

**PE1662/T**

Petitioner submission of 13 February 2020

Patient Story – petitioner Lorraine Murray

August 2014:

I remember seeing a little black thing crawling in amongst soapy suds but it didn't register at the time that I was looking at a Tick. It was the size of an apple seed. I must have knocked it off my leg while washing.

I fell ill quickly, and I would actually say that it was within 24hrs from knocking that tick off. That evening I had taken the children to my parents house. I have no idea how long it may have been attached, it certainly wasn't in an obvious place.

The next day I was away celebrating my 10<sup>th</sup> Wedding anniversary. The minute we arrived I fell violently ill.

I all of a sudden got an extremely high temperature, random stabbing pains to my head, a flu like exhaustion, difficulty walking, stomach was unsettled for approximately 5 days.

On returning to my Dr I was told I had probably had my first Flu.

I mentioned at the time that there had been no warning of this and I was perfectly healthy up until that point also it was the height of Summer and unusual time for Flu or so I thought.

After 6 days I began to feel a bit better, but I was never right from that first flu like illness, and I did get tired much more easily than normal.

Over this period I was training to compete in Olympic distance Triathlons. This was my hobby and I was then well above average fitness. My training was becoming a problem as when I tried to jog I did not have any energy.

As the months rolled in I was constantly exhausted. I could sleep 12hrs a night and also be sleeping during the day. Every month I seemed to get another Flu like illness, in fact I was diagnosed with 5 Flu bouts within 6 or 7 months!

Within 9 months I had developed a wide range of symptoms and had to close my Business as I was just too ill and exhausted to keep up.

I had about 80 different unusual symptoms that didn't make sense considering I was perfectly healthy prior to this, and some of the more bothersome symptoms were daily:

A sore stiff neck, difficulty walking, heart palpitations, random stabbing pains, sweats and fevers day or night, sensitive to light and sounds, flu like, I felt toxic, buzzing and tingling sensations in my legs which turned very painful like nerve pain, permanent nausea, excessive fatigue even after sleeping all night.

I couldn't think straight or process conversations, I was jumbling up my words and I suddenly couldn't spell properly. I was also struggling to wash myself and cook meals due to the unbearable fatigue as I couldn't stand or stay awake long enough.

My husband worked offshore and I had two children to look after, next thing I know my blood pressure was dropping too low and I was admitted to hospital. I spent the next part of a year bed bound unable to look after my children most days, my parents came in and helped with meals and small chores and during holidays while he was away. I really struggled. I would get up and make the kids' breakfast and be back on the couch shaking with flu symptoms and all the above!

My husband had to give up work for a few months to look after our children as I became unable to. That still haunts me to this day. I felt a failure as a Mother although it wasn't my fault.

I was unable to drive because of the way I felt and low blood pressure and relied on family support to take my children out places.

There was no support for us at all as my blood tests were coming back normal. I was supposedly in perfect health yet I had never felt so ill in my life! This just did not make sense at all!

9 months from first falling ill I was diagnosed with Chronic Fatigue Syndrome, I was told all my symptoms were because of this. I had seemingly burnt myself out.

I knew deep down that there was something being missed, as I wasn't functioning, and had no quality of life at all. I was deeply distressed. I really thought as I felt so ill all the time that one morning I wouldn't wake up. I thought I was going to die from a mysterious illness no one had ever heard about.

January 2016 – I stumbled across Lyme disease symptoms.

On looking up the symptoms and progression of it suddenly we realised that I fitted exactly all the "Classic listed symptoms" of Lyme disease, even down to the progression.

I went back to the Dr and told him my symptoms and history and that I thought this is perhaps what I had.

I was given a clinical diagnosis of Lyme disease based on my history, the Tick in the shower, progression of illness and symptoms.

I had never noticed a bulls-eye rash!

I began treatment and was put on Doxycycline and I have to say the change within me within about 48hrs was profound. All the symptoms I had just stopped for about two weeks!

Then I had a “Herxheimer reaction” due to the bacteria die off, then all my symptoms were back and worse than ever. The medication was stopped.

My NHS Lyme test came back negative but I insisted on being referred to infections Diseases at Ninewells, as I was confident this is exactly what I had. My Doctor was also supportive at that time but did not know how to help me. The referral took 8 weeks to come through, during those 8 weeks I found a private clinic and we ran some more tests.

This came back positive for Lyme disease.

I took this positive test to the NHS clinic and explained my symptoms, they agreed to run a Lumber puncture the following week.

I got a call from the clinic saying that test was also negative and that I probably now had Post Lyme disease symptoms, I was offered no other treatment.

I was horrified that the NHS could not help me, and I have to say very confused. How on earth could I fit all the symptoms and not get a positive test. On more research I discovered why and learned how unreliable testing actually was.

I was left with all the symptoms of Lyme Disease, extremely ill with two Children and expected to just get on with it. I have never felt quite so low and abandoned by our NHS.

I researched and found a clinic that would treat me. I began private IV treatment for several weeks. This cost several thousand pounds.

The change again was very profound, I was again responding to treatment and my neurological problems cleared for the first time in a couple of years.

Unfortunately, over the year I wasn't responded fully to only Lyme focused treatment. I had some obvious improvement, but was then seeing some symptoms come back.

I have discovered not only do I have Lyme disease. Further testing revealed I have tested positive for Lyme disease, Babesia Microti, Bartonella H and Ehrlichiosis.

I am about to have further testing to see I have a form of Rickettsia as I have a palm rash, fevers every few days. They are also testing me for relapsing flu of which I get every four days. This becomes obvious when my antibiotic is swapped and perhaps not targeting it all. I pay for all these tests. My clinic are trying to hone in and cover all the infections.

All I can say is that I am infected with multiple different bacteria species and parasites. I have never tested positive with NHS testing, but I display all the symptoms past and present for all these infections.

I also took my positive Babesia Microti test result to my GP, they sent off more testing to Tropical diseases in London. That was the week after my positive Igenex tests for Babesia.M and before I began any treatment for it.

Again this was negative. I then asked to be referred yet again to Ninewells Infectious Diseases but as my NHS test was negative they will not see me. They also stated that I didn't display any of the symptoms for Babesia on a letter, which is a very strange thing to say without seeing me in person. My symptoms were never investigated and were ignored by the NHS infectious disease Department. The very people I thought could help me! Treatment was all hinging on a positive NHS test, regardless of the fact I already had several positive tests from two separate accredited Labs.

Needless to say I feel shocked and badly let down by the way Lyme disease and other Tick born illnesses are diagnosed and treated in Scotland.

I consider myself one of the lucky ones, as we have been able to finance my private treatment, which has cost thousands of pounds. Many people could not afford this.

I continue to slowly improve.

I am a complex case with multiple infections, and without treatment I know it may have killed me.

My autonomic system continues to improve, however I do not know the extent of any permanent damage to my body. My blood pressure has now stabilised thanks to other medications. I now periodically sweat again properly and my adrenal glands are now being supported, my endocrine system is improving and again being supported and I feel a good bit better, I am treating the very symptoms and the known infections that are keeping me ill.

I still can't walk far and have to use a wheelchair as I get flair ups of pain in my legs and severe fatigue, but who wouldn't be with all of this going on. I am not sure if any damage will be reversible, but I am very hopeful that I will continue to improve as each infection gets treated and lessens in severity. I am also treating the biofilm and cyst form of the bacteria, which often complicate a case in later multiple infections.

I fully support this petition.

The current NICE guidelines have failed me and many others, by insisting on using known inaccurate testing, inadequate treatment, Not testing for other tick born infections, not checking for immune dysfunction, completely ignoring obvious symptoms of Lyme disease and many other areas that come with such a complex illness.