

In November 2001 Gill Reese founded EuroLyme, an internet based support group. The European site where patients and professionals can find friendly support about Lyme and other Tick-borne Infections. By October 2005 membership had increased to over 900. This is Gill's story in her own words.

Gill Reese



Early September 1997 one of my terriers came in from rabbiting covered in thousands of tiny ticks, the sizes of poppy to mustard seed. I am quite used to dogs bringing ticks home (farming family) but had never seen so many and such tiny ones. We washed the dog in insecticidal shampoo, but nothing seemed to remove them. The dog was distressed by them so I spent a week combing my finger nails through her coat and scraping them off her skin. Many burst on my finger ends, covering them in dog/tick blood.

Sometime over that period a headache slowly developed. It was dull and wouldn't go away, even when I had long exhilarating gallops on horseback. It started to wake me at nights, so eventually after a month I went to see my doctor. We are a very fit family and we very rarely have to consult our GP. After a few quick tests he diagnosed STRESS and prescribed codeine and paracetamol tablets. I was staggered at this and went home wondering how he could diagnose this in an almost complete stranger.

At the same time my left arm was becoming weak and tired and I remember asking my husband if he could see any difference between it and my right one. Whilst out horse riding I was having to hold the reins in my right hand and

whilst driving the car I was having to rest my left elbow on the steering wheel. At the time I thought I'd just strained the arm from over work and that was why the brachialis muscle was wasting away. I didn't imagine a connection between the headaches and my arm at this stage.

Three days later the headache was much worse and on the evening of October 13th I took some of the tablets. My husband was fast asleep, my son doing homework in the kitchen, my daughter in the bath, and I was sitting watching tropical fish. I had to tilt my head slightly back to see them and each time I returned my head to the neutral position a strange feeling went down my spine. I stood up and I went very cold, but not as if to faint. I couldn't wake my husband so asked my son to do so and to call an ambulance. My GP was automatically called also, as we live in the country, and he gave me a quick examination and could find nothing wrong. By this time my body was in a RIGOR, all my muscles twitching and trembling inside me. He sent the ambulance men into the hall and took my husband into the kitchen. They seemed to be away for ages and I was left alone and thought I really was going to die.

Eventually they returned and said that there wasn't anything seriously wrong with me, but did I still want to go to hospital. I thought that at least there they would know instantly what was wrong with me, so I asked to be taken. The GP wrote a sealed letter to take with me. At The hospital I was on observation for the rest of the night, just in case it was meningitis. I wasn't allowed out of bed, but needed to urinate every half-hour though out the night, so I was tested for a UTI. Nothing found. The next morning I couldn't stop sweating and a fan was brought in to keep me cool, though I didn't have a temperature!

I was sent down to a Gastro ward for observation (the only bed available) and things got much worse. I was very hot and couldn't sleep at night. Then gradually a fire-like pain developed in my neck, so I couldn't rest my head properly. Night nurses would ask what was the problem at home.

This very much puzzled me until my husband told me that he had been taken into the kitchen and asked if we had been arguing before my rigor attack.

From the questions they kept asking me they obviously thought there was some domestic problem and I was a 'bit of a joke'. Nothing could have been further from the truth. We had moved 8 months before into a beautiful house and my son had just got excellent GCSE's. Everything was just wonderful at home.

I wanted to go home as I had left children, pets and horses, all needing my care. As I didn't improve I was kept in for the week and then sent home to have some physiotherapy on my neck. They had now decided that I must have damaged my neck horse riding. My neck got worse and worse, so that I couldn't sleep and I couldn't get out of bed. My GP arranged for physiotherapy and a soft collar. The collar helped a little. The physiotherapists could do nothing for me, and had never seen such a complaint before! They offered acupuncture and advice on pain control. All helped a little, but I was getting worse.

At the same time the little dog that had been covered in ticks was becoming ill. She was subdued and had a nasty cough. We took her to the vets, who agreed that she was a sick dog. He thought it likely to be Kennel Cough as she had a slight temperature. I remarked that the other two dogs were fine, and the vet then said that it couldn't be kennel cough as it's very contagious and they ALL would be ill. He didn't know what it was but gave her a big shot of long acting antibiotic 'just to be on the safe side' The dog slowly recovered as I got much worse!

- By now muscles were twitching on my face and everywhere down to my feet and my GP said he didn't know what was causing it.
- My head ache was so bad (not relieved by concoction of painkillers)
- I couldn't sleep at all now and was having to sit up at night in a state of panic and nausea. I was given valium and anti nausea tablets.
- Muscle pain was getting worse by the day, so I could hardly breath (intercostal pain) or walk.
- I would get shooting pains down my arms and legs.
- I could feel tremor everywhere.
- I would either be sweating or shivering. But my temp never came up to normal (37C) and fluctuated between 35.5-36.5C
- My joints hurt esp ankle feet and fingers
- Severe fatigue
- Palpitations that would bounce the mattress, my heart felt as if it would burst out of my chest
- Short periods (half-hour) of tachycardia, up to 150, when normally 62-64bpm
- Tingling in fingers and feet
- Numbness in hands
- Left Brachialis muscle was wasting away - hand used for squashing ticks
- Severe facial pains, couldn't smile, then a feeling that insects were crawling over it or I was walking into a cobweb
- Sinusitis-like pain
- 'Wobbly' vision, also 'gritty' eyes
- Tinnitus in both ears, started in left one
- Extreme anxiety real panic attacks
- Burning sensation on skin of face, neck, shoulders and left arm.
- A strange pain between my shoulder blades as if I had been hit there very hard
- I also occasionally developed a strange red rash over the top of my chest, up either side of my neck and face to my ear lobes, which often appeared red/purple.

After about a month of symptoms I asked my doctor if I could have caught something from the ticks I had removed. (I keep a diary and kept going back to that week, prior to that I had been athletically fit). He dismissed it saying I had to have been bitten. He called all my symptoms 'Bizarre'.

I kept telling people that I suspected the ticks and then one day my elderly father said he had seen an article in the paper about a man who got such a disease. By this time we all thought I was going to die with out a proper diagnosis. He posted me the paper and it turned out to be a colleague of my husband who had Lyme disease. We contacted him and our symptoms were identical. I had solved my own medical mystery!

I returned to the GPs armed with lots of info from the Internet. My GP was away and so I saw another, who had been my neighbour for 10 yrs prior to moving house. I could tell he didn't believe me and said he couldn't treat me without a second opinion from the Infectious Disease (ID) Specialist. I had to wait weeks to see him and was told not to take any antibiotics till then. I knew that time was of the essence and realised that no one knew anything about Lyme disease or they would treat first and ask questions afterwards.

I saw the ID Specialist 8 weeks after the initial infection and could hardly walk to the room. He gave me thorough examination and said that nothing serious was wrong and that I MAY have Lyme (but knew nothing about it) OR Brucellosis. I had dismissed this early on as milk has been pasteurised and tested for years now, tho' my family were dairy farmers. Demonstrating even further his ignorance of Lyme, he told me to wait for the blood test results before commencing any treatment!

I ignored his advice and acquired some doxycycline from my GP as I knew this would treat Brucellosis OR Lyme!!!

My symptoms seemed to improve a little, but all my blood test results came back as negative in early December 1997.

I was taking 200mg daily and got a little more active, till Boxing day when I had an enormous relapse – probably a HERX - though I didn't know it at the time! It was another rigor very similar the first one.

We called an ambulance.

At hospital I explained about my Lyme treatment, but on one knew about it of course! I gradually came out of the attack and was sent home after a few hours of close observation.

In the New Year 1998 I became much worse and my doctor said the sweating was menopausal and made me take HRT against my better judgement! (I had NEVER wanted HRT and I didn't think I was menopausal either)

Then in February I started to improve a little. My GP had increased my doxy to 300mg, then in March he hinted that it must be time to stop the medication.

As I didn't seem to be improving anymore I stopped at the end of March. I quickly began to relapse badly, and my doctor realised it. I asked to see the Infectious Disease Specialist again, but now he was worried and thought it better that I should see a Neurologist. My Lyme friend was better by now, but he had had a +ve test and I had not!

By now I had a 'burnt' tongue, a cough, burning throat as well as worsening of all the other symptoms. My neck was quite unbearable now. I was almost completely bed bound and I used to dream that a gunman entered my room and I begged him to shoot me and put me out of my misery.

I had to wait to the end of April to see the Neurologist, privately, otherwise it would have taken 6 months!!!! In the interim my GP asked if I wanted to recommence the doxy. I told him I'd like to try the Amoxicillin plus probenecid instead.

Though I was only given about 1.5gm a day the results were catastrophic. The first night I felt as if had been doused in burning petrol, and I became VERY ill for weeks until I saw my Neurologist. I was very frightened that my own diagnosis was wrong and nobody knew what was really the matter with me. The pain became unbearable especially between my shoulder blades. I was VERY frightened by now.

My Neurologist told me there was nothing seriously wrong with me, that if I had Ever had Lyme the doxy would have cured it, and that the neck was a whiplash injury from horse riding. - How after I had been in bed for 6 months I really don't know!

I stopped the treatment grateful that he could find nothing seriously wrong with me. He told me to take as much Valium and amitriptyline as I needed to control the pain.

I slowly started to improve throughout the early summer of 1998, but as the summer progressed I knew that I was relapsing again.

I had day after day of nausea, my fingers were now very painful and had lumps on the joints - which I was told was arthritis. I was told that the cough and itchy eyes were hay fever, tho' I had not suffered from it previously. My right leg also felt as if it might give way.

My father wrote to my Neurologist and told him to find out what was really the matter, and I was admitted to Hospital for CT and MRI scans and lumbar puncture at the end of JULY 1998 - ALL showed nothing abnormal.

I was treated like an idiot and NOT even told what tests they were carrying out or even what substance was being injected into my arm for the MRI scan! In fact fun was made of me by the ward doctor who kept asking me if I'd remembered 'any more symptoms'. Even my Neurologist made fun of my tinnitus, saying most on the ward had it and there wasn't any explanation for any of us.

Sept 1998 I knew I was relapsing.

- I had no energy
- Legs felt numb
- Dry cough esp at night
- Mentally I felt like a Zombie
- Tongue felt permanently 'burnt'
- Regular nausea
- Chest, neck and ear rash almost constant now
- Phobia about certain normally pleasant smells, eg coffee
- I had become obsessive about doing certain activities a specific way.

I returned to my GP and DEMANDED 2gms amoxy 1 gm probenecid and 200mg doxy per day. He nearly hit the roof, but knew I meant it and that also I knew far more than he did about my infection!!!

I had now spent a year studying Lyme disease as I was unable to do anything else. These amounts were the max recommended in Britain for Lyme so I knew I was on safe ground.

- Things happened fairly quickly. The 'Burnt' tongue went, as did the cough. Cheek bone pain improved and also the rash on my chest and neck and the purple earlobes.
- My phobias about the smell of coffee, loud sounds, fluorescent lights and vibrations improved.
- Also itchy nose, tremor, tingling in hands and feet, sweating, shivering, memory, dizziness, and insomnia all improved within a few months.
- I noticed that I was able to write words down without getting the letters in the wrong order -Dyslexia, something that had been puzzling me for ages!
- New symptoms started to develop
- Deep pain in inner thighs, I was worried about a DVT!
- Joint pains worse esp on fingers, wrists and ankles and feet
- Neck worse always the occipital region
- Itchy skin and at night a deep burning pain esp on hands and feet

- Pain all the way down my spine now, but esp between my shoulder blades.
- Severe pain in back of head
- Bones in hands and feet too tender to touch now esp the lumps on fingers.
- Also skull would get very tender 'bruised patches' which migrated around.
- Symptoms were always worse in the evenings, esp in areas of old scars and injuries – intense pains
- Also severe muscle pains
- Mobile head pains
- GP told me I was too hypersensitive to my own body!!!!!!
- Limbs or trunk would jump when I was resting
- Increase in red patches esp knee caps after bath also ?? secondary bull's eye rashes
- Now I would get Bradycardia (down to 46 bpm) with a feeling that I was about to pass out.
- Tinnitus did not change

When I next saw my Neurologist he was impressed at my improvement, tho' very surprised that I had relapsed. He told me to continue with all the abx until next my visit - I ended up taking it for 12 months.

October 1999 I saw Dr Xxxx again. It had been a very hot summer and I had had a difficult time trying to keep out of the sun, as the doxy made me very photosensitive. I am naturally an outdoor person, and though not very active I liked to potter in the garden. I asked if I could stop taking the doxy and to double the amoxy to 4gms daily. He agreed.

At first I thought it was improving me, but by the New Year 2000 I was having my doubts. Mid Jan. I suffered a period of about a week of Bradycardia (down to 42). An ECG at my GP's showed there was some delay in the conduction bundle.

Late one evening at the end of this week my heart had an hour long attack of Tachycardia (over 150) and my body went stone cold and shivery for a few hours, except for my face which was bright red.

Back at the hospital nothing serious was found and after a night of observation I was discharged

From then to mid April I thought that I was relapsing again, and told my GP. I had heard of a British man working in the States who was having success treating late Lyme cases with Flagyl. I asked my GP to contact him and ask his advice. As a result I was put onto 1200mg Flagyl daily on top of my 4gm amoxicillin.

I am now in my 7th week of this treatment and at last feel that we are getting to grips with this most devastating of infections. Head pains and fuzziness are improving as is my stamina and my temperature comes up to 37C on occasions now. My joint pains in ankles wrists and feet have worsened (?? temporarily) So I feel that I still have quite a way to go before I can declare myself 'cured' But I must admit that I now feel that I'm becoming a member of the Human Race again.

written by Gillian S Reese 13 June 2000

PostScript

Later in the year 2000 I received a diagnosis from the Bowen labs in Florida USA. They found I was infected with BOTH Lyme disease and Ehrlichia. Both my GP and Neurologist were pleased that I'd at last got a diagnosis and allowed me to tailor my medication to address both these infections.

At the Sept 2001 conference Drs Meer, Kroun and Shoemaker confirmed that I'd been carrying Lyme for a very long time prior to the 1997 'picking ticks off my dog' event?

It was reading Polly Murray's book 'The Widening Circle' that made me realise that I'd had the EM rash in the mid 1970s from a visit to the New Forest and had been slowly developing more and more mild symptoms. The second infection was just too much for my immune system to cope with!

Unfortunately I relapse when I stop taking antibiotics - proved my a blood test by Dr Wright in June 2004 which showed my blood to be still heavily infected with Borrelia bacteria.

At the 2004 Tick Borne Disease conference held in York, I was advised by Professor Sam Donta to take Clarithromycin and Plaquenil. I am now feeling much better than I've done for a very long time, but still don't feel I am completely cured of these infections.

G Reese 02/03/2005.