

LYME DISEASE ON THE NHS

CAUDWELL LYME DISEASE CHARITY
PATIENT SURVEY RESULTS 2016

Q9: GP VISITS

IN THE PAST 12 MONTHS, HOW MANY TIMES HAVE YOU BEEN TO YOUR GP?

132 TEXT RESPONSES RECEIVED IN THE "OTHER" BOX

26 respondents reported never going to the GP

106 reported going to the GP more than ten times in the last year

1. Plus plus plus
2. More than 10 times
3. 20
4. Loads of times
5. Gave up seeing him 2 years ago
6. 27 times
7. Phone call most weeks
8. Phone call most weeks
9. I have all but given up with G.P who will not treat me for Lyme. I only use the NHS for repeat prescriptions to manage pain.
10. On average I see nurse once a week and GP once a month
11. 20 ish
12. Possibly more for different symptoms
13. Approx 10+
14. 20+
15. Been in icu for nearly 2 years
16. Too many to count!
17. 30
18. Too numerous to count
19. more
20. Given up on NHS too afraid to visit any specialists any more no longer trust NHS
21. My doctor misdiagnosed pneumonia as a water infection and gave me pills for a water infection!
22. There is no point
23. 20 or more
24. More than 10
25. 48 times
26. Lost count
27. once, because I don't think he has enough of an understanding of the disease.

28. I lose count.
29. TOTAL LYME DISMISSAL HUNTINGTONS DISEASE ONLY
30. over ten I recall, but also various specialists
31. Pointless - cant get an appointment so I go to Breakspear
32. 40++
33. Over 20 times
34. Approx 30-40
35. I see "alternative " practitioner in my Drs clinic so I presume that info gets fed down to her but maybe not? I guess I have given up using what little reserves of energy I have trying to "help" my Dr understand the nature of what am going through. Sometimes I see her while waiting in the clinic and she did say she thought she hadn't seen me and I was all better. She did say to come and see her sometime I guess I don't really see the point. I spent a lot of time in the past sending my Dr research papers re. Lyme spirochetes and many examples of studies and information re. why tests are unreliable etc to be fair to my Dr she did respond and say it was helpful and I was glad at least that she took the time to read them all.
36. They can not do anything.
37. Over 10, couldn't count I've been so many times
38. 0 - see naturopath -Seeing GP pointless as no understanding or appetite to research and understand condition
39. Monthly
40. Very frequently for many things I beli
41. Lost count!
42. Only tel consultation to get sick line for benefits.
43. there nothing they a gp can do for me When i learned in 2010 3 lymes tests from years before were positve Not negative as told by Id in writing 2 tesats And 1 test by gp I gave up going As didnt like there attitude to me .I only go to nurse practioner if have a chest infection
44. 30 to
45. There is no point with regards to Lyme
46. GP has to visit me or telephone appointment as I am bedridden/housebound.
47. I cannot bear how useless they are and use USA doctors when desperate
48. Don't go as much as I used to because I don't get anywhere
49. 30
50. More than 10...
51. Home visits by GP
52. Typo many to state towards the end I was going every other day
53. A lot more than 10
54. lost count
55. At least once a month
56. 40 more or less
57. more than 11
58. Not sure lots of times also loads of consultants
59. Don't bother anymore waste of time !!
60. At least 12
61. Won't go back as they said I will never get well or find out what's up with me
62. 40
63. Loads and loafs
64. Twice a week.
65. At least 20
66. Around 20
67. 12
68. Every month
69. 27

70. I totally gave up
71. Once a week
72. in the past I used to see GP quite a lot, but they didn't do much for me at all. In the end I went privately
73. I opt not to go as refuse to be patronised, dismissed and neglected
74. I see 2 doctors privately and a herbalist
75. No point going, no help with Lyme
76. 15
77. go to Lyme physicians, acupuncture, herbalists, etc.
78. more than once month, for injections and prescriptions. has to be done this way
79. Countless and now have been deducted from their surgery as they feel I am a liability as I have had a PICC line placed in the USA
80. easily over 20
81. At least 12 times
82. 4 appointments and many telephone calls
83. More than ten!
84. Lost count
85. 20+
86. Lost count!! Most weeks!
87. 10+ times in fact, I am sick of going
88. over 12 times
89. More than 12
90. Often telephone consultations.
91. 15
92. Over 100 times
93. >20
94. No point any more, just repeat pain meds
95. 15
96. I won't go to the Doctor's as my GP refuses my non-NHS diagnosis of Lyme Disease and this makes me too anxious to see him. He refuses to treat my Lyme so it seems pointless to go anyway. I trust my LLMD to look after me instead.
97. 20 plus
98. 10 plus
99. Min 10 times but many email exchanges too
100. Mainly because we moved house three years ago and I do not know any of GPs in the practice and secondly there are no regular GPs at practice filled with locum etc
101. At least 12 times
102. 13+ I go every 4 weeks for a checkup plus more if I get an infection in between those.
103. 14
104. Rarely, there is no point the NHS can't help me and they've made that clear
105. I go at least once a month.
106. private practice GP
107. In excess of 20 times but given up don't go there for each problem I'd never leave!
108. I am so sick now, I have to see my GP every 2 weeks for a double appointment. Also been seeing GP nurse twice a week for 4 months.
109. I avoid my GP as they do not accept my Lyme diagnosis and make me feel frustrated and hopeless
110. 50
111. every other week
112. 17
113. probably on 12 occasions, not including antibiotic injections 24 times for assistance via private healthcare.
114. 20

115. 12 times - I have had a year long ear infection that the doctors kept saying wasn't bad enough for treatment. They didn't understand I am immune suppressed. Eventually they referred me to a consultant who said I obviously have an infection and I ended antibiotics so then asked my GP to give me those. Two courses have not worked as the infection is now deep seated. I may now have to have them drained. Had understanding of immune suppression with Lyme been better then I could have got prompt treatment and may not have needed a surgical procedure.
116. I can't remember it's that many times
117. 15
118. Certainly more than 10
119. More than 10
120. I'm mainly bedfast/housebound so have to rely on phone consults with my GP as I can only very rarely attend the surgery
121. more than 10 times but lost count.
122. Over 20
123. No point
124. 20
125. Too many to remember
126. I would go more often, but am unable to access GP as wheelchair user and unable to drive. NHS do not provide home visits for me, even when bedbound.
127. 15 +
128. Weekly
129. At least 12
130. Countless!
131. 19 plus