

LYME DISEASE ON THE NHS

CAUDWELL LYME DISEASE CHARITY
PATIENT SURVEY RESULTS 2016

Q5 ADDITIONAL DIAGNOSES

DO YOU HAVE ANY ADDITIONAL DIAGNOSES (ACCORDING TO THE NHS)? SELECT ALL THAT APPLY.

"OTHER" OPTION – 209 RESPONSES

1. Graves' disease, coeliac disease, bile acid malabsorption, b12d, helicobactor pylori, polyneuralgia, shingles 60/70 times, PHN
2. EDS, Addison's Disease, Inter-cranial hyper tension
3. Thyroid, abnormal liver function tests
4. eds3 pots
5. Neurally mediated hypotension
6. Eosinophilic esophagitis
7. Interstitial cystitis, sleep apnea
8. Gastroparesis diverticulosis suspected ME/CFS Tachycardia joint hypermobility syndrome
9. Hyper mobility, mental health hypothyroid herpes
10. Delusional schizophrenia
11. Delusional schizophrenia
12. Migraine
13. costochondritis, polymyalgia rheumatica
14. Interstitial Cystitis
15. Psychosomatic
16. Nerve damage, seizures, head pain, joint swelling and heaviness in left arm
17. MND/ALS and lymphoma
18. endometriosis
19. Hypothyroid
20. Graves' disease, coeliac, b12 deficiency, bile acid malabsorption, left frontal lobe lesions, vit d def
21. Arthritis, hypertension
22. pernicious anaemia and Hashimotos
23. ALS
24. Lupus
25. "It's in your head"
26. GERD Hiatus hernia
27. GP and hospital said nothing was wrong with me. Had to go to another hospital's neurology department
28. Hypothroidism and Coeliac disease
29. Interstitial cystitis, Raynauds, border personality disorder , major depression ,
30. Lewy Body Dementia/Fronto Temporal Dementia
31. Hypothyroidism
32. Functional neurological disorder
33. Postural orthostatic tachycardia syndrome
34. Back problems - Scapula Dyskinesia (weak muscles)
35. aspergers gut problems autoimmune disease (arthritis)
36. They say they don't know what it is as don't accept Armin. They were looking at Autoimmune Disease.
37. Underactive thyroid

38. I.S.
39. Hashimoto's Disease
40. Irregular heartbeat
41. Myositis. I also was diagnosed with fibromyglia until MRI scans showed possible myositis etc.
42. Psittacosis and glandular fever
43. Misdiagnosis Rheumatoid Arthritis
44. Schizophrenia (however, I built my own case and eventually had this dx revoked)
45. Uveitis
46. POTS (and joint hypermobility)
47. Neuro problems /random pain/joint deformity /swelling
48. Eye infection unexplained
49. Post Infection Syndrome
50. Thyroid disease
51. migraine associated vertigo
52. EARLY DIAGNOSIS OF HUNTINGTONS DISEASE
53. MND , Parkinson
54. MGUS
55. Pleurisy pneumonia torn ligaments UTI
56. Postural orthostatic tachycardia syndrome ... EDS
57. My GP would not accept the Dr at A& E diagnose
58. Crohn's Disease (via Australian Gastro I visited)
59. POTS
60. Chiari Malformation
61. Thyroid, arthritis, osteoporosis, EBV,CMV, Coxsackie viruses
62. tremor, memory problems
63. fatigue, weight gain
64. Ptsd. Low blood pressure.
65. Morgellons disease
66. Postural Orthostatic Tachycardia Syndrome, Fibroelastomer in heart awaiting surgery
67. pots syndrome
68. Autism
69. Immune deficiencies - IgA, IgG subgroups, b cell deficiency, mannose binding lectin deficiency; Chronic daily migraine
70. Adrenal insufficiency
71. Epstein Barr, Coeliac and Hashimotos
72. Coeliac disease, query lupus (SLE)
73. POTS, autoimmune thyroiditis
74. Probable primary biliary cirrhosis, hypothyroidism which is Hashimotos, too many brain lesions for my age, demodex infestation and an enlarged spleen.
75. I have since argued these two diagnosis above- 1.5 years after my Lyme diagnosis, I was still feeling poorly (given 6 weeks antibiotics at acute stage), ID consultant tried to argue that my Lyme was now ME and I also had depression. I have subsequently proved these two diagnosis wrong, so they do not currently stand as diagnosis for me. (But are in my records incorrectly!)
76. leaky gut syndrome
77. Kept being told I had ME before positive Lymes test but didn't!
78. Autistic Spectrum Disorder, Cytomegalovirus
79. Cancer
80. RSD/Chronic Neuropathic Pain
81. Fictitious and factitious illness and paranoia (false accusations!)
82. Myxoedema, non articular arthritis, sleep apnoea, Pompholyx, golfers elbows, bursitis of hips, impingement of both shoulders, palpitations, herpes simplex of back of thigh, fluid on the knees, asthma, vitamin d deficiency, osteoporosis, Restless body syndrome
83. Hashimotos Thyroiditis
84. Post-lymes Syndrome.
85. Angina, Allodynia, Arthritis, Autoimmune, Diverticular,

86. Arthritis
87. autonomic heart failure
88. GERD. Tinnitus
89. Hypothyroidism, tendinitis, hypertension, palpitations
90. Neuropathy
91. DID
92. SLE
93. Chronic migraine
94. Hashimoto's thyroiditis
95. Gout
96. Connective Tissue Disease
97. Interstitial cystitis; vitelliform pattern dystrophy of the retina.
98. Hypothyroidism
99. Hypothyroidism
100. EDS. POTS. Dysautonomia
101. POTS, Gastroparesis, Pelvic Floor Myalgia, PANS, Sarcoidosis, Sleep Apnea
102. Psoriatic Arthritis
103. Motor neuron disease. Parkinson epilepsy
104. Peripheral neuropathy, heart arrhythmias, left eye problems, sleep problems, sensitivities to sun, intolerances of many foods
105. Ehlers Danlos Syndrome, Aortic valve leak, Postural Orthostatic Tachycardia, depression, anxiety, chronic fatigue, IBS
106. POTS
107. Hashimoto
108. Migraines, Insomnia, Tremors, Floaters, Pain that travels, Rage, Memory Issues, Rheumatoid Arthritis, hip dysplasia, hypoglycemic, hypothyroidism, hormones deficiency, vit D insufficiency, electrical stabbing pains, stiff neck and severe back pain, neurological issues, thinking and concentration issues, fingers and hands tingle and go numb, digestion issues, candida, jaw clenching while sleeping, sleep disturbance, chronic pain and chronic fatigue.
109. Cirrhosis of Liver
110. Coeliac disease, fowlers syndrome/dysfunctional bladder, interstitial cystitis
111. Pris traumatisk stress symptom.
112. ALS
113. Diabetic II Polyneuropathy
114. ASD
115. Interstitial cystitis
116. Bladder issues, BCC & frequent infections.
117. Arthritis
118. Alzheimers
119. cartilage damage to joints, bi polar, sleeping disorder, etc.
120. arthritis, various types anaemia
121. This was a diagnosis given many years ago, long before I knew what I was suffering from
122. POTS, Interstitial cystitis, Costochondritis, anaemia, hyperthyroid
123. Orthostatic Tremor, Restless leg syndrome, GERD, Hashimoto's
124. personality disorder
125. Chronic sinusitis; dry eye; enlarged spleen; high serum ferritin and abnormal bloods
126. POTS, Ehlers Danlos, polycystic ovary syndrome, joint hypermobility
127. Tinnitus, short term memory loss, pains in elbows and knee joints, eye sensitivity to light, chronic fatigue, mouth ulcers
128. EDS, POTS, B12 deficiency, folliculitis
129. Chronotropic incompetence and severe autonomic dysfunction
130. Mitral valve prolapse, s node arrhythmia, available node arrhythmia, hypothyroidism, hypoglycaemia, angina, hyper and hypo tension...varies...same with bradycardia and tachycardia.
131. still left in limbo waiting with no answers
132. Stress

133. ulcerative colitis, reactive hypoglycaemia, chronic vestibular migraine, probable MCAS, EDS-III, 'tendency to POTS', chronic trochanteric bursitis, iron deficiency anaemia
134. Vestibular migraine
135. Epilepsy
136. Hypothyroid, coxsackie virus B
137. Symphysis Pubic Dysfunction, Tendonitis
138. Epilepsy and being heart problems
139. Autoimmune thyroiditis, kidney cancer, tinisitis, er
140. Encephalitis
141. neuropathy / neurodicitus , brain plaquen mithchondria diseases, joint disease, arthritis , sleep apnoea, vertigo high blodd pressure
142. Functional Neurological Disorder
143. hip cartilage damage
144. Undifferential connective tissue disease
145. Folliculitis
146. Joint hypermobilty syndrome and arthritis
147. Lupus
148. Post infectious syndrome / keratitis & episcleritis (rare)
149. POTS, EDS
150. arthritis, gout, gouty arthritis
151. Asperger's Syndrome
152. Heart attack
153. arthritis, premature ageing,
154. Consultant acknowledges history and EM rash but as seriology is negative has not confirmed CURRENT Lyme infection and report to GP infers I am therefore not infected and wasting his valuable time, and theirs too.
155. Post viral fatigue
156. Possible brain tumour, stroke
157. Allergy
158. Cellulitis
159. Arthritis
160. Tinnitus, Depersonalisation, Derealisation
161. Langerhans Cell Histiocytosis
162. Interstitial cystitis, and vitelliform pattern dystrophy of the retina
163. Paladromic arthritis
164. I was offered anti-depressants when I described Lyme pains and other symptoms, so may be they think I'm depressed?
165. Migraine associated vertigo, stress, anxiety, hiatus hernia, hashimotos, urticaria, 'viral' infection (that's what they say when they have no clue!)
166. Previously misdiagnosed as post viral, CFS and ischemic episode of the brain (causing atypical silent chronic migraine)
- Lyme disease was the causative factor so only that is considered on my file
167. autism
168. Pepheral neuropathy, small cell neuropathy, erythmelalgia, HPV SSC - Cancer, neurogenic bowel, bladder, stomach need catheters, TMJ, sjogrens, etc
169. Endometriosis
170. EDS type III, PoTs, IBS,
171. Clinical isolated syndrome (with possibility that it may progress to an MS diagnosis)
172. Colitis and PCOS
173. Mon Neuritis multtipler plus undiagnosed skin rashes and knee problems
174. Erythromelalgia, Restless legs
175. Arthritis, Angina,
176. Hashimotos thyroiditis
177. Hypermobility, arthritis, lupus
178. Interstitial cystitis; vitelliform pattern dystrophy of the retina.
179. EDS, Sinus Arrhythmia, PCOS, Adenomyosis, Endometriosis, Degeneration of disks,
180. osteoarthritis and alepica and pelvic inflammatory disease

181. ALS
182. Insomnia, neuropathy, recurrent HSV infections that take years to suppress on medication, some kind of mast cell/allergic type response to foods and environment that came on after trying to kill Bartonella with herbs. Currently preventing further killing. Have also had repeated yeast outbreaks (oral, skin rashes, thrush) and ongoing GI issues which I think is related but the GI consultant makes no connection. The NHS endo however feels I have systemic yeast issues but can't treat me for this. GP won't treat me for this without an NHS consultant telling her to so am getting no treatment. Also have gastritis diagnosed and NHS endo has diagnosed Bartonella.
183. asthma
184. Costochondritis
185. Arthritis , optic neuritis, plantar fasciitis polyarthralgia, pelvic inflammation disease, lupus, sjroger syndrome , flavivirus, herpes simplex 1&2, bacel cell carcinoma ,
186. Peripheral neuropathy
187. Spastic paraparesis
188. Endometriosis, back pain
189. Functional Neurological Disorder, Hyperchondria disorder!!!! Hashimotos
190. Inflammatory Bowel Disease
191. ACA, Osteoarthritis possibly unrelated to Lyme and anxiety
192. Erythromelalgia
193. Rheumatoid arthritis
194. Polymyalgia Rheumatica, Musculo skeletal disease
195. hypothyroid, asthmatic, central sleep apnoea, SLE
196. hypertension. Osteoarthritis
197. Hypothyroidism
198. back pain
199. Stress
200. MGUS. thyroid Nodules
201. Syncope/Dysautonomia
202. POTS, thyroid problems
203. Chronic vestibular migraine
204. EDS (Hypermobility), MCAS, Asthma/lung fibrosis.
205. Arthritis
206. Partially sighted, iih
207. Poly reactive arthritis
208. tinitus or arthritis
209. Psoriatic arthritis, diabetes