Nicola Seal Neuroborreliosis with a happy ending

I am an ecologist, entomologist and general outdoory person. Before I had Lyme disease, I had never been seriously ill and was a hillwalker, mountain biker and climber. Lyme disease ruled my life for around 19 months, and after long-term antibiotic treatment, I now consider myself cured. I have had no symptoms for 20 months now, and have a healthy baby and have my life back. I am currently trying to inform and help others who have not been so fortunate and are still suffering.

Timeline of my Lyme infection

17th May 2008 Bitten by tick on the Isle of Rum, west coast of Scotland, attached for approx 24hrs.

28th May 2008 First Symptoms- headache, stomach ache, sore knees, swollen glands, fluey, stiff neck. Note, I did not have a rash at any point.

29th May 2008 GP consultation. Legs begin to weaken, sore muscles.

30th May 2008 Admitted to hospital. Unable to bear weight on legs, headache, stiff neck, photophobia, sore knees, elevated temperature, sweaty, muscle pain. Lumbar puncture PCR negative. ELISA negative. Start 200mg/day Doxycycline

1st June 2008 Discharged from hospital, legs still very weak but can walk around the house holding onto furniture.

10th June 2008 Second ELISA negative. Continued symptoms. Off work. Walking with a myopathic gait (knees turned in, legs have poor control, feet plonk down). On good days can walk around a supermarket, on bad days can only crawl around the house. Very low stamina.

19th June 2008 Dose of Doxycycline increased to 400mg/day.

15th June 2008 Third ELISA negative. Continued symptoms, waxing and waning.

21st June 2008 Second admission to hospital due to continued symptoms despite doxycycline. Lumbar puncture negative, Neurological examination normal. Nerve conduction tests normal but electrophysiologist observed L2 nerve root disturbances summised from pattern of numbness on legs and muscles affected by weakness. MRI shows no MS but 2 nonspecific hyperintensities. These findings are dismissed as not important/relevant by infectious diseases consultants.

25th June 2008. Discharged from hospital with diagnosis of 'post viral fatigue' or 'software problem' . Referred to Psychiatrist (who found no evidence for psychiatric illness). Antibiotics stopped.

31st June 2008. Lyme diagnosis based on clinical symptoms from private specialist. Igenex western blot IGG positive (CDC criteria negative). Had to get wheelchair through Luton airport. Symptoms had worsened. Ataxia (unable to touch finger to nose on one side, keep dropping things, knocking things off tables, poor spatial awareness), myopathic gait and swollen thigh (myopathy?) observed by private doctor.

6th July 2008 Second consultation with second private specialist. Again Lyme diagnosis based on symptoms and history. Symptoms worsening and increasing. Poor concentration (e.g. struggled to maintain thread of a conversation, could not read well), ataxia, slowed mental processing (e.g. found simple tasks such as typing, adding two numbers together almost impossible), memory problems (e.g. forgot PIN number, could not recall names for everyday items), re-started Doxycyline whilst waiting for NHS decision on IV ceftriaxone.

25th July 2008. Began IV ceftriaxone 2g/day. (12 weeks: 4 NHS, 8 privately). Improving symptoms, especially mental processing, concentration, memory, ataxia, dental pain improved. Weak legs improved but some weakness remained. Other symptoms (dizziness, headache, nausea, shooting pains in muscles, jaw pain) remained after IV ceftriaxone.

17th October 2008. Ended Ceftriaxone, began oral antibiotics (privately). Combination Amoxicillin/Azithromycin/Tinadazole followed by Rifampicin and Artesunate. Gradual improvement in symptoms, waxing and waning, approx 4 weekly 'cycle' emerged. Herxheimer-like reaction on starting new antibiotics. Stopped antibiotics, had relapse, restarted. Phased return to work.

December 2009. Last symptoms experienced (Leg weakness).

February 2009. Stopped all antibiotics. Continue to be well, no residual effects.

Nicola Seal, August 2011