

LYME DISEASE ON THE NHS

CAUDWELL LYME DISEASE CHARITY

PATIENT SURVEY RESULTS 2016

Q25 PATIENTS' QUESTIONS

PLEASE ENTER YOUR QUESTION HERE.

OPTIONAL FREE TEXT QUESTION. 143 RESPONSES WERE RECEIVED.

DATE AND TIME	PATIENT'S QUESTION
Wednesday, Apr 27th 4:10PM	Been told I am cured but it may come back in ten yrs!!
Wednesday, Apr 27th 2:35PM	I want my quality of life back. I want to be able to enjoy time with my children. I want that back please?????
Wednesday, Apr 27th 2:40PM	So many people are ill and testing positive, how can you deny that Lyme is a serious problem?! How many people may be misdiagnosed?
Wednesday, Apr 27th 2:42PM	can we send our doctors to America or Germany to be ILADS TRAINED.
Sunday, Apr 24th 4:49PM	To the NHS: Why are you using inaccurate, insufficient ELISA testing? Why will you not improve this testing/adopt other testing methods which already exist and are proven more accurate?
Saturday, Apr 23rd 8:52AM	There is so much more to say I could write a book about how strongly I feel. I can't think of a question to ask as I am too upset
Friday, Apr 22nd 3:12PM	Electro sensitivity UK said like in Sweden we need electro pollution free zones wifi can not be used only hard wired. The benefits agency have to recognise both Lyme and electro sensitive as an illness I can get care for someone to look after me at the moment I asked for help with my home and Mail it's been impossible to find some one.
Friday, Apr 22nd 3:12PM	Electro sensitivity UK said like in Sweden
Friday, Apr 15th 4:36AM	I don't ask questions anymore for fear of beration, however I would like to thank John Caudwell and his team, also to wish his family well in their own journey, good luck.
Tuesday, Apr 12th 4:34AM	Why was I only prescribed Doxycycline for one week after seeing my GP with a bulls eye rash all over my body?
Friday, Apr 8th 2:10PM	Why do we not co-operate with other countries doing research into Lyme?
Monday, Apr 4th 11:30AM	Why does the NHS not recognise Lyme disease?
Monday, Apr 4th 4:54AM	Why can Doctors diagnose CFS/ME without positive blood tests but they can't diagnose Lyme without a positive blood test?
Sunday, Apr 3rd 5:10PM	Lyme is a disease so needs to be treated like one. Syphilis can be treated on long term antibiotics so why not Lyme? It's also spirochetes.

Sunday, Apr 3rd 5:13PM	Why is Lyme disease DISMISSED when there is positive serology from accredited labs?
Saturday, Apr 2nd 1:09PM	What is behind all the controversy about this particular disease?
Friday, Apr 1st 4:13PM	Why do good, honest, hard working people get ditched whilst at their lowest point?
Friday, Apr 1st 12:55PM	Also help me get better so I can go home with my family :-)
Friday, Apr 1st 7:53AM	Why do I feel Lyme Disease is not taken seriously?
Saturday, Mar 26th 10:38AM	More information needed regarding treatment options for gps and patients is imperative. Is this beginning to come about as it's hard to see any changes occurring .
Thursday, Mar 24th 11:56AM	no nhs consultant wants to treat my Lyme disease, can you please recommend someone who is not afraid of th gmc, and would treat my Lyme disease?
Tuesday, Mar 15th 5:01PM	Would it please be possible for there to be a GP in every practice who is Lyme aware and will recognise the symptoms as possible Lyme.
Wednesday, Mar 9th 1:49PM	Q15 is ambiguously worded.
Tuesday, Mar 8th 3:10PM	Why do families have to go abroad to get diagnosed? What has happened to the UK being the ones to develop cures? Why the ignorance? Shame on the UK and its professionals and government
Friday, Mar 4th 12:26PM	Why do we have to pay for private testing in Germany because we get a negative result in the UK, we tested positive with armin labs only to find our test results will not be recognised in the UK so no treatment available for us here. WHY.
Wednesday, Mar 2nd 10:02AM	Why is chronic Lyme disease not taken seriously and why are people left to suffer horribly?
Tuesday, Mar 1st 5:17AM	NHS help is urgently needed to stop misdiagnosis, when will this happen ?
Monday, Feb 29th 6:35PM	Will there be more research into congenital cases of Lyme
Monday, Feb 29th 1:35PM	When will the NHS realise the horror of this disease and help us?
Monday, Feb 29th 11:07AM	Why is it that doctors are so against helping people who think they may have Lyme disease?
Sunday, Feb 28th 3:12PM	I want to see an awareness campaign on the scale of the aids campaign. Its outrageous that this devastating disease is still largely being ignored & that very ill patients are being forced to actively bring about awareness & change. Can you please tell me when you are going to step up & take on this responsibility from the poor suffering patients & their families & raise awareness of this dreadful disease yourselves?
Sunday, Feb 28th 3:03PM	When will the NHS become fully funded to treat Chronic patients the same way HIV and Cancer patients are treated. Both long term illnesses.
Sunday, Feb 28th 2:53AM	Surely it is cheaper to diagnose and treat Lyme at the outset rather than leave it until a multiple consultants are required to treat all the symptoms arising from untreated Lyme disease?
Saturday, Feb 27th 9:57AM	Why do doctors in the UK get struck off when prescribing long term antibiotics for Lyme patients?
Friday, Feb 26th 10:40PM	WHY, DESPITE ALL THE EVIDENCE IS LYME DISEASE STILL NOT ACKNOWLEDGED/TREATED ADEQUATELY IN THE UK
Friday, Feb 26th 7:44PM	Is it possible for Britain to lead the way in finding a cure and raising proper awareness to control Lyme Disease?

Friday, Feb 26th 7:59AM	Do you know of a Lyme literate doctor in the uk? I'm desperate and would pay.
Thursday, Feb 25th 1:14PM	Britain used to be a driving force in medical science, why are we so far behind other countries with regards to Lyme Disease?
Thursday, Feb 25th 1:20AM	Why can't the UK lead the way in Lyme Disease research and treatment?
Tuesday, Feb 23rd 11:09AM	The above statement really says it all - I understand John C and I share the same consultant? (Prof P)
Tuesday, Feb 23rd 9:27AM	An average lyme patient in the UK knows much more about the illness than most medical professionals; could they please start to listen to the patients? Oral generic antibiotics (long term if necessary) taken at home are cheap and effective to getting better, why is this not done?
Tuesday, Feb 23rd 10:51AM	The above statement really says it all - I understand John C and I share the same consultant? (Prof P)
Monday, Feb 22nd 7:25AM	Why is Porton Down controlling the lyme 'test' and the lyme debate? Why are these scientists who are security services trained involved in controlling our health and recovery? Where are the trained medical doctors?
Monday, Feb 22nd 9:29AM	Why was are we not taken seriously ! By NHS
Friday, Feb 19th 7:44AM	It is common knowledge the UK Lyme test is wholly unreliable. With this in mind when will you develop a Lyme test sufficient enough to be depended on?
Thursday, Feb 18th 9:28AM	Why despite using a test kit that is known to be highly unreliable have you continued to not only use it but refute the claim that a patient who has symptoms can not have Lyme after a negative test result???
Thursday, Feb 18th 8:40AM	The NHS has consistantly let me down. In the last 12 months, I have not used the NHS much, but in the early years of the disease I was in and out of hospital regularly, seen by neurologists privately and on the NHS regularly, seen by psychologists, and all failed to diagnose Lyme until I finally showed them a bullseye rash. Then I got 28 days of Doxy, which was useless, and then ignored again.
Thursday, Feb 18th 3:39AM	Every illness should be treated .
Thursday, Feb 18th 3:20AM	They do not believe me
Wednesday, Feb 17th 8:23AM	WHEN IS PORTON DOWN GOING TO PROVIDE THE BEST TESTS FOR LYME
Tuesday, Feb 16th 8:40PM	Why was I put on wrong drug for 8 years, despite protests. Will the NHS ever acknowledge their omission, let alone apologise?
Monday, Feb 15th 7:25PM	I live in a tourist area locally it is felt that Lyme is deliberately covered up as it is feared that tourist trade will be affected. I would like to think that one day nhs will apologise and compensate those who have found their lives ruined by Drs burying their heads in the sand
Sunday, Feb 14th 5:34PM	When are you going to listen to people suffering and not textbooks or people who have studied them ?,
Saturday, Feb 13th 7:00PM	At the Infectious Disease Unit I was referred to St George's Tooting I was told they have no specialism in Lyme Disease and yet it's the closest IDU to the royal parks (Richmond and Bushey). Also told that they are seeing people (like me) with symptoms, negative NHS test and por
Saturday, Feb 13th 7:49AM	Why are kids with Lyme given SSRIs when these have been shown to exacerbate symptoms?
Saturday, Feb 13th 5:14AM	I cannot afford a specialised clinic in the UK or abroad to get treated, where do I go now that my GP has run out of knowledge and/or his hands are tied by the NHS?

Saturday, Feb 13th 2:38AM	Why is the NHS still using such a flawed Lyme test?
Friday, Feb 12th 6:27PM	Why must we suffer from a man made disease????
Friday, Feb 12th 5:23PM	Why has lyme disease been ignored fo so long, and why have doctors that have taken an interest in treating it been hounded and hauled in front of the gmc to talk to panels that don't listen.
Friday, Feb 12th 6:05PM	Why are there so few doctors in the UK that know enough about Lyme Disease and fully understand and believe the life changing effects it ha on lives ?
Friday, Feb 12th 4:32PM	Why do the nhs say it's easy to cure
Friday, Feb 12th 4:33PM	will i live to be helped ; to be supported to be taken seriously
Friday, Feb 12th 4:19PM	What year did you become ill? (I've noticed locally a number of people became ill with the same symptoms the same year as myself - 1987)
Friday, Feb 12th 3:16PM	Is the NHS able to extract its head from up its own arse?
Friday, Feb 12th 2:42PM	Please can you tell me what you are doing to getting better testing and treatment for suffers
Friday, Feb 12th 2:16PM	Why is nothing being done for Lyme patients, why are we left to suffer alone
Friday, Feb 12th 10:52AM	Why do you ignore all the information published by recognised medical practitioners regarding Lyme and associated disorders?
Friday, Feb 12th 10:31AM	My children have also been diagnosed with Lyme Disease contracted in utero, I would like to know what the NHS is going to do to help them?
Friday, Feb 12th 9:50AM	Why is public health eerily quiet on the subject of Lyme disease?
Friday, Feb 12th 8:18AM	will I have to beg for help when this disease returns after my antibiotic wear off,even though I've never felt better with any course as it isn't enough to do a though job!
Friday, Feb 12th 5:44AM	Why are blood samples taken and then not run?
Friday, Feb 12th 5:39AM	why are the nhs not taking this disease seriously
Friday, Feb 12th 2:41AM	Why are you ignoring so many people? In the long run it could save the government money not having to support people with benefits and also save the NHS by not having to treat people for the rest of their lives for undiagnosed Lyme.
Friday, Feb 12th 12:59AM	What is the UK government going to do to stop our suffering?
Thursday, Feb 11th 5:10PM	I can't think of a question, except to ask why the denial of all the antigen-based testing methods (microscopy, culture etc)
Thursday, Feb 11th 5:29PM	When will funding start on research & new blood diagnosing trsts?
Thursday, Feb 11th 11:21AM	When will the NHS wake up to this plague?
Thursday, Feb 11th 11:23AM	Can you help lyme disease research, awareness, treatment, education and create free clinics worldwide with accurate testing and proper treatment and support?
Thursday, Feb 11th 11:05AM	Why are you so resistnt to using or developing a more sensitive test?
Thursday, Feb 11th 10:37AM	Why don't the nhs just act on the rash, if it's there ? If you have a chicken pox rash you don't need a blood test to diagnose it. It's just like that for Lyme disease surely!!!!
Thursday, Feb 11th 10:23AM	Why can't doctors treat patients? Just why do we have to suffer?
Thursday, Feb 11th 10:06AM	I have a rare heath condtion now because of lyme and can not eat or drink anyone without medicine

Thursday, Feb 11th 9:30AM	HPE and the former HPA should be made accountable for those results that were a positive and left too many unmanaged or treated. Why do they still allow invalid testing to continue or accept a Em/sx as suffice to start treatment immediately
Thursday, Feb 11th 9:33AM	thank you
Wednesday, Feb 10th 3:44AM	Don't have one but I sincerely hope this survey will help in some way
Tuesday, Feb 9th 7:22PM	When will the nhs provide adequate training to gps to recognise the symptoms of Lyme disease ?
Tuesday, Feb 9th 4:38PM	Why have I been refused a clinical diagnosis by the NHS based on my EM rash and multi systemic medical history?
Tuesday, Feb 9th 6:00AM	Why can't the NHS accept that we have a growing epidemic emerging in the UK?
Monday, Feb 8th 7:09AM	How can what is supposedly one of the world's best health care systems be allowing sick people to get even sicker?
Monday, Feb 8th 10:11AM	How do the NHS plan to change the and suffering that patients with Lyme disease (knowingly or not knowingly) currently face?
Monday, Feb 8th 7:45AM	Not a question but a statement - i do hope that any media about lyme is balanced and not making broad sensational claims that its' the cause of every single ailment.
Saturday, Feb 6th 1:56PM	Why have there been no further double-blinded controlled trials of antibiotic treatment for tick-borne infections in the last 20 years?
Saturday, Feb 6th 12:32PM	A proper care plan needs to be initiated into the NHS for those presenting Lyme symptoms, how soon will it be before the NHS understand that this country has a high incident level of Lyme that seems to be at epidemic proportions
Saturday, Feb 6th 7:28AM	Why leave patients ill when it must be more cost effective to ensure correct treatments?
Saturday, Feb 6th 5:50AM	Why is the NHS/HPA/NICE guidelines so polarised when there is so much evidence going back to the 80s that it can be tricky to treat and the current antibody testing is poor?
Saturday, Feb 6th 2:38AM	Why do we need to go through all this misery without any help from NHS??
Friday, Feb 5th 2:44PM	How many people with ME (umbrella term of symptoms!) also have lyme?
Friday, Feb 5th 3:12PM	Why are we losing our LLMD's ? We are self treating !!!
Friday, Feb 5th 1:45PM	The Virastripe instructions (pg3/6) say a test results is recorded as POSITIVE, EQUIVOCAL or NEGATIVE; why do RIPL record patient tests as "INHIBITORY"? http://www.viramed.de/images/stories/pdf/Arbeitsanleitungen_EN/2550_Borrelia_ViraStripe_IgG_AL_en.pdf
Friday, Feb 5th 1:41PM	Why is this mass murder allowed to continue? Can you imagine that someone whit Lyme would have a serious cancer than Lyme disease.
Friday, Feb 5th 9:05AM	I'm very grateful that you're working hard to change the situation. I'm so tired now I can't think of anything else.
Friday, Feb 5th 1:11PM	Why hasn't thorough research been carried out on patients who know that their Lyme has been under treated? Why hasn't a physiological research study been done, I know many medical personnel who have had to fight to get treatment and could offer invaluable insight into the effects of this disease and the impact of being told they are treated when they know that they are still not clear.
Friday, Feb 5th 1:04PM	thank you,x,x,x,

Friday, Feb 5th 11:42AM	When will the NHS begin treating Lyme patients appropriately? If I had a diagnosis of cancer you would treat me even if you knew that you might not be able to cure me!
Friday, Feb 5th 12:43PM	When will this epidemic be recognised?
Friday, Feb 5th 12:24PM	Can the NHS afford to properly diagnose and treat Lyme?
Friday, Feb 5th 12:32PM	Why, after so many years, are we still blaming a patient for the illness that suffer?
Friday, Feb 5th 12:33PM	Whaaaaaaat
Friday, Feb 5th 11:09AM	When will the NHS wake up to the vital role of nutrition in all this?
Friday, Feb 5th 12:09PM	Why does there seem to be a denial of this disease's existence and severity by the NHS?
Friday, Feb 5th 11:29AM	Why are we being treated as second class citizens, we have no future with Lyme Disease, until the NHS and PHE get to grips with the real problem, it would not surprise me that Lyme is the major disease here in the UK for many useless diagnosis
Friday, Feb 5th 11:03AM	This is a question my then ten year old son asked about the NHS, prior to starting (private) treatment and when he was extremely ill: " Why are they just leaving me? Why won't they help me? Why don't they do something? I don't want to carry on if it means living and feeling like this all the time"
Friday, Feb 5th 10:24AM	What percentage of ticks in the UK carry each strain of borrelia and which of these strains are currently tested for in England and Scotland.
Friday, Feb 5th 10:05AM	For the Prime Minister: when it emerges that the NHS has neglected to treat people with this serious and debilitating disease, do you want to be the Prime Minister condemned by history for this negligence and discrimination, or the one that confronted it and saved the lives of thousands?
Friday, Feb 5th 10:13AM	Why did the Lyme clinic close after 6 months? Why did Dr. Dryden deny Lyme after positive testing? Why is Bartonella not tested??
Friday, Feb 5th 8:48AM	Please can we have a copy of our survey data as it wouldn't let me copy & paste my answers
Friday, Feb 5th 9:30AM	Why not accept test results patients already have from reputable labs? Why must all uk test go via a military base that sends all results back neg?? Too much similarity with a Stephen King or Nazi regimen!
Friday, Feb 5th 8:27AM	Why is the 2 tier test still clung to, when BMJ Dec 2015 issue acknowledged it is not accurate? Why is there so much bad press against Igenex & Armin Lab Lyme tests, without proof backing up the claims that they are not accurate?
Friday, Feb 5th 8:51AM	Once active, healthy and ambitious people who contributed to society have been left to rot in a life of prolonged suffering and pain, all because of an encounter with an insect in the outdoors. When will the NHS realise the extent of the damage done to those individuals and the extent of burden placed on the health service by ignoring the cause of many illnesses? I want to know how in 2016 the NHS plans to look at the available scientific studies and literature to make better informed decisions?
Friday, Feb 5th 9:14AM	What research is the government currently doing into Lyme disease?
Friday, Feb 5th 9:02AM	What research is the government currently doing into Lyme disease?

Friday, Feb 5th 8:54AM	How can you be sure that Borrelia does not cause chronic lyme disease when so many patients are testifying the same issues?
Friday, Feb 5th 8:42AM	Why is the MRC doing a witch hunt against the few Drs who try to help us?
Friday, Feb 5th 8:25AM	? I can't remember what sort of question you are expecting here. My general question is "Why did no one tell the public about Lyme in 1993, after the NATO meeting at St George's hospital?" and of course, the main question is "Who are the ultimate decision makers in this. The Health and safety executive are the ones who paid for the research, much of it, that was shown at the 1993 meeting, and I wonder, are they the ultimate decision makers in this process of denial?"
Friday, Feb 5th 8:33AM	Why is PHE failing in its remit to ensure doctors, Health Authorities are trained/made aware.
Friday, Feb 5th 8:34AM	Survey lacks detail. eg - many A and E visits over 10 years, just not in last 12 months.
Friday, Feb 5th 4:55AM	PHE keep saying foreign blood tests have not been validated. Why don't we get on and validate them so we can work with those results?
Friday, Feb 5th 7:52AM	Why does the NHS continue to deny the possibility that Lyme disease may need more than 2 weeks of antibiotics if symptoms persist, they do not do this with any other illness?
Friday, Feb 5th 7:13AM	Private overseas tests are recognised by the NHS for other illnesses or conditions, why not Lyme disease?
Friday, Feb 5th 7:16AM	Please go with an open mind and listen to your patients !
Friday, Feb 5th 5:44AM	After private diagnosis with Lyme there is no advice available as to what protocol to try. I find the Lyme UK Facebook page very hard to get into, certainly in terms of a self treatment protocol for a low budget patient
Friday, Feb 5th 6:48AM	Why can the nhs prescribe long term antibiotics for acne and not a life threatening bacterial disease?
Friday, Feb 5th 6:06AM	Why do many thousands of patients with Lyme find our symptoms improve on antibiotic treatment and decline when treatment stops - this can not all be dismissed as placebo effect nor can it be dismissed as anti inflammatory effect. It needs to be studied and reasons found as to why inflammation is so frequently found in these patients by often visible signs.
Friday, Feb 5th 5:37AM	Will there be a cure for this disease?
Friday, Feb 5th 5:48AM	3 of us in my family have Lyme. We all have Lyme specific symptoms and have all had a Lyme specific rash. Why have we all been pushed aside by the NHS?
Friday, Feb 5th 5:04AM	How can I contribute to the Caudwell charity? How can I support with my research data.
Friday, Feb 5th 4:58AM	Why when you realise how serious Ebola and the Zika virus is and the ways it is transmitted, you don't do the same with. Lyme.
Friday, Feb 5th 4:58AM	Why when you realise how serious Ebola and the Zika virus is and the ways it is transmitted, you don't do the same with. Lyme.
Friday, Feb 5th 4:48AM	Successive governments and medical establishment have continually ignored the situation, and we would like to know for what purpose?
Friday, Feb 5th 5:15AM	Why has Lyme from Stone Age man all of a sudden from the 1950 onward evolved or been developed to the devastating multi form versions it is today.

Friday, Feb 5th 5:09AM	Would the NHS accept Armin labs tests?
Friday, Feb 5th 5:02AM	why do the NHS insist on using a test that is so unreliable?
Friday, Feb 5th 5:06AM	Susan