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Addressing Tick Borne Diseases in Ireland

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Farmers pick ticks off animals every day. Pet owner pick ticks of their dogs every day. Every farmer and forestry worker in Ireland know their animals are bitten by ticks and become sick with a variety of bacteria. The sick animals are suffering from tick borne diseases such as Lyme (Borrelia), Anaplasma (a Rickettsial infection) and Babesia (which causes ‘red water disease’ in cattle).

Do you think these ticks might be biting humans as well?

The HSE HPSC website describes Lyme disease, a tick borne infection, as a rare disease in humans in Ireland, with 10 cases reported annually, and estimates of 100 cases nationally occurring. A study from the blood bank in Dublin in 1991 showed 9.75% of blood donors were positive for the Lyme antibody. An antibody means exposure to or active infection. That means almost 10% of over 4 million Irish have been bitten by a tick—400,000 persons! How does the HSE estimate of 10 to 100 cases a year compare to 400,000 exposures or active infections?

In addition to Lyme, people also become ill from the same infections sickening livestock, such as Anaplasma and Babesia. The HSE HPSC website, however, makes no mention of the many co-infections that are also carried and spread by ticks.

When I did a study of ‘chronic fatigue’ two years ago, 25% of the patients were positive by antibody for Anaplasma. The majority of patients I saw responded to antibiotics. These patients had been misdiagnosed with ME/Chronic Fatigue when in fact they had a chronic tick borne infection that was missed by the medical community.

Many believe there are huge underestimations of the true burden of tick borne disease in Ireland. Thousands of annual cases are more likely than hundreds of cases of tick borne infections.

Consider these scenarios. A person goes for a hike in Wicklow and gets bitten by a tick, they not ever see the tick that bit them. Three days later they develop a fever and numbness and tingling all over. Another hiker gets a summer ‘flu’ and aches and pains all over. A farmer develops migratory arthritis and strange neurological symptoms.

Some of these persons may have a rash, some may not. They may or may not remember or see the tick bite.
Where do people sick from tick bites go? Their GPs. Those who remember the tick bite are often told by their GP, ‘There are no ticks in Ireland. Ticks don’t spread Lyme in Ireland. You only get Lyme in Connecticut, have you travelled to America? You have ringworm. You have cellulitis.’

I saw a child from rural Carlow, an area with many deer all around. The child had a bull’s eye rash behind the right ear and no memory of a tick bite. A prior doctor had diagnosed ‘shingles’ and started the child on antivirals. Two months later the child developed a facial palsy and saw a specialist who says viral infection caused the palsy. The mother shows a picture of the rash to the consultant who considers Lyme as a diagnosis. A test is ordered, and the results come back positive for Lyme four weeks later. A short course of antibiotics is given but the child remains ill. The consultant says the condition is ‘post infectious’ and the child will eventually ‘get over it’. The child, however, deteriorates further.

I then see the child and prescribed a longer course of antibiotics and finally the child’s health improves. I am then ‘criticised’ for not following treatment guidelines because this condition is ‘post infectious’ and no further antibiotics are needed. In fact, I had followed guidelines that meet internationally accepted standards for evidence-based medicine and provide treatment options that are applied according to patient response.

Even though tick borne infections are common in Ireland, many GPs and specialists are missing the diagnosis. They do not consider Lyme as a possible diagnosis or when they do consider Lyme, they wait for a positive Lyme test to begin treatment. The Lyme test, an antibody test that picks up certain strains of Borrelia, is very unreliable. The test is roughly 50% accurate and does not capture many of the different strains of Lyme circulating in Ireland. The test often does not show positive in patients with active Lyme disease.

Without a positive test result, people cannot get treatment. Persons who can afford the cost often go to Germany to get specialist tests done on Lyme with the hope a positive test result will secure treatment. It is not uncommon for these tests—designed to capture more strains of the bacteria—come back positive when the Irish tests were negative. When presented with the positive test results, Irish GPs and consultants say, ‘We don’t recognise these tests because these German laboratories are not accredited.’ These German laboratories are accredited—it appears doctors have been misled and they are misleading patients.

Sadly, many patients who get a tick bite, a rash, have a negative test by the Irish system, and who then pay 1000 euros to get private testing, are rejected by the Irish healthcare system.

Those patients who are positive for the Irish test are given two weeks of antibiotics, sometimes four weeks, and some of them get better. Some patients remain ill but are denied further treatment because their condition is ‘post infectious’. When they are given longer courses of antibiotics, they often get better. Some patients improve on treatment and then deteriorate when antibiotics are stopped, and their health improves again following more treatment.
Irish consultants say the patients improved response to extended treatment is the ‘placebo effect’, however, they do not say the first short course of antibiotics is the placebo effect. This thinking appears illogical and does not consider the well documented complexity and multisystemic nature of the illness. 

Doctors are supposed to use their clinical judgement and treat according to patient response and not blindly follow guidelines. Yet doctors who do not follow the guidelines’ short course of treatment are criticised by their colleagues, and often reported to medical societies within the EU. 

The EU recently released a memorandum recognising the Lyme burden disease in the EU at 850,000 cases and the unreliability of current testing. The USA’s CDC estimates over 400,000 cases for 2018. IDSA, the American Society’s opinions that dominate Lyme diagnosis and treatment, has now stated the current testing is unreliable and there is need for tests that detect the bacteria in the body instead of the antibody response. 

There are multiple peer reviewed publications by IDSA members showing this infection can persist after a short course of antibiotics. Yet IDSA fails to recognise the existence of persistent Lyme infection and claims a short term treatment cures the patient. They also claim this infection resolves without treatment. A draft of the HPSC Lyme document similarly states that even with infection, and without treatment, the disease spontaneously resolves. 

These views stand in contrast to many peer reviewed publications. A USA study by Stricker (an IDSA member) describes the ‘natural history’ of Lyme disease. Without treatment two years down the road, 75% of these infected individuals have arthritis, 15% have neurological diseases, and 10% have cardiac disease. Research studies have shown that these individuals are still infected with live Lyme bacteria. Animal and human studies have shown the presence of live bacteria following short course treatment. Persistent untreated Lyme does exist, and persistent, partially treated Lyme does exist. 

During the revision of the international classification of diseases to the ICD11, the WHO developed new categories for Lyme disease that identify five life threatening complications, many late stage and possibly chronic conditions, severe complications related to the brain and the risk of congenital Lyme—Lyme spread in the womb from mother to child. 

In contrast, the status on Lyme policy, opinions and stakeholder process in Ireland appears very outdated. The Irish government has been fully engaged in the ICD11 revision process, yet the Infectious Disease Society of Ireland and the HSE HPSC continues to present outdated views on Lyme. They claim Lyme is a rare disease, ‘easy to diagnose, treat and cure’ and do not recognize persistent Lyme infection or chronic Lyme. 

The HPSC is rewriting their Lyme guidelines. Their process, however, only includes the opinions of consultant doctors who do not ‘believe’ in persistent infection and who advocate to maintain the unreliable testing strategy and repudiate the longer
course treatment options for patients as described in guidelines that meet internationally accepted standards. They are planning on adopting the NICE Guidelines, a review done in the UK that excluded most studies worldwide on Lyme and rejected many of the peer reviewed publications recently validated by WHO and used to develop the new Lyme codes. NICE does not recognise most of the complications validated by WHO, chronic Lyme. So why are we copying inaccurate guidelines rather than independently reviewing all the evidence.

I recently announced the opening of a Lyme Resource Centre, supported by private donor funding. Lyme patient groups helped us to determine the services of this Centre. Education and Research are the two main objectives of this Centre and activities will include:

- **public education**—for example, knowledge of physical symptoms so they will seek medical care and signage of ‘high risk’ areas for tick bites.
- **training of GPs**, those first in line to see patients— for example, so they will better consider Lyme in their differential diagnosis, and to be able to recognise bull’s eye rash instead of confusing it with ringworm, cellulitis or shingles

- **fund- raising for research on these infections**— we need to understand the burden of active disease for lyme and co-infections in animals, ticks, and humans in Ireland. We need to better understand the complex interaction of infection, inflammation, and autoimmunity that these infections trigger.

The CDC and EU have announced increasing rate of Lyme infections and WHO has validated the seriousness of the disease. The HSE, the Universities and the Hospitals in Ireland should be actively supporting such initiatives. Education, prevention, better diagnosis and treatment are what our patients need, and indeed is not this the mission of these organisations. Better health of those we serve?

**What does Ireland need to do to address tick borne diseases?**

The costs of undiagnosed, untreated and undertreated tick borne diseases in Ireland is not known. Estimates of these costs in the USA are 25 to 75 billion annually.

Patient groups and politicians have taken the lead in identifying the lack of diagnosis and care experienced by Lyme sufferers in Ireland. Those persons who have resources can travel abroad and access the more sensitive private tests and the treatment options offered by private care. But what about those persons who cannot afford private tests and care?

There is a clear disconnect between what doctors and the Health Executive is doing in Ireland, as compared to the advances proposed by Irish in the EU forums in Belgium and in WHO forums.

HSE and the Minister of Health leadership need to disband the current committees who appear to ‘rubber stamp’ the IDSA opinion and appear unaware of new developments announced worldwide regarding tick borne infections.
New open-minded leadership to address tickborne infections in Ireland is needed.

The current available testing is lacking sensitivity. Current treatments and guidelines on treatment are outdated and do not acknowledge new information following the IDSA 2006 Lyme guidelines. In contrast, we have found cures for Hepatitis C during this time period.

Clinicians must treat those who suffer with tick borne diseases with dignity and support their right to care.

Chronic Lyme infection and all of its complications is devastating millions of lives across the globe. It is unprofessional for a doctor who cannot find a cause of illness to resort to telling the patient they are depressed or suffer from some sort of psychosomatic illness—yet this is a common experience for those persons suffering from Lyme and other tick borne diseases.

Kind compassionate medical care requires clinicians who understand the limitations of their knowledge, limitations of their testing strategies, and who believe their patients when they say indeed they are ill but the healthcare provider cannot identify a source. Rather than dismiss the patient’s experience, it is better to acknowledge they are sick even if the reasons are not well understood. Clinicians need to work with the patient to find the cause of the illness and work with them to get them better.

Better tick borne diseases education and support for GPs on the front lines is required so the cost of debilitations and disability can be reduced.

An immediate investment of monies into the public hospital system to establish a public clinic for tickborne diseases is required. All patients in Ireland with these conditions deserve access reliable testing and individualised treatment.

We need to do better for those with ‘chronic untreated infection’. Currently they have been labelled with ‘syndromes’ that often don’t fit. Many of them will get better with appropriate diagnostic tests, and appropriate antimicrobial therapy and immune support, where chronic Lyme infection, previously missed, is identified.

A funded campaign to educate patients on prevention and early identification is recommended.

In closing, Ireland is a nation of compassionate people who enjoy many recreational activities provided by this beautiful island. Many of us love to hike, garden, play football or rugby and simply enjoy the natural beauty of this land. Many Irish livelihoods depend on the land. Our population travel frequently to tick endemic areas and bring back these illnesses. These factors make most of us at risk for tick borne diseases. I believe these factors are also incentives for Ireland to become a leader in the science and medicine of tick borne diseases.