Karen Smith Attachment 1: A little More on Patient Story. I originally wrote my “story” in 2011. This is attached. As is my positive blood results (Australian bio) and brain/spect scans. Attached also is a picture of an EM on daughters face – She also has a positive PCR blood result. She has never left Australia. And nor had I before I went to the UK for Lyme treatment in 2012.

K. Smith My Story: Written 2011

It was only a little over two years ago when I was content with what I achieved thus far my life. I had worked, raised three beautiful children, and completed a four year university degree with grades that enabled me to be granted a scholarship to do my Phd. My social life was not that of a party animal, but it was good, with friends and acquaintances nicknaming me “smiley”. I enjoyed a friendly game of poker, loved the sound of music and there was nothing better than dancing the night away and chatting to mates. Now, I am unable to work and have had to defer my Phd. I don’t go out anymore because even the noise of a simple conversation is granting to my brain most days and due to muscle wastage, a night of dancing is not really an option. My children went from seeing a Mum whom was on the go for 16-18hours a day, to someone who was in bed for that length of time. My youngest missed out on things I had done with her elder siblings, my son, being the man of the house for many years became extra concerned in his quite ways, and my daughter went from a carefree life of just having entered the workforce and enjoying the freedom that a license brings, to having to fit the shopping and cooking for the house into her routine. My current health situation lies squarely on the shoulders of the Australian Health Departments lack of recognition of Lyme disease in our country.

My journey to this discovery started in April 2009. It began with a case of Bells Palsy, a trainee doctor keeping me on steroids for months too long, followed by months of not being able to get out of bed and feeling like I was dying. Trips to specialists followed, with one mentioning that my problems may be due to an underlying autoimmune disorder. Whilst not an answer, this visit led me to do more research and finally in July 2010 I came to the realization that all my symptoms were associated to Lyme disease. I learnt that Bells Palsy is one of the symptoms and whilst initially I had assumed that the speedy withdrawal from the steroids had led to adrenal problems, what I came to understand was that the steroids had shut my immune system down, allowing the bacteria responsible for this disease to spread throughout my body. When the steroids were stopped and the immune system starting recognizing the bacteria again, the bodies natural reaction was to start fighting and I experienced very many of the symptoms associated with Lyme one after the other. These included, constant headaches, bone pain, muscle weakness, hand tremors, burning sensations, loss of taste, hearing problems, heart palpations, memory problems, and stuttering, to mention just a few.

Whilst I remembered a tick bite in 2007, I could recall various health problems starting before then, and I tracked these back to a re-occurring rash I had had in 2003. This immediately made me think of a rash that my youngest daughter had in December 2002. At the time the doctors had no idea what it could be, sending pictures to specialists in Brisbane who concluded it was a rare fungal infection, possibly due to the mice we had for pets at the time. If the doctors in Australia were made aware of Lyme disease when the first known cases were reported here in 1982, they would have known that her “rare fungal infection” was in fact a Eyrtthma Migrans – the typical bulls-eye rash that around 40-50% of Lyme patients develop. With this knowledge, I may have also been more aware of what the re-occurring rash signified for my health as well as other signs to be aware of regarding my other two children.

It has now been over two years since I first became sick, and just over 12months since I suspected Lyme disease. Rather than getting easier, the ongoing nightmare of trying to get appropriate tests and treatment in my own country has been nothing short of insane. I have a clinical diagnosis of Lyme disease, with this diagnosis being supported by blood tests. These are not acceptable to the Australian Health department as they were not done through their testing pathology laboratories. If the clinical diagnosis and the supporting blood tests weren’t enough, I also have had a brain scan in which the summary reads, “widespread inhomogeneous cortical hypoperfusion with involvement of the basal ganglia, but sparing of the frontal lobes is non specific, but can be due to the encephalopathy of Lyme Disease”. But wait ……. I have never left Australia, and with the involvement of the basal ganglia…. Well surely it must be early onset Parkinson’s; because “Lyme disease is not in Australia”. If I hear this statement one more time, I think I will just have to scream.

This is up on my website: with Link to Today Tonight interview: http://www.lymeaustralia.com/karen-founder-lara.html
Karen Smith Aust Bio Results; first one equivocal – 2\textsuperscript{nd} Probable Positive.

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>Karen Smith</th>
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<tr>
<td>Date Received:</td>
<td>5/8/10</td>
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<td>Sample Type:</td>
<td>Whole Blood</td>
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<td>Date of Birth:</td>
<td>9/2/71</td>
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<td>CE0269</td>
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**Testing by:** Nested PCR

**Results:**

Borrelia species +/- Equivocal
Borrelia/Lyme: Australian Bio – An Equivocal and a Positive (As above)

Igenix – 4 Bands indicative of Lym

My Australian Lab (SNP) test for Borrelia was Negative.

My brain scans were suggestive of encephalitis – see below for more
Karen Smith Spect Scan summaries: (I can forward originals if need be)

**Spect Scans: Karen Smith**

*Date: 10th November 2010*

**Findings:** There is heterogeneous but generalised hypoperfusion of the parietal, temporal and occipital cortex and there is also reduced tracer activity within the basial ganglia. There is relatively normal perfusion of the frontal lobe cortices. Cerebella activity is normal.

**Summary:** The pattern of widespread inhomogeneous cortical hypoperfusion with involvement of the basal ganglia, but sparing of the frontal lobes is non specific, but can be due to the encephalopathy of Lyme Disease.

**December 2011/January 2012-- Developed short term working memory problems/ lost the ability to multi-task and plan ahead.**

*Date: 24th February 2012*

**Comparison** has been made with the cerebral SPECT study performed in 2010. There is moderately reduced perfusion to the occipital lobes and mildly reduced perfusion to the temporal and parietal lobes. This has a similar appearance to the 2010 study.

**Comment:** There has been minimal interval change in the scan findings. There is mildly reduced perfusion to the temporal and parietal lobes and moderately reduced to the occipital lobes. This would suggest the changes are stable and non specific. It may be worthwhile performing a PET/CT scan of the brain to confirm these findings.

**March 2012: Went to UK for treatment.**

*Date: 13th February 2013*

**Findings:** Since the earlier study the defects in the occipital lobes and temporil and parietal regions have improved. The distribution of isotope is now within normal limits. No cortical defects are seen with no lobar hypoperfusion. The caudate heads and thalamic nuclei appear normally perfused. No further pathology is seen.

**Conclusion:** Appearances are now within normal limits.

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I still have short term/ working memory problems/organizational/planning problems. Problems with spelling (ie: two/too/to) and concentration. Will no doubt take time to repair damage due to hypoperfusion: A reading on this: “Chronic cerebral hypoperfusion elicits neuronal apoptosis and behavioral impairment”  
http://137.122.232.177/NRL%20publications/BennettNeuroreport98.pdf

It was late 2011/early 2012 that i started having short term working memory problems – and lost the ability to concentrate/multi-task. I have many problems still – and have gone from someone that used to study 10-12 hours a day – to averaging 20minute blocks. I used to also drive over 1500km for University – now I cant drive more than 15-20km as my brain cannot handle too much sensory input and becomes overwhelmed.

My then 20 year old daughter (after seeing me unable to walk for a few days) took out a $15,000 dollar loan for me to travel overseas. My father took out $20,000- from his retirement fund. With the $35,000 I was able to travel overseas for treatment – and within weeks noticed huge improvements in my health. The long term damage (and numerous other co-infections) means my treatemet and repair/recovery process is long term. I try for the main part to stay positive – and know that its possible to “get back to normal”, but I also get so disheartened, angry, that even at my sickest, I could not get help in my own country.
Ashleigh Smith – EM rash pictures – December 2002. At the time – the doctors ended up placing this as a “rare fungal infection”. It wasn’t until I learned about Lyme in 2010, that I realised what it actually was.

PCR positive test below.
**Patient Name:** Ashleigh Smith  
**Date Received:** 28/9/10  
**Sample Type:** Whole Blood  
**Date of Birth:** 18/8/95  
**Laboratory No:** CE0796  
**Copy to:** Patient  
**Testing by:** Nested PCR

**Results:**

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<tr>
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<td>Negative</td>
</tr>
<tr>
<td>Mycoplasma fermentans (separate run)</td>
<td>Negative</td>
</tr>
<tr>
<td>Chlamydia species</td>
<td>Negative</td>
</tr>
<tr>
<td>Borrelia species</td>
<td>Probable Positive not able to confirm through sequencing</td>
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