Opening Remarks to Joint Oireachtas Health Committee - DRAFT

Introduction and thanks
Tick Talk Ireland would like to thank you for inviting us here to present today. We welcome the opportunity to raise our concerns with you and to discuss the priority issues for people with Lyme Disease and other Tick Borne Infections.

Lyme Disease
Lyme Disease is only one of a number of bacterial infections that you can catch from a tick that can go on to cause serious, long term, life changing health issues. If it is allowed to progress it is very complex to treat and does untold damage to people's health and lives.

Who are Tick Talk Ireland?
Thousands of Irish people are effected. Tick Talk has over 2,700 members which gives you an idea of the scale of the problem. Remembering how many people aren't on social media and the countless others who are suffering in isolation.
Our members come from all parts of Ireland – North and South, Urban and Rural – and encounter a range of difficulties in accessing diagnosis and treatment for Lyme Disease and co-infections.

2019 will be our 10 year anniversary. 10 years of organised patient advocacy for Lyme Disease patients. We are very proud of all the work so many people have done over the years. It is a reason for celebration. However, it is also a indication of how long patients have been left without adequate care. In those ten years how many people have gotten bitten that could have avoided it? How many people have gone on to become seriously ill because of misdiagnosis? How many people have been denied adequate treatment and had their lives turned upside down as a result? Just how many people have the Irish Health System failed?
What is the current situation?
We know much more about Lyme Disease than we did 10 years ago. There have been huge developments in research, in diagnosis and treatment and yet the Health Protection Surveillance Centre (HPSC), the HSE, the Department of Health all remain stuck. Rigidly clinging to out dated and delisted guidelines from the IDSA, the Infectious Disease Society of America, while ignoring other international guidelines. Borrelia is thought to be the most complex bacteria known to man. Yet we are still insisting on a one size fits all approach to its treatment.

Equally damaging - and damning - they ignore the patient experience and evidence from Lyme Disease specialists such as Dr Lambert which show that alternatives are possible and that people can and do recover with proper treatment and supports.

Myths around Lyme Disease - the obstacles we face in trying to effect change

Lyme Disease is rare
When you meet with the Department of Health you will no doubt be told that Lyme Disease is relatively rare and that the HPSC estimate there are 100 to possibly 200 cases a year. But they have no real way of knowing the true figure as the criteria used for notification is limited and overly narrow.

In August 2018 the WHO assigned additional ICD codes for Lyme Disease and its complications. There are now 15 different complications of Lyme Disease recognised by the WHO, five of which are identified as Life Threatening. So why is only one form of Lyme Disease monitored for incidence in the Republic of Ireland?

Lyme disease is hard to catch and early to treat
Again they simply don’t know. As they don’t keep records of the numbers of people who present with symptoms, the number of confirmed infections. We don’t follow patients so we have no idea how people, who are lucky enough to get a diagnosis here, do after their initial course of treatment. And more crucially we have no idea of how many people are misdiagnosed. 64% of respondents in the last Tick Talk membership survey were infected in Ireland. Yet some GPs still insist there is no Lyme Disease in Ireland.

We don’t even know what the prevalence of ticks is in Ireland or what bacteria they carry. There hasn’t be a comprehensive tick drag since the 1990s and even then only Borrelia was studied, other tick borne infections weren’t included. More recent small scale local studies would suggest that there are new strains of Borrelia out there, strains that aren’t tested for. Infected ticks have been found all over Ireland in woodland, open countryside and even urban parks and back gardens. But still we are told the risk is low. When they
simply don’t know. This constant down playing of the risks and realities impedes proper diagnosis and treatment and patients suffer.

**There is no need for over seas testing**
The Department of Health may tell you that the Two Tier Testing model used in Ireland- the Elisa and Western Blot - are accurate and can be relied on to diagnosis Lyme Disease. Yet science says others wise. The UK NICE Guidelines on Lyme Disease - imperfect as they are - nevertheless now recognise that a negative result on the Two Tier Testing method does NOT rule out Lyme Disease. That patient history and patient symptoms should guide diagnosis.

In October 2018, even the IDSA - whose guidelines the HSE follow- published an article, conceding that the current testing has serious shortfalls and that “Continued reliance on serologic testing for early Lyme disease is suboptimal.” But still Ireland does just that.

We have people coming to Tick Talk week in week out telling us they have tested negative in Ireland. That even with a history of a tick bite, symptoms of Lyme Disease, in obvious need of care, they are told “the test says you don’t have Lyme Disease, there is nothing we can do for you”.

There are alternatives. But these aren’t accepted. If fact they are openly dismissed as if there has never been new science and evolving science. The lack of acceptance for the Elispot and TICKPLEX results, from accredited overseas laboratories, cuts off an important aid to diagnosis of Lyme Disease, particularly Chronic Lyme Disease.

**That people who test positive on the Two Tier Testing can access adequate treatment**
Even if you are “lucky” enough to get a positive test result on the Two Tier Testing very often patients report not getting enough treatment. There is a marked resistance to give antibiotics at the level required and for the length of time required. The NICE Guidelines in the UK -now recommended a minimum of 3 weeks antibiotic treatment with a further 3 weeks if symptoms persist. Why are GPs in Ireland not doing this? The NICE Guidelines are hardly radical. Patient groups - here and in the UK - have huge issues with how they were developed, how they excluded so much meaningful research, how far they fall short of what is required. BUT they do at least offer a rating point for better care for people at the acute stage, that is for people who have been recently bitten.

We need more done to support clinical diagnosis of Tick Borne infections through primary care . The Lyme Spotlight Project in the UK has appointed a GP Champion develop a tool-kit and run workshops. It has been overwhelmed with the demand. The on line resources

1.2.12 Use a combination of clinical presentation and laboratory testing to guide diagnosis and treatment in people without erythema migrans. Do not rule out diagnosis if tests are negative but there is high clinical suspicion of Lyme disease [https://www.nice.org.uk/guidance/ng95](https://www.nice.org.uk/guidance/ng95)
have free open access to anyone including outside the UK. Why aren’t we supporting our GPs?

**Chronic Lyme Disease doesn’t exist**

There are conflicting opinions about how best to treat Late Stage or Chronic Lyme disease. Some health professionals refuse to accept Chronic Lyme exists, preferring to believe that people are sick with some unknown mystery illness rather than accept the diagnosis. In the meanwhile, patients are suffering.

Those of us lucky enough to be able to access the information, access the money to pursue other options, access the support to get well still meet resistance and barriers put in our way. So even though overseas labs confirm we have Lyme Disease, even though we get clinical diagnosis from Dr Lambert and specialists outside Ireland, even though we respond to effective treatment we are still told it’s all in our heads. No such thing as Chronic Lyme Disease.

In our most recent membership survey, 50% of people spend over a year searching for a diagnosis. This leads to people becoming sicker and sicker. 86/127 respondents have been ill for more than a year in TOTAL including pre & post treatment. 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. But also that people who do have Chronic Lyme need to be supported to get well.

**That current strategies and the work of the HPSC is enough**

Tick Talk Ireland believes official sources of information on Lyme disease in Ireland is inconsistent, out of date and missing much of the key information on best practice in diagnosis and treatment.

We believe more research is desperately needed into other modes of transmission, for example via sexual contact, the blood supply and organ donation.

**Tick Talk Ireland believes Ireland needs a national strategy for the prevention, diagnosis and management of Lyme disease and other tick borne infections in Ireland, based on best practice internationally.**

**Immediate Action is Required**

The denial of treatment options that meet internationally accepted standards for Chronic Lyme disease patients is a human rights violation.

- In June 2017, the Office of the UN High Commissioner for Human Rights (OHCHR) Special Rapporteur for ‘the right to the highest attainable standard of health’ entered this violation against Lyme patients into record. He also entered into record violations regarding the denial of access to diagnostic technologies that meet national, regional (EU) and/or
global standards.

On June 5, 2018, the OHCHR’s Special Rapporteur for ‘the situation of human rights defenders’ entered into record the harassment and discrimination against medical professionals who care for those suffering from persistent/chronic and complicated cases of Lyme.

**Chronic Lyme Disease must be recognised as a Chronic Illness and included in the Long Term Illness Scheme**

Something must be done for patients who were failed who were allowed to become chronically ill. Chronic Lyme Disease is not recognised. So people struggle to access Invalidity Pensions and other social supports. Remember we are sick due to medical negligence, due to the failure to diagnosis early and treat effectively. Then we are further denied treatment.

The supplementary medications and treatment required for Chronic Lyme are not covered by the GMS and the Drug Treatment Scheme. To the best of our knowledge and in our experience, the Hardship Scheme refuses all applications.

Dr Lambert is the only ID in Ireland. He is currently only accepting new patients into his private practice. Others have to travel abroad. Others still may not respond to antibiotics or not want to go that route and need herbal and other treatment approaches.

Yet none of this is currently covered under the health system. So there are ways and means to get well. But only if you can afford them. Only if you can fund raise for treatment. This is a scandal.

**What we need from you?**

We need your support in seeking a meeting with the Minister of Health and Taoiseach. We need your endorsement of our priority issues. We need political pressure to be brought to bear on the HSE and Department of Health so that Ireland can keep pace with current science and patient centred best practice. We need a move away from this damaging mindset of following the IDSA de listed guidelines where the patient ultimately suffers.

**Because we have done so much work. But we can only go so far without your support.**

**Cost to the Health Service**

An annual incidence of 4-5,000 cases of Lyme Disease in the UK has been estimated to result in a societal cost of between £3million - £3.5million per year. Why would Ireland be much different? So this isn’t just about the human cost of late diagnosis and treatment, its also a huge drain on the health service and exchequer overall.