



Some helpful tips for the newcomer by Tick Talk Ireland

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Lyme can be mild & self limiting illness but can also often be life changing & very serious. It's for this reason that we strive hard to raise awareness. If you are a doctor or research student we have a useful [links](#) section grouped in alphabetical order - listing items such as Lyme & the heart, Lyme & the bladder, Lyme & MS, Paediatric Lyme & so on. Patients may also find some of these links very useful.

- **Doctors may also be interested in the following pages:**

[Health Care Professional's own experiences with Lyme Disease](#)

[Neuro Lyme Guide written by UK doctor](#)

[NHS Map of Medicine showing uncertainties with regard to Lyme Disease](#)

- **Scientists & students may find these links of interest:**

[Chronic Lyme Disease & Persistence](#)

[Structure of Lyme Bacteria](#)

[Under the Microscope](#)

[Co-infections](#)

- **Patients Information:**

For anyone newly diagnosed or indeed looking to seek diagnosis &/or treatment, Lyme can be a very challenging beast to tame. We have created this section to help explain various aspects of the issues faced by patients & doctors alike, please note that we are not health trained professionals & information provided on this page is for informational purposes only & not intended to replace the advice of a specialist doctor. Feel free to skip to the relevant section of interest below! If you prefer to download a shortened leaflet instead these are available at <http://www.ticktalkireland.org/leaflets.html>

- **Background on Lyme Disease:**

Lyme was first given its name after a cluster of childhood arthritis was discovered in the town of Old Lyme in Connecticut US in the 70s. Allen Steere who was lead investigator at the time suspected the cause to be viral, however scientist Willy Burgdorfer concluded that the causative agent of Lyme disease was indeed bacteria, found in the mid-gut of infected ticks. The bacteria was named *Borrelia Burgdorferi* & the disease can cause wide ranging symptoms affecting the heart, muscles, joints, the nervous system & the brain. Even mental health can be affected in some patients & there may be an additional strain on organs, endocrine system & digestive system. *Borrelia* are spiral shaped bacteria (spirochetes) & are transmitted into the blood stream & skin of the host whilst the tick is feeding. It may take several days for the tick to swell up with the blood of the host & drop off, but the host is often unaware due to the anaesthesia in their salivary glands. A tick bite is often not itchy, so the unsuspecting host is largely unaware that they are today's feast!

Lyme disease was named after a town in the States however the bacteria causing Lyme Disease has been known in Europe for centuries even going back as far as the [ice age](#)! Also known as *Borreliosis*, Lyme disease is becoming more & more problematic & is now the most common vector-borne

disease in the Northern hemisphere ([PDF](#)). Experts believe that numbers are much worse than being presently recorded, especially as symptoms may mimic many other conditions & sufferers are often unaware of being bitten at the time. Misdiagnosis often occurs causing tracking of numbers very difficult.

Useful link: [History of Lyme Disease](#)

- **Ticks:**

The type of tick carrying Lyme Disease in Europe is typically the sheep tick, also known as the European Castor Bean Tick. Contrary to popular belief ticks aren't only carried by deer but hitch rides on warm blooded animals, humans, birds & even cold blooded animals such as lizards. [Ticks](#) start off life as 6 legged larvae & are the size of a speck of dust. At this stage it is thought that they are unlikely to be infected with *borrelia* bacteria but obtain the infection from their hosts as they feed. Younger ticks typically prefer animals or birds that are low to the ground such as mice, squirrels, hedgehogs & ground feeding birds such as thrushes, blackbirds & robins. Once they've found their first blood meal they drop off & crawl somewhere safe, before moulting into an 8 legged nymph. At the size of a poppy seed nymphs are still very small & could potentially be infected, if indeed their first host did have lyme disease or other tick-borne disease in their blood.

Nymphs also seek smaller animals but are able to find their way up taller grasses & may target larger mammals such as sheep, cattle, horses & deer as well. Of course humans & pets are just as tasty!

Ticks are able to detect carbon dioxide & crawl to the tips of grasses with their front legs splayed (known as the 'questing' position). This allows them to grab on to a passing host & the hooks on the end of their legs provide them with extra grip. Their [mouth-parts](#) are serrated to allow for cutting into the skin & a cement type material helps them to stay in place while they feed.

After their second host the tick will drop off & moult again, this time ready to be transformed into an adult. The female if mated will have her last feed, drop off to lay her 2000-3000 eggs & die soon after. The male will often seek out a mate whilst the female is still feeding on the host! The life cycle may only be a year or two in length & ticks are most active in Spring, parts of the Summer & again in Autumn/Fall.

At each stage of life the tick will start off as very flat & then begin to puff out whilst feeding resembling the shape of a [raisin](#). As they feed they also change colour, sometimes to a pale grey colour but other colours may occur. Adult ticks are around the size of a sesame seed, with the female being larger than the male.

[A great video on the life cycle of ticks](#) (UK vet)

[Pics of ticks](#) (Dartmoor Tick Watch, UK)

[Ticks found in Portumna Forest](#) (Ireland)

- **Lyme Disease Symptoms:**

Stage One – within days to weeks of a bite from an infected tick, an expanding [rash](#) may occur. Sometimes the rash (known as erythema migrans) can appear as multiple concentric rings forming a bulls-eye pattern. It's important to note that 'any' rash following a tick bite (other than some local redness immediately after the bite) should be reported, as Lyme rashes have been known to [appear](#) differently to the typical bulls-eye. It is also important to note that the EM rash may NOT develop or be noticed in some patients. A flu-like illness may also occur in the early stage of disease.

Stage Two – otherwise known as disseminated disease, symptoms may include migratory joint pain,

head and neck pain, sore throat, swollen glands, Bell's palsy (facial paralysis) and severe fatigue. Cardiac problems may occur as well as bladder irritation in the form of Interstitial Cystitis. Some patients may miss stage one of the illness and develop disseminated disease within months to years of the initial bite.

Stage Three – symptoms for late stage Lyme disease may include neurological changes such as tingling, numbness and tremours. Nerve pain, poor temperature control, brain fog and disturbed sleep patterns are common.

Complications may include optic neuritis, depression, panic attacks, muscle weakness, tissue damage, meningitis, paralysis and chronic arthritis.

Co-infections – ticks may carry several different infections including bartonella, ehrlichiosis, babesiosis and rickettsia. In mainland Europe Tick-borne encephalitis & Mediterranean Spotted Fever can occur, in the States Rocky Mountain Spotted Fever & Powassan Virus, in Africa Tick-borne relapsing fevers. More infections are emerging from Australia & tick bite prevention methods would be warranted worldwide.

Symptoms Patient.co.uk (link)

[Download list of co-infections in Europe](#) (doc)

- **Testing:**

Testing is a contentious issue & a Lyme patient may find themselves confused as to where to turn. The considered 'gold standard' is 2 tier testing (1st tier ELISA, if negative test no further, if positive then test with Western Blot to confirm diagnosis). A bulls-eye rash should be considered as clinical diagnosis as at this stage testing is usually negative. The 2 tier test comprises of antibody testing which may take weeks to develop - if a patient doesn't have a rash but feels ill after a tick bite they may be re-tested at a later date, to see if they have sero-converted. The downside of this is that antibiotics (if given to help alleviate symptoms of suspected lyme or other disease) may abrogate immune response affecting the test result*. Steroids in principal could affect the immune system (in fact some labs request the patient be off antibiotics & steroids for many weeks before testing). Studies have shown that patients respond differently to antibody testing depending on the state of their own immune health & the strain(s) of *borrelia* the tick was carrying.

*[*although antibiotics can affect test results it's important that treatment be made early to prevent disseminated lyme disease from occurring, which is why often a rash is considered diagnostic]*

In addition a vaccine introduced in the 90's caused lyme testing to be 'dumbed down' - too many patients would test false positive if they had the vaccine so lyme specific bands (xIs) were taken out to reduce the likelihood of false positives. This however increases the likelihood of false negatives (the vaccine was since discontinued as latent infections were being triggered & antibiotic refractory lyme can occur in susceptible patients with gene HLA-DR4) ([PDF](#)) however the restricted bands were not re-introduced after the vaccines demise).

Labs in Scotland found that by looking at local strains that patients previously testing negative on standard 2 tier testing were borderline or positive in their in house test. Other studies have shown that lyme antibodies can be sequestered in immune complexes & therefore less free antibodies are available to be picked up in testing. Another study found that patient's immune responses would change & some sero-converted throughout the illness. It's also be known for patients to be negative in the 1st tier (Elisa) but positive in a Western Blot, however a WB is seldom even offered when the 1st tier is negative.

The [test kit](#) manufacturer states “*The diagnosis of Lyme disease must be made based on history, signs (such as erythema migrans), symptoms, and other laboratory data, in addition to the presence of antibodies to B. burgdorferi.*”

Negative results (either first- or second step) should not be used to exclude Lyme disease.

Thus, (in their own words) “*serological tests for antibodies to B. burgdorferi are known to have low sensitivity and specificity, and because of such inaccuracy, these test cannot be relied upon for establishing a diagnosis of Lyme disease*”.

Due to the underlying problems with 2 tier testing some alternative labs have been suggested here that have been used by patients & their Lyme treating specialists; *however it's worth mentioning that mainstream consultants & public health officials are often unwilling to consider them as they fall outside the 2 tier system.* This is strange when the CDC (US) states that criteria used is for surveillance purposes & not intended for use in clinical diagnosis. As mentioned above, the test kit manufacturers themselves say a negative does not rule out infection! We have listed some alternatives therefore below for informational purposes...

LTT test:

This is a lymphocyte transformation test (T cell test) seeking antigenic responses against *borrelia*.

This T cell technique is FDA approved for IB but not currently for Lyme however patients find them useful for staging their treatment outcomes.

Elispot kits used by Borreliose Centre Germany, or Armin Labs are also known as an LTT test. The test kit is CE approved. For more details on the test go to: <http://elispot.com/>

Labs that are using LTT technique in Germany include: [Armin Labs](#) / [BCA Labs](#) / [Melisa Labs](#)

LTT studies...

LTT study: The Lymphocyte Transformation Test for Borrelia Detects Active Lyme Borreliosis and Verifies Effective Antibiotic Treatment (*see our [Issues on Testing](#) article page 2 for more info*).

LTT study: A novel lymphocyte transformation test (LTT-MELISA) for Lyme borreliosis.

Igenex Western Blot:

When the vaccine was released (as mentioned above) the types & numbers of bands for a positive test was subsequently changed. It was later found that children who tested positive under the old criteria would be negative under the new, providing the real scenario of false negative serology. Californian lab [Igenex](#) report on several of the restricted lyme specific bands & is a test that many specialists like to use. Igenex can also offer PCR testing (a direct test looking at DNA of the bacteria). They are strictly quality controlled & are well respected in the Lyme field. *As with LTT testing they are considered to be outside the 2 tier testing system & may not be accepted by consultants in Ireland (as the process skips 1st tier Elisa & uses a 2nd tier Western Blot with different band criteria).*

For a look at lyme specific bands check out our [WB comparison chart](#) (xls).

PCR:

Polymerase Chain Reaction tests are often used for identifying strains of *borrelia*. It is a direct test looking at DNA of the lyme causing bacteria. Similar to antibody testing it can produce false negative

& false positive results. It is seldom used in blood serology but sometimes utilised in spinal or joint fluid or assessment of rashes. The sensitivity of PCR is mixed depending on studies observed, this article has a number of studies listed to compare.

Culture:

Culture can be tricky as a special BSK medium is required & spirochetes are slow to develop. A new test by Advanced Labs has been released which shows promise. As far as we know this is not yet available in Europe.

CD57:

This test indicates strength of the immune system & purported to be low in patients suffering from Lyme disease compared to say MS. It cannot be used to diagnose Lyme disease but can be useful for staging treatment outcome ie improvements in levels maybe seen with improvements in symptoms, as the immune system begins to recover. BCA Labs & Armin Labs in Germany offer the test, although this is not recommended for acute lyme sufferers.

New tests emerging:

Lab on a chip:

A new test called is under development in Europe. **HILYSENS** will develop a specific multi-antigen assay in a lab-on-a-chip device to detect *Borrelia* infections (both acute & chronic). For more information go to: <http://hilysensproject.eu/>

Spirofind:

This newly developed test measures cytokine response after a tick bite. Patent is pending & early trials have been completed. http://boulderdiagnostics.com/us/?page_id=32

- **Standards of Care:**

There are two main standards of care, one governed by the Infectious Disease Society of America which is followed by health departments across the world. This guide ([PDF](#)) calls for 2-4 weeks treatment & only if the patient tested positive via 2 tier testing (1st tier ELISA, if negative test no further, if positive then test with Western Blot to confirm diagnosis). A bulls-eye rash may be considered as clinical diagnosis as at this stage testing is usually negative.

The International Lyme & Associated Diseases Society believe however that the 2 tier test & guidelines are too rigid missing many patients. This can lead to missed diagnosis &/or under treatment & can result in long term, difficult to treat infections. In some cases IDSA treatment & testing 'is' adequate, however many patients find that they are better suited to the flexibility provided by the ILADS Burrascano treatment guide ([PDF](#)). This is more patient focussed ie treatment is based on response to treatment, co-infections are considered, cases sometimes diagnosed using tests outside the 2 tier system & treatment made empirically based on the needs of the patient.

Although the IDSA claim that Lyme infection is treatable with those 2-4 weeks & therefore no further treatment warranted, on their own website they say '*It is important to realize that guidelines cannot always account for individual variation among patients. They are not intended to supplant physician judgement with respect to particular patients or special clinical situation. IDSA considers adherence to the guidelines listed below to be voluntary, with the ultimate determination regarding their application to be made by the physician in the light of each patient's individual circumstances.*'

Voluntary rule http://www.idsociety.org/Guidelines_Patient_Care/

Patients are therefore stumped then when their doctor offers to treat outside the system are then faced with harassment for doing so!

Dr Waisbren (deceased) who was a founding member of IDSA even found the society's stance objectionable. He states *'It's a conundrum why a group of respected physicians who are members of the Infectious Disease Society of America have not recognized this [existence of chronic lyme] and have, instead, written a guideline that essentially denies that the syndrome exists. This guideline has resulted in literally hundreds of patients unable to be treated for Chronic Lyme disease.'*

Conclusions regarding this conundrum may be [in his words]:

- 1) *The physicians who wrote and signed the guidelines of the Infectious Disease Society of America may have seen what they expected to see in the manner of the populace described in the Hans Christian Anderson's perceptive fairy tale, "The Emperor's New Clothes."*
- 2) *Perhaps the authors of the guidelines had too much respect for authority and decided to sign the guidelines based on the opinion of some of the members of the society without having personal involvement in the treatment of the syndrome.*
- 3) *Perhaps they were unduly influenced by the expenses incurred in the many factors concerned in the empirical treatment of Chronic Lyme Disease.*
- 4) *Most probably they were influenced by controlled studies in the medical literature, which were based on Deductive conclusions rather than Inductive conclusions as described by Francis Bacon in 1622. Have they forgotten the well accepted statistical dictum – absence of proof does not equal proof of absence.*

<http://www.waisbrenclinic.com/chronic-lyme-disease-idsa.html>

In practise any consultant not following these guidelines are criticised by the authorities which seems strange, when so many patients are finding that rigid treatment in a box mentality still leaves them ill & unable to re-claim their lives.

In Europe the European Centre for Disease Control provide a [factsheet](#) for professionals & they state with regards to testing *'Further improvements in diagnostic tests are also required'*

& treatment *'Note: The information contained in this factsheet is intended for the purpose of general information and should not be used as a substitute for the individual expertise and judgement of healthcare professionals.'*

Therefore we believe that until more studies are done that patients should be treated & monitored for longer durations if this is deemed suitable.

- **Treatment:**

Treatment offered will depend on whether the attending doctor is supportive of IDSA or ILADS (see standards of care section for more details). The [IDSA](#) approach is to use short term treatment, [ILADS](#) approach is to consider longer term where warranted & to consider co-infections, as well as to add supportive therapies to improve the immune function, with added gentle exercise as the patient recovers. Some patients respond within months, some may take years to see improvements. There is much debate on whether persisting symptoms are a result of immune damage, auto-immunity or persistence of infection. It is possible that all of these are at play! Lyme bacteria can also take on many forms which are discussed further down the page...

Lyme disease is a very complex disease & certainly does not respond the same way in all patients, some may have different mix of tick-borne infections, genes can affect outcome (HLA-DR4 gene can lead to antibiotic resistant lyme arthritis for example) & the specialist has to be aware of the different forms of the bacteria to be able to tackle each form effectively (for instance doxycycline has been known to push motile bacteria into dormant form, only to re-emerge once treatment stopped, so a drug designed to tackle cell wall deficient bacteria may often be required.) Some patients therefore do well on combination therapy under the care of an expert.

A useful guide by Dr Burrascano on the management of Lyme disease can be downloaded here (PDF). Often the patient responds better to an overall treatment protocol looking at antibiotics or anti-bacterial herbs, supplements & lifestyle changes such as diet & rest with light exercise to build back strength over time. For Burrascano's supplement guide head on down to (PDF).

NB: New ILADS guidelines for 2014 are available in the National Guidelines Clearinghouse

Studies on persistence & seronegativity

Chronic Lyme Disease & Persistence

Herbs that help combat all forms

Antibiotics that help combat all forms

Getting rid of biofilm! <http://ticktalkireland.wordpress.com/lyme-links/biofilm/>

Lots more info at: <http://www.lymeinfo.net/lymeinfo.html>

Useful herbs: <http://ticktalkireland.wordpress.com/lyme-links/alternative-treatment/>

Please note that during treatment a herxheimer reaction may occur:

The herxheimer reaction occurs when large quantities of toxins are released into the body as bacteria (typically spirochaetes) die during antibiotic treatment. Typically the death of these bacteria and the associated release of endotoxins occurs faster than the body can remove the toxins. It is manifested by fever, chills, headache, myalgia (muscle pain), and exacerbation of skin lesions. The intensity of the reaction reflects the intensity of inflammation present. It can be very severe & debilitating. For more information check out <http://whatislyme.com/the-herxheimer-reaction/>

- **Structure of borrelia:**

Knowing the structure of lyme bacteria can be insightful as to why it's so difficult to treat.

Motile: Corkscrew shaped spirochetes readily zip around the blood stream at lightning speed but can as easily push their way into collagen, joint fluid, organs & even the brain & optic nerves. Can be tricky for antibiotics to reach them & as they are slow growing (maybe replicate once every 24 hours) so it takes longer to take affect (staph bacteria multiplies every 20 mins so a shorter course of antibiotics designed to weaken them each time they replicate does the job much faster than with a Lyme infection!)

Learn more at: [The motile menace by Tom Grier](#)

L-form (cell wall deficient):

Motile spirochetes have developed an excellent way to protect themselves from adverse conditions such as antibiotics or changes in pH & temperature; they lose their cell wall & become dormant making antibiotics targeting cell wall bacteria no longer able to fight the fight. It's a defense mechanism that sure works! Lida Mattman specialised in cell wall deficient forms of bacteria & identified lyme spirochetes as being in the same class of bacteria that sheds its cell wall when the time is right.

For more information go to: [Notes & observations on cell-wall deficient forms by Tom Grier](#)

Biofilm:

Biofilm is a protective slime layer often found in nature (think stagnant water collecting slimy bacteria!) But do spirochetes & L-forms of *borrelia* also use biofilm in their life cycle? Eva Sapi, Alan Macdonald et al discovered that yes they do!

- **Some useful links:**

Check out this [video](#) (interview with Dr Eva Sapi)!

Plus this [clip](#) showing biofilm & spiro up close & personal..

Selection of links on borrelia forms: <http://ticktalkireland.wordpress.com/lyme-links/structure/>

Ticks & borrelia magnified: <http://ticktalkireland.wordpress.com/lyme-links/under-microscope/>

Pics of the little critters...cysts, spiro, granules & blebs

<http://www.lymerick.net/videomicroscopy.htm>

Did you know that borrelia bacteria is the fastest moving thing in the body & holds far more plasmids than many other bacteria? Check out our [Did you know](#) section for more!

Lots more useful info at lymeinfo <http://www.lymeinfo.net/lymeinfo.html>

Tick Talk pages: [facebook](#), [blog](#), [twitter](#), [herbal group](#), [mainsite](#)

Tick Talk useful links selection below (we have loads more on our site!)

[blood tests](#), [book by Tick Talk](#), [chronic lyme](#), [co-infections in Europe \(doc\)](#), [did you know?](#), [FAQ \(doc\)](#), [herx reaction](#), [Irish articles](#), [leaflets](#), [letter of concern \(PDF\)](#), [letter to IDSI \(PDF\)](#), [looking at patents \(doc\)](#), [lyme clinic Germany](#), [lyme conference Ireland](#), [lyme links](#), [lyme or ME?](#), [meeting with hpsc \(PDF\)](#), [mythbusting](#), [persistence & seronegativity](#), [protect your kids \(doc\)](#), [protect your pets](#), [protest video](#), [rashes](#), [structure](#), [surveys](#), [suspect lyme](#), [symptoms chart](#), [talk on lyme disease](#), [testing issues \(PDF\)](#), [tick removal](#), [tick twisters](#), [under the microscope](#), [useful books](#), [WB test comparisons \(xls\)](#)

Useful links for UK & Ireland:

[BADA UK](#) / [Blood Microscopy](#) / [Children's Book](#) / [CFS clinic Ireland](#) / [CFS clinic UK](#) / [Dartmoor Tick Watch](#) / [Louise's Blog](#) / [Eurolyme \(forum\)](#) / [HSE Ireland](#) / [HPSC Ireland](#) / [ID Clinic Ireland](#) / [Lyme Aid UK](#) / [Lyme Disease Action UK](#) / [Lyme Research UK & Ireland](#) / [Lyme Voices UK](#) / [Lyme Wifey Blog](#) / [Looking at Lyme Blog](#) / [NHS Map of Medicine](#) / [N Ireland FB group](#) / [Online GP Course](#) / [Tick Talk on Facebook](#) / [Tick Talk Main Site](#) / [Tick Talk Twitter](#) / [UK Discussion Group](#) / [Worldwide Lyme Protest](#)

NB: for other countries check out our menu to the right at: <http://ticktalkireland.wordpress.com/>

- **In summary:**

I hope you enjoyed learning more about Lyme & I hope one day that patient testing & treatment will improve to allow for swifter diagnosis & return to good health.

If you have further questions we can be contacted at <http://www.ticktalkireland.org/contact.php>

We are a very small team & have no-one available medically qualified. Please note this site is made available for information purposes & not meant to replace the advice of an attending doctor.

For more useful links such as books, leaflets, guides, worldwide groups etc check out our menu down the right hand side at <http://ticktalkireland.wordpress.com/>