



Awareness & Support  
For Lyme Disease  
In Ireland

#### Attendees Details:

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#### Opening Statement:

##### How can we ensure 'equal access' and 'human dignity' in public services?

As members of Tick Talk Ireland, we would like to thank the Chairperson and the Joint Committee on Disability Matters, for their invitation to attend the Seanad Chamber and discuss our roles in self-advocacy under UNCRPD.

We are here to provide an insight, based on lived experiences, that patients with Lyme Disease (LD) and co-infections are adequately represented and treated in a timely manner whilst adhering with international best practices.

We feel strongly that LD needs to have greater awareness if we are serious about protecting quality of life, dignity, and human rights!

The pervasive culture of ambiguity must cease immediately!

It is imperative that such treatment is administered through a centre of excellence, preferably in Ireland.

LD is one of the fastest growing vector-borne diseases in the western world and the threat it poses has become increasingly apparent in recent years.

New cases of LD in the U.S are more common than breast cancer, HIV/AIDS and tuberculosis combined.

More than 14% of the world's population likely has had tick-borne LD.

LD bacteria is spread to humans through the bite of an infected tick.

LD is known as the '**Great Imitator**' as symptoms are nonspecific and can mimic many other conditions such as ME/CFS, fibromyalgia, anxiety, depression, Alzheimer's and Parkinson's. The chance of misdiagnosis is high.

Ticks are often referred to as '**nature's dirty needles**' because in addition to LD, ticks while feeding on mice, birds, and other animals (hosts), also carry numerous other infections "**Co-Infections**".

Infected ticks have been found all over Ireland in woodland, open countryside and even urban parks and gardens.

LD infection can occur at any time of the year.

Early diagnosis and prompt antibiotic treatment are crucial to prevent life altering complications.

**Symptoms include but are not limited to.**

- Fever, chills, headache, fatigue, muscle and joint aches, swollen lymph nodes and may occur in the absence of rash, along with multiple other symptoms.

It is irrefutable that there is a culture of medical ambiguity worldwide, with inappropriate timely interventions for patients and their families, that are not aligned with best practice on multiple fronts.

Such is the current impact that family breakup, sale of the family home, sustained heightened stress levels, child and parent alienations are encountered over many years.

This is further exacerbated and compounded with patients regularly experiencing unequal access to and in the quality of legal services, such as differences between public and private legal practice and gender bias through the courts.

- We have deep concerns that persons with LD continue to face barriers with their participation in society as equal citizens.
- The fact that the majority of persons with LD are pushed into poverty enforces the critical need to address the negative impacts accordingly for the patients and society!
- The over reliance on **DELISTED** and **DISCREDITED** guidelines has seen people with LD question their own sanity, emotionally invalidated, ignored, maligned, misdiagnosed, denied medical treatment and adequate care! Quite simply lives are being put at risk!
- Not having access to modern, accurate testing, diagnosis and treatment is significantly impacting people's health, degrading individuals rights and dignity, is a **"human rights violation"**!
- Internationally accredited laboratory testing within the EU is being ignored!
- Policy needs to adequately reflect the fluctuating nature of the realities people with LD live with.
- We seek the implementation of medical treatments with a **"whole system approach"** for the care of patients with LD.
- Together with the pooling of knowledge with the patient, based upon honouring the interconnection of the whole person, the pathology they are faced with and the multitude of treatment options that are available to formulate customised treatment plans!

In the same way that clinical attention, public awareness, and funding were brought to the issue of HIV/AIDS and other once-mysterious conditions, similarly today this must be done for LD!

We are solution focused and will be happy to contribute in any way we can to develop these outcomes!

In conclusion, we therefore need urgent intervention, based on best practice!

There have been far too many medical personnel across a range of disciplines that have been happy to adopt a deflective and evasive approach for far too long, which centres on a culture of **'willful blindness'**!

This serves no one well, not the patients, their families, the development of a more equitable society, the scale of expenditure on mental health and it does not abide with the principles of open Government.

Can we agree here today that we will meet again in six months, with a clearly defined pathway to achieve **"patient centric Irish guidelines"** for LD and co-infections building on **ALL** available best practice?

Kind Regards

Anthony Morris /Kathy Forde



**IT'S TIME TO  
TACKLE LYME**