery time. **86 out of our 127 respondents have been ill for more than a year in TOTAL** including pre & post treatment which is an alarming 68%. Nearly a THIRD of these patients (25 out of 86) have been ill for **10 years or longer**. This supports the claim that Lyme **MUST** be treated quickly to avoid chronic and persistent infection.

It is encouraging to note that over the years a few more respondents indicated that they had been tested & treated during the early parts of their infection. Three respondents were treated based on EM rash alone & therefore never developed symptoms. It is very promising that some patients reported an EM rash & the treating physician was able to recognise the importance of early treatment. Disseminated Lyme (2<sup>nd</sup> & 3<sup>rd</sup> stages) is much more difficult to treat so early diagnosis is critical for the patient's recovery. In 2009 we reported that only 33% of patients were diagnosed within a year which is now 43%, this is very encouraging (however in 2012 it was 49%). It is well known that patients treated earlier have a much better prognosis, however there is still room for improvement – for example, **52% of patients are reporting their diagnosis took more than a year**.

As mentioned in the previous report there is difficulty in treating the long term chronically ill patients, partly because symptoms vary so much between patients & partly because there is difference of opinion as to whether persisting symptoms are caused by active infection, or a post infection stage of autoimmunity. Research in both humans & animals have shown that *borrelia* (Lyme bacteria) can survive antibiotic treatment & can evade the immune system which points to the probability of active infection – more studies are needed to help ascertain the best way to manage chronically ill patients to shorten the length of suffering for the patient.

We found that 64 of our respondents were diagnosed through the HSE or NHS using Elisa or Western Blot testing. 48 respondents had used private labs. in Germany or America to support their diagnosis.

We found that 78 of our respondents were diagnosed through the HSE or NHS using Elisa or Western Blot testing. 57 respondents had used \*private labs. in Germany or America to support their diagnosis (some using both private & public). *\*Reasons for using a private lab. can be down to several factors – the antibody Elisa test is not always effective in detecting borrelia infection in early cases and in some manifestations of late disease. Private labs may use antigenic/ T cell testing methods, as opposed to the 2 tier antibody test and are often equipped to test for co-infecting diseases, which may be in addition to the Lyme infection. Examples include bartonella, ehrlichia (anaplasma), babesia, mycoplasma and Chlamydia pneumoniae.* 23 were diagnosed clinically from symptoms alone (ie from a previous rash or history of tick bites, where not all tests were positive).

59% (48 out of 81) were diagnosed via the HSE to Dec 2012. We now have 61% (similar to 2014 results) diagnosed via the NHS/HSE (78 out of 127). 40% used private labs up to 2012 which is now at 45%, a slight drop from 46% from 2014. (NB: some patients have used both public and private tests). 18% were diagnosed from clinical symptoms only, similar to previous surveys in 2014 & 2012, although some said that their symptoms or overseas test results were being ignored. It's important to note that Lyme should be a clinical diagnoses supported by, but not solely reliant on test results.

As quoted by [Trinity Biotech](#), manufacturer of Elisa & Western Blots test kits based in Ireland:

*'Negative results either 1<sup>st</sup> tier or 2<sup>nd</sup> tier should **not** be used to exclude a Lyme disease'.*

*'B. burgdorferi strains exhibit considerable antigenic variation. Patients in the **early** stage of disease and a portion of patients with **late** manifestations may not have detectable antibodies. Early antimicrobial treatment, after appearance of EM may lead to diminished antibody concentrations. Serologic tests have been shown to have low sensitivity and specificity and, therefore, **cannot be relied upon** for establishing a diagnosis of Lyme disease.'*

Regarding misdiagnosis, 32 people indicated they were previously diagnosed with ME (chronic fatigue syndrome), 18 people were told they had psychiatric disorders, 12 had FMS (fibromyalgia), 9 MS (multiple sclerosis) & 1 person was misdiagnosed with Parkinson's disease. [Unfortunately Lyme mimics many other illnesses, particularly in the third stage. Lyme should therefore be considered when ruling out other possibilities, particularly if there is a history of tick bites or a rash.]

Regarding misdiagnosis, 38 people indicated they were previously diagnosed with ME (chronic fatigue syndrome), 21 people were told they had psychiatric disorders, 15 had FMS (fibromyalgia), 10 MS (multiple sclerosis) & 1 person was misdiagnosed with Parkinson's disease. [Unfortunately Lyme mimics many other illnesses, particularly in the third stage. Lyme should therefore be considered when ruling out other possibilities, particularly if there is a history of tick bites or a rash.]

The types of misdiagnosis were similar to previously reported, however the numbers reporting a diagnosis of psychiatric disorder doubled in size from 7 to 14 people between the years 2011 & 2012 & trebled from 7 to 21 between 2011-2016 (our respondents had increased two fold however psych cases increased three fold during that 5 year period).. While it is true that Lyme can cause mental health problems in the form of depression, rage & thoughts of suicide it should not be assumed there is no underlying cause such as a bacterial infection, particularly where the patient complains of a wide range of symptoms. In addition there was also suspicion of meningitis, west Nile river disease, Guillian Barre syndrome & motor neuron disease as well as rheumatoid arthritis & Lupus. Symptoms vary greatly between patients & disseminated Lyme can affect all parts of the body including muscles, joints, nervous system & various organs including the brain, heart, bladder & eyes. Some patients can develop symptoms quickly; others can develop more slowly, or experience

a latent infection which erupts during periods of stress or unrelated illness. This makes it a very difficult illness to diagnose & treat, particularly in chronically ill patients.

Symptoms among our respondents were wide ranging, particularly in those that have been ill for a long time. The highest response rate of symptoms included profound fatigue (82%), weakness (80%), muscle aches (79%), poor concentration (75%), tingling/numbness (70%), migratory joint pain (70%) sleep disorders (70%), stiff neck (70%), poor memory (68%), dizziness (66%), headaches (66%) stiffness (66%) and brain fog (65%). It is interesting to note that the erythema migrans (EM) rash was only present in 45% of the patients at the start of the illness and 24% have multiple EM's during the course of the illness. This shows that a rash is not always present or noticed during Stage One of the disease. A shocking **59% of our respondents suffer 20 symptoms or more** as part of their illness.

Symptoms among our respondents were wide ranging, particularly in those that have been ill for a long time. The highest response rate of symptoms included profound fatigue (81%), weakness (79%), muscle aches (78%), poor concentration (74%), migratory joint pain (70%), stiff neck (70%), tingling/numbness (68%), sleep disorder (67%), poor memory (66%), headaches (66%), dizziness (64%), stiffness (63%) & brain fog (62%). It is interesting to note that the erythema migrans (EM) rash was only present in 43% of the patients at the start of the illness and 22% have multiple EM's during the course of the illness. This shows that a rash is not always present or even noticed. A shocking **55% of our respondents suffer 20 symptoms or more** as part of their illness.

The numbers of symptoms being reported were similar to the previous report however the number of respondents with EM rash went from 45% to 43%. The presence of an EM rash can be affected by the strain of *borrelia* infection (which can be affected by which country the infection takes place) & the immune response of the patient. Also some patients may not spot the rash for instance if the rash is in the hairline, back of the knee or on tanned/darkened skin. Profound fatigue & weakness is very high on the list which often causes the patient to be diagnosed with chronic fatigue syndrome.

The amount of respondents reporting 20 symptoms or more has dropped from 67% in our first report in 2009 to 55% in this report. This is due to some reporting early diagnosis & treatment, again highlighting the fact that early treatment creates less need for longer term management & therefore less suffering for the patient. Not only is the patient's well being affected by the debilitating effect of the disease, they also they suffer financial consequences as a result of being unable to work for long periods of time as well as in some cases needing private health care to help manage their symptoms. Coupled with the lack of consensus on how best to treat long-term ill patients this can add a great deal of burden on the doctor & the patient, as well as the added burden on the patient's family who often have to take on a caring/supportive role during the illness.

18 respondents have consulted a Lyme specialist in the UK, 15 went to the USA, 13 went to Germany, 2 to Switzerland, and 2 to other parts of Europe (France & Portugal). 13 saw a private consultant in Ireland. [Patients may be forced to seek private specialists for help with treatment, diagnosis and management of this complex disease].

20 respondents have consulted a Lyme specialist in the UK, 17 went to the USA, 14 went to Germany, 2 to Switzerland, 3 in other parts of Europe (France, Portugal & Hungary). 17 saw a private consultant in Ireland. [Patients are often forced to attend private specialists overseas for help with treatment, diagnosis and management of this complex disease].

The number of patients consulting a Lyme specialist in the UK dropped from 17 to 16% (20 out of 127), those attending US specialist dropped from 14 to 13%. Those who went to Germany dropped from 12.5 to 11%. Switzerland dropped from 2% to 1.5%. An encouraging sign is that the number of patients seeing a private specialist here in Ireland rose from 4 to 10% between 2009-2011 & is now at 13.5% showing that Irish consultants are beginning to take Lyme more seriously.

For treatment protocols 69% have used tetracyclines (e.g. doxycycline), 32% penicillin (e.g. amoxicillin), 30% macrolides (e.g. zithromax), 30% IV antibiotics, 25% metronidazole (e.g. flagyl) and 19% cephalosporin (e.g. zinnat). For alternative therapies 32% of respondents have tried Co-enzyme Q10, 30% acupuncture, 29% Massage, 27% have taken Cat's Claw/Samento, 24% Homeopathy and 16% Glutathione. To help with symptoms, 49% use probiotics, 45% painkillers & a quarter of the patients reported they take anti-depressants.

For treatment protocols 69% have used tetracyclines (e.g. doxycycline), 34% penicillin (e.g. amoxicillin), 26% macrolides (e.g. zithromax), 26% IV antibiotics, 22% metronidazole (e.g. flagyl) and 18% cephalosporin (e.g. zinnat). For alternative therapies 29% of respondents have tried acupuncture, 28% Co-enzyme Q10, 28% massage, 23% have taken Cat's Claw/Samento, 21% homeopathy, 14% Alpha Lipoic and 14% glutathione. To help with symptoms, 48% use probiotics, 45% painkillers & just under a quarter of the patients reported they take anti-depressants.

89 people responded to the last question – as to which type of treatment had been the most helpful. 75% answered antibiotics, 36% rated alternative therapy, 34% of people found supplements to be helpful, 29% found painkillers helped them whilst 29% mentioned 'other' methods helped (including massage, yoga, supporting adrenals, dietary changes, infra-red saunas & physiotherapy). Some had skipped the question causing a drop in overall percentage & in some cases the question was not applicable, for instance a patient was treated based on EM rash only so had no need for painkillers, supplements or alternative remedies.

109 people responded to the last question – as to which type of treatment had been the most helpful. 74% answered antibiotics, 32% rated alternative therapy, 31% of people found supplements to be helpful, 26% found painkillers helped them whilst 29% mentioned 'other' methods helped (including massage, yoga, infra-red saunas & physiotherapy). Some had skipped the question causing a drop in overall percentage & in some cases the question was not applicable, for instance patients treated based on EM rash alone had no need for painkillers, supplements or alternative remedies.

The overall response was similar to the previous study in that antibiotics were the most helpful in treating their illness, whilst regular use of painkillers was the least helpful. In the previous question we found that 45% of our respondents indicated they took painkillers in managing symptoms but only 26% found them to be helpful.

This highlights again the level of discomfort that the patient is in. Antibiotics can worsen the symptoms due to a [herxheimer](#) reaction (where the die off of the Lyme spirochetes causes an inflammation response in the body creating a 'flare up' of symptoms). Some patients are sensitive to medication creating difficulty in finding the right course of treatment & pain levels are often not helped by use of analgesics. Added to the mix is that co-infections (other infections that may be carried by ticks) can prolong or complicate patient recovery.

### Summary

To summarise, it is very encouraging that more patients are being treated here in Ireland & that recognition of an EM rash allowed a patient to recover with no other symptoms present. We are also pleased that Lyme has now been made a [notifiable illness](#) from September 2011, although we would like to see earlier Lyme cases reported not just stage 3 neuroborreliosis. ***It is alarming that more patients are being diagnosed with a psychiatric illness before a Lyme diagnosis is made (the number in fact trebled between 2011 & 2016). 52% of patients are waiting more than a year for diagnosis, with 55% of our respondents suffering with 20 or more symptoms.***