LYME DISEASE ON THE NHS

CAUDWELL LYME DISEASE CHARITY

PATIENT SURVEY RESULTS 2016

Q24 PATIENTS’ REQUESTS REGARDING THE NHS

WHAT DO YOU WANT THE NHS TO DO TO HELP PEOPLE WITH LYME DISEASE?

FREE TEXT QUESTION.

440 ANSWERS WERE RECEIVED.

DATE AND TIME	COMMENTS
Wednesday, Apr 27th 3:25PM	The NHS has tested me repeatedly for anaemia, thyroid function, arthritis, and also for ankylosing spondylitis, but never for Lyme, even when I suggested it. Could it please just be considered rather than ignored?!
Wednesday, Apr 27th 3:50PM	Start listening and believing. Begin acting on information heard. Stop wasting money on unnecessary tests and treatments. Listen to other countries and follow their examples
Wednesday, Apr 27th 3:47PM	I'm lucky to be able to pay privately, but others may not be able to & I shouldn't have to either.
	GP's need to step back from their deeply rooted arrogance & understand they do not know everything, and stop patronising us by asserting we are imagining symptoms & opening their closed minds.
Wednesday, Apr 27th 3:19PM	I would like them to acknowledge Armin Labs as a valid test so patients can get on with their treatment.
Wednesday, Apr 27th 3:01PM	Use ILADS guidelines.
	Change testing as ELISA and Western Blot totally unreliable
	Make claiming benefits easier.
	Lastly stop leaving people to rot and die through this awful disease.
Wednesday, Apr 27th 3:02PM	Adequate testing, belief in chronic Lyme, care and compassion, please.
Wednesday, Apr 27th 2:35PM	I want recognition that Lymes is real
	I want NHS to realise this won't go away, more and more research and training needs to be given to NHS to help patients.
	Proactive and take ownership to help people with a quality of life.
	Give support and counselling for family members to understand how it is for a Lymes sufferer
Wednesday, Apr 27th 2:40PM	Use accurate testing correctly, know more about Lyme disease and co infections, accept other recognised test results, support patients emotionally (I've been dismissed by doctors a lot), supply long term antibiotics, GPs need to be less condescending/judgemental!
Wednesday, Apr 27th 2:42PM	Proper testing... Ltt elispot for chronic lyme with cd57. Proper thyroid testing for low T4... not just tsh. A general understanding not to be swept under the table because gp does not have any knowledge there fore dismisses you.
Wednesday, Apr 27th 2:39PM	Find a proper treatment that work. More doctors to understand and recognize Lyme disease

Wednesday, Apr 27th 2:11PM	I would prefer it if the NHS took a holiday from Lyme disease for the next 10 years or so and let some other competent organisation deal with it, because so far the NHS has been worse than useless. The NHS has been harmful and neglectful. It has done nothing good.
	One simple improvement the NHS could make is this-
	Understand that taking antibiotics for a few weeks does not automatically magically cure Lyme. There is an horrible, illogical, unscientific attitude that is very common in the NHS, which goes as follows: the patient has taken antibiotics, so the Lyme can't possibly remain.
	The NHS should go on the waiting list for a brain transplant.
Wednesday, Apr 27th 2:23PM	Hey you stupid guys, its your job to make people better so why aren't you doing it?
Tuesday, Apr 26th 2:33PM	Find an accurate test for lyme and co infections
	Research trials for effective treatments
	Listen to patients and treat us as a whole person
Tuesday, Apr 26th 1:49PM	Listen to patients when they say they may have Lyme. Listen to patients who say two weeks antibiotics doesn't cure them. Listen to patients who say your treatment guidelines are wrong. Treat us with respect.
Sunday, Apr 24th 4:49PM	Sufficient testing for Lyme disease, sufficient testing for co-infections, sufficient psychological support (such as CBT, mindfulness, etc), sufficient referrals (such as to neurologists, cardiologists, occupational therapists). This disease should be diagnosed by clinical findings, NOT just diagnostic findings: a lung infection would not require a diagnostic test, nor would a UTI, nor would a sinus infection - so why is testing so heavily relied upon for Lyme? I believe the answer to this is that doctors do not understand the disease and all its symptoms, and therefore are under-confident to diagnose it. They are therefore reliant on ELISA testing which is entirely inaccurate and unreliable. This disease needs to be treated with urgency upon discovery, and it needs to be treated correctly upon discovery.
Saturday, Apr 23rd 8:52AM	I want them to recognise Lymes Disease and to put forward more advanced tests to be done on the NHS and to have Doctors in England who specialise in this field instead of going abroad to find help.If I do have Lymes disease and other people in England have this it should be made free on the NHS with the same treatment you have to go abroad for.I feel very very strongly about this issue as I also know someone who has lost his job,life savings to try and go abroad to get help.This country has let people down in a very big way for all the people suffering with Lyme Disease and I and many others struggle with this problem every single day.
Saturday, Apr 23rd 3:28AM	Be open minded and aware of lymes. Not be dismissive. It is soul destroying when you have a GP shout at you and phone you up at home to shout at you. To be told there is nothing the medical profession can do is awful when you know that you don't feel well. To provide testing that is accurate and recognise the American and German test results.
Friday, Apr 22nd 9:08PM	we need testing accurately in UK on nhs for Co infections western blot for Lyme.
	doctors need to be given updated info that shows them how to treat and help patients; Dr horowitz has written done many recent 2016 research on Lyme and Co infections he treats people all over the world and written many papers that it should be a new law the follow up and learn about not from the 1950s the nhs guidelines are based by doctors need to stop dismissing patients with real.problems and giving them anti depressed pills when there clearly suffering because of the disease lyme and yes the pain makes you feel down but this needs treating via the co infections as we dont want to be left in our bedrooms for days due to being so sick!
	**I want them to treat with effective treatment and treat Co infections also do better blood testing in UK western blot I don't want to die but I cannot afford private I've spent all money I had on natural remedies
	we need nhs to provide lyme literate specialists at nhs that test Co infection and is trained to treat them or at least all doctors receive document by Dr horowitz how to cure lyme disease what to look out for how to treat diognose Co infections from lyme ASAP
Friday, Apr 22nd 3:12PM	What I want the NHS to do is to proved use with safe houses and treatment for Lyme Disease.
	Because I am too ill to clean my home sufficiently well.
	This needs specialist teams.
	To clean the home and spray both inside and outside the immediate area as they do in the US.

	I had 50ft tree on council own propity just feet away.
	Vegetation is supposed to be kept short. Also electro pollution needs to be removed as this increases problems . But councils and the government have not a clue.
	Industry know but they are making money.
Sunday, Apr 17th 4:45PM	A reliable test, a GP that will listen and consider and an open mind to advancement in medical science in terms of diagnosis and treatment.
Sunday, Apr 17th 4:34AM	1. Provide adequate and up-to-date testing and diagnosis
	2. Provide effective treatments
Friday, Apr 15th 4:36AM	Get up to spec with the blood tests, conduct more research into zoonotic infections, prescribe antibiotics until something else is discovered and stop the denial which in the long run is costing British tax payers countless sums which would be better used elsewhere.
Tuesday, Apr 12th 4:34AM	It would be far more helpful for GP's to retrace previous appointments/symptoms etc At my practice they do not I have to retell everything maybe they would have realised I had Lyme Disease sooner considering I had a bullseye rash. I was instead told I had work related stress, anxiety.
	Also I found that my two appointments at the Infectious Diseases Dept in Sheffield (which is quite far from my home town of Brighouse)to be unhelpful. I was informed that the live bacteria in my body must be dead and no longer making me unwell as I had already been treated with a couple of short courses of antibiotics. They recommended that I take Ibuprofen for the pain in my joints. 2 Years on and I feel like I am constantly at the doctors-they have mentioned the possibility of Fibromyalgia but have again tested me for thyroid and diabetes to rule this out again (my results for these came back normal again)I am deficient in vitamin D and awaiting another appointment with another GP to discuss where to go from here as I have flares that resmeble MS. Not one GP has mentioned the possibiliy of it being Lyme Disease even though I tested positive in 2013.
	Are my symptoms caused by Lyme Disease?
Monday, Apr 11th 8:39AM	More research, better testing, better education of all NHS staff that not everyone has a bite and see's it so takes antibiotics late and that's where problems arise. Too many paeople think have bite, get treated and recover. It's not like that. We also need consultants who understand the disease. I feel lost and unsupported.
Sunday, Apr 10th 4:15PM	If Lyme disease is endemic as suggested then we should have specialist clinics in ALL areas of the Uk to cope with the multiple problems we have. We should not have to spend our lives running around the world and paying out of pocket having worked and paid in to the NHS all our lives for what appears to be everyone elses benefit. We need hollistic treatments including hyperthermia, IV Meyers Cocktails, IV ozone, HBOT, heavy metal detox plus fully trained herbalists. You have NOTHING to offer any of us at all except mental health services and well thats it isnt it ?
Sunday, Apr 10th 3:55AM	Be more Lyme aware,so many Professionals dont have a clue and say so.
	Take symptoms seriously,no one and certainly not me wants to feel this way on a daily basis.We want a normal life where symptons can be controlled.
Saturday, Apr 9th 8:10AM	1. Awareness and understanding of acute and chronic Lyme disease, particularly within primary care. This should be incorporated into GP training.
	2. Accurate testing for Lyme disease in primary care.
	3. Understanding of the association between Lyme and other co-morbidities (CFS, Fibromyalgia etc).
	4. Treatment for acute and chronic Lyme via antibiotics (intravenous and oral).
	5. Awareness of private treatment and treatment options outside UK.
Friday, Apr 8th 3:38PM	To develop and/or acquire more accurate tests to detect borrelia in the early stages. Also, to improve treatment offer for early, or chronic stages.
Friday, Apr 8th 2:10PM	Recognise test results that indicate Lyme infection. Be prepared to treat extensively using proven protocols from other countries. Agree with Nice to use other drugs as appropriate outside the normal antibiotics allowed by Nice for general use.
Wednesday, Apr 6th 3:41PM	To recognise private blood tests but also be able to correct the NHS test so they can pick up Lyme disease and then treat the patient with nessasary treatment.

Monday, Apr 4th 11:30AM	I would like the NHS firstly to acknowledge Lyme disease is a serious debilitating Issue throughout the Whole world, Also I would like the NHS to train G.P.'s in dealing with all aspects of Lyme disease, including all of its co-infections and train G.P's to recognise Lyme disease and symptoms.Also I would like to see the NHS create a Protocol to treat Lyme disease and its co-infections.Neurologists Should follow up test results and Infectious disease clinics, instead of just fobbing people off and sending them home without any further testing or treatment, also Neurologists should be better trained in Lyme disease and stop believing that it doesn't happen in the UK!! Cardiologists also need t have more training in Lyme disease symptoms, also Immunologists need t b aware of Symptoms of Lyme Disease, also Optholmologists need more training in Lyme disease, infact just about every specialist needs t b retrained in dealing with Lyme disease, it appears that its only the younger doctors have any knowledge of Lyme disease in the Uk, the older doctors do not wish to recognise that it exists in the UK.
	Also I would like to see the NHS bring Awareness of Lyme disease to the public ie. Notice boards in G.P surgeries,Hospitals,Schools,Colleges,Universities, offices, workplaces, parks and gardens, councils, school camps, scout groups, brownies groups etc. athletics groups/sports groups, ramblers groups, any groups that spend time outdoors, veterinary surgeries, holiday brochures(particularly countryside holidays)Pet owners, Farmers, Zoo keepers.Anyone that works with animals
Monday, Apr 4th 10:54AM	Treat them properly, with respect. Listen, the doctors never listen. I am tired of GP's acting like I have mental problems. I am constantly told my symptoms are psycho-somatic or from stress.
	My symptoms are real, and horrible.
	Look into all the research done into Lyme. Look at Germany and USA and how they treat it. It needs intensive and prolonged treatment.
Monday, Apr 4th 4:54AM	Improve testing, educate GP's & ID/RA consultants. Set up clinics for Lyme & Co infections
Sunday, Apr 3rd 5:10PM	Develop accurate tests!
	Research properly how to treat it
	Change the infectious disease guidelines! To recognise various stages eg early/late stage and treat appropriately
	Train doctors to spot it and be suspicious of nothing showing in blood tests for sick people cfs/me. Also teach them at medical school while training as a Doctor.
Sunday, Apr 3rd 5:13PM	New testing procedure with greater accuracy.
	Awareness for GPS to look for symptoms with out the need for the bulls eye rash as a diagnosis.
	Create research into disease and co infections.
	Look at link to other illnesses I.e MS, Parkinson's etc. Do own research to back up Dr Alan Mc Donald. WHY HAS THIS BEEN DISMISSED?
	Develop Lyme centre with ongoing research within UK and help people out of this missery.
	Look into the obvious cover ups surrounding Lyme and forget the past but embrassed the future.
	Work with other countries to provide greater knowledge and treatment.
	BELIEVE US. PLEASE. This has taken so much from me I want my life back and as a 28year old Husband and father of a 2 and 4 year old I want to work and provide and make them proud again.
	Please change the guidelines and stop people profiting on the I'll. Where's our duty of care and human rights?
	Where humans with families who deserve a better chance.
Sunday, Apr 3rd 3:08PM	GP's should be more aware of this disease.
Sunday, Apr 3rd 8:23AM	More accurate testing
	Not be ignorant that this disease is rife in the uk
Saturday, Apr 2nd 1:09PM	Stop lying about this disease would be a start. It is easy to catch and very difficult to treat, unless it is caught very early.
	I have had Lyme Borreliosis for 20 yrs and, together with my Endocrinologist husband have studied the disease for 20 yrs. I am sick and tired of the ignorance of medics in the UK who have either learned nothing in the last 20 yrs, or who have been told to learn nothing.

	Who gives a Politician the right to dictate Medical Policy? The Electorate certainly don't. Why do we slavishly follow USA IDSA guidelines, when they are clearly outdated and incorrect? Why are so many lies told about this particular disease. What is being kept hidden?
	I want the NHS to stop denying this disease, and start treating patients Clinically, NOT by a set of rules devised by Politicians. I would like to see the NHS totally divorced from Government, as Politicians are absolutely not fit for purpose. The NHS should be run by Medics alone.
Saturday, Apr 2nd 4:27AM	Accept chronic Lyme disease exists and change the recommended protocol so GPs can prescribe what is needed. Have compassion for Lyme sufferers!
Saturday, Apr 2nd 3:51AM	Develop better testing, develop treatment for chronic Lyme and all those who missed the acute stage from poor diagnosis.
Saturday, Apr 2nd 3:16AM	Listen to the patient and not presume the patient is a hypochondriac and knows nothing about their own body
Friday, Apr 1st 4:13PM	I want the NHS to listen. Try and understand what hell we are going through and stop treating us like we are insane and emotionally unstable. We're the intelligent ones. We know our own bodies. They should treat us like they care.
Friday, Apr 1st 12:55PM	Treat them
Friday, Apr 1st 12:12PM	Firstly, use a more accurate test and do not dismiss patients who complain of multiple ailments as making them up, or imagining them. Lyme should be taken seriously by the medical profession as the longer it is undiagnosed the more serious it becomes and the more costly it is to treat. UK citizens pay taxes to the NHS to receive appropriate treatment for their illnesses, not to be ignored and dismissed.
Friday, Apr 1st 7:53AM	I'd like the NHS to take the disease more seriously and to undertake more research to, at best, find a cure and at worst develop a protocol for treating the various symptoms.
	I try not to visit the GP now as all she offers is stronger dose pain relief but these affect my brain and I can't cope at work with a brain that is not functioning fully!
Thursday, Mar 31st 1:30PM	Agree on a treatment program. Training for GPs. Don't discriminate against young people saying it's just they're age being tired!! Information and after care provision.
Wednesday, Mar 30th 4:59PM	Listen to patients. Trying to save money at point of diagnosis is short sighted.
Wednesday, Mar 30th 3:55PM	The NHS needs to stop being selective about what health conditions it treats. I already have to manage non-standard hypothyroidism and buy my own meds. I now have to consult with a private doctor re Lyme disease and pay for my own meds.
Tuesday, Mar 29th 12:11AM	Just to recognise it is more prevalent than they acknowledge. Update testing to a type that works. Help us more with treatment and test our families
Saturday, Mar 26th 10:38AM	To train doctors / gps more comprehensively about recognising Lyme disease symptoms and have more adequate Tests and treatments available . Lyme patients face brick walls almost everywhere they turn within the NHS and many just give up on the struggle to get well . It's simply unfair!
Thursday, Mar 24th 3:28PM	There should be much more support and training for Drs. I was treated terribly after diagnosis.
Thursday, Mar 24th 11:56AM	IV antibiotics for 3 months minimum, with 2 types, one for cysts, one for spirochetes, treat the illness they have diagnosed, treat me with respect, not keep telling me the nhs believes Lyme disease goes away on its own!!!
Wednesday, Mar 23rd 9:01PM	Follow the ILADS guidelines, not the CDC/IDSA. Standard tests for Lyme has false negative 60%. Money into research; testing - the correct test like Armin/Igenex; treatment. Do not bully medical doctors do treat Lyme.
Tuesday, Mar 22nd 4:25PM	Listen to patients and not dismiss health problems as a mental illness.
	Consultants with knowledge in the area
	Tests that work
	Some support rather than feeling like an outcast
Tuesday, Mar 22nd 2:54PM	Recognise the condition throughout the NHS services. Accept blood test results from trusted International Private Companies. Don't just stop at oral antibiotics if the patient's health hasn't improved.
Tuesday, Mar 22nd 2:30PM	New and better Lymes testing
	Acknowledge chronic Lyme and related conditions
	All chronic fatigue like symptoms qualified for a Lymes blood test automatically

	Treatment for Lymes goes beyond basical oral medication, but extends to iv drips and follow up appointments.
	Co-infections must be tested for and treated
Monday, Mar 21st 1:34PM	Take notice of tests being conducted in both the USA and Germany and more openminded to co-infection
Tuesday, Mar 22nd 4:02AM	Take us serious and help us.
Tuesday, Mar 22nd 3:44AM	Treat them
Tuesday, Mar 22nd 3:18AM	Recognize that 4 weeks antibiotics does not cure Lyme.
	Better more accurate testing
	Recognize confections
	Recognize chronic Lyme (not post treatment LD symptoms)
	Recognize symptoms and misdiagnosis of other diseases such as ME/MS etc may be Lyme
	Offer better treatment options such as pulsed multiple antibiotics
	Offer alternative medicine/rife
	Treat co-infections
	Research
Tuesday, Mar 22nd 3:13AM	I think the NHS should provide more accurate testing for Lyme and treat it!
Monday, Mar 21st 4:34PM	Listen to where the patient has been - we live in Newcastle on Tyne but had been to the New Forest
	Recognise the symptoms and if the first test is negative, repeat it after 6 weeks. This is in the NHS guidelines but our hospital failed to repeat it
Monday, Mar 21st 12:02PM	I would find it very helpful if the condition could be monitored. For example, once I was diagnosed and had had the antibiotic treatment, I was told "you are now cured". Am I naive to think that it would need a follow-up blood test to ascertain if the medication had any effect? Also, after the initial treatment I found an improvement, but again started feeling lethargic after a while. However, there does not seem to be a willingness to re-test patients.
Monday, Mar 21st 9:54AM	The nhs does not recognise Lyme therefore there is not an epidemic bubbling away under the surface. I also believe that the system 'keeps Lymies' ill and on medications that benefit the pharmaceutical companies. The aim to make money from repeat prescription not in healing those who are unwell.
Sunday, Mar 20th 2:07PM	CDC needs to change there guidelines
	Accurate tests
	Treatment affordable for all
Thursday, Mar 17th 7:45PM	Please develop testing . Please develop treatments . Please help us ,
Thursday, Mar 17th 4:47AM	Proper testing
	More research into effective treatment
Tuesday, Mar 15th 5:01PM	Sensitive accurate testing for chronic Lyme, not just antibodies as currently.
	Recognise current private testing from USA and Germany and prescribe the recommended treatment.
	Listen to the partners of the sufferers as they know the person better than anybody and they know what is normal for that person
	Automatically test for Lyme with every patient who presents with strange, diffuse, varying symptoms and not just assume they are making it up.
Monday, Mar 14th 1:25PM	All NHS medical staff should be trained in Lyme disease. the NHS should use a test that works.
Sunday, Mar 13th 6:46PM	Fix the Lyme tests, to stop the false negatives; research which bands the BCA clinic look for.
	Put adverts on the mainstream tv - get Lyme out of the closet properly; then it'll be given its long overdue respect and attention. Lyme patients will stop being treated as a small bunch

	of self-diagnosed hypochondriacal Internet spotters. Then maybe we can get our friends and family back, if they learn we weren't so barmy after all.
Sunday, Mar 13th 3:48PM	Proper diagnosis and treatment.
Sunday, Mar 13th 1:41PM	Acknowledge that chronic Lyme exists, even if they don't know how to cure it.
Sunday, Mar 13th 9:53AM	test properly and treat
Saturday, Mar 12th 8:24AM	Treat us !!!!
Wednesday, Mar 9th 1:49PM	1. Start using better lab tests. It seems that the false negative rate is far too high with current test.
	2. Use clinical factors to aid diagnosis.
	3. Improve GP education on Lyme.
	4. Improve treatment regimes. This means use current research to choose the most effective antibiotics, and investigate and use alternative treatments. (See Q21). Powerful antibiotics have significant and long-term side-effects and consequently are often not the best option. Alternative treatments, such as monolaurin, have negligible side-effects and are just as effective, if not better.Taking multiple antibiotics for periods of months or even years can seriously damage one's health. Monolaurin has no such side-effects, even after years of use.
Wednesday, Mar 9th 10:03AM	There should be Lyme literate GP's in each area of the UK. Education is key - if my original GP had known even the tiniest thing about LD back in 2007, I would not have had to endure 9 years of poor health and confusion.
	Guidelines need to be clearer and patients should be offered the test based on tick exposure, rash and symptoms - not on the GP's 'opinion'. The media should be involved and patients should be given a voice, instead of being laughed out of the office.
Tuesday, Mar 8th 3:10PM	Have significant testing not just for lyme but for co-infections. Use tests to find the DNA not just antibodies. Take it seriously and help people get better which is what they should be there to do. If it was cancer help would be there. I just want my life back as my family are going through this and I wouldn't be here if it wasn't for them as I could quite easily end it.
Monday, Mar 7th 12:09PM	The NHS need to dramatically improve their knowledge of Lyme Disease, my GP said she didnt know about Lyme and had googled it the night before she saw me, but she still said I didnt have it.They need to change their testing procedure and accept accredited tests from abroad.They need to offer long term treatment, and try and find a cure for this terrible disease.
Friday, Mar 4th 12:26PM	I want NHS doctors to get educated and admit this is a REAL life threatening disease and treat us with the same care other as chronic disease sufferers. Don't dismiss us with other diagnosis because they are uneducated, please refer us on to someone who IS who can help us not leave us in despair. ADMIT the test for Lyme in the UK is useless and use the Armin Test in the Uk as it is proven more effective. PLEASE
Wednesday, Mar 2nd 10:02AM	Take Lyme disease seriously and take me seriously instead of treating me like some kind of malingerer or crazy or uneducated yob which is how I have been made to feel by arrogant know it all NHS doctors who I am sure would not put up with feeling as unwell as I do and not try to do something about it. Treat Lyme disease and learn as much as possible about it to better understand and treat it. Utilise other more successful tests. Create support. Treat people on the basis of evidence in the absence of a positive test. Understand that people with Lyme disease can't function properly and find it extremely difficult to present their case to a GP or to actually remember all their many symptoms. Understand that all the symptom are extreme and not just everyday niggles. Care and understanding go a long way.
Tuesday, Mar 1st 5:17AM	Educate and update GPs.
	Fund clinics.....the first clinic in UK in Winchester only
	lasted 6 months and had to close due to promised funding
	not happening.
	Investigate which antibiotics work best for this disease
	and inform GPs.
	Research coinfections....every tic is different and when
	it bites it passes everything it has to the patient,including

	Lyme Disease……hence so many different symptoms.
Tuesday, Mar 1st 3:07AM	Acknowledge it exists in the first place, and widening the testing. Also development a treatment plan.
Monday, Feb 29th 6:35PM	Better testing. More
	Training. Doctors don't even suggest testing. My own cosmetics to both neurologists and infectious disease never once asked me to have a Lyme test in 15 years of attending over ten consultants.
Monday, Feb 29th 6:05PM	Yes! We need our Health Insurance plans to cover our much needed long term treatments!
Monday, Feb 29th 1:35PM	I believe that there should be trained doctors who are able to access a range of treatment for Lyme sufferers which would include physiotherapy, occupational therapy, and other valid treatments. Counselling support would be fantastic. This is becoming endemic. My own GP is very supportive and wants to be informed about which treatments I choose to follow but tells me he feels very ignorant about the disease. There certainly needs to be more awareness and more training. More information on walking websites and tourist websites to cover up when out walking in the forests.
Monday, Feb 29th 11:07AM	The NHS should recognise test results that have been done abroad.
	All doctors should stop telling patients that Lyme disease does not exist in Great Britain. They should start doing some research or have training and be prepared to have a conversation with and be more supportive to patients who wish to talk about it.
	Blood testing should be improved so that people should not have to look abroad for testing.
Monday, Feb 29th 8:35AM	Proper testing. Treatment. Set up clinics dedicated to treating Lyme disease. Train all , educate all doctors, specialists in what Lyme disease is how it can affect people especially those with it who been left untreated or not properly treated. Look at some what abroad are doing. Sort it here so no one has to go abroad for help etc.Recognise the disease. Treat it before it leads to other serious diseases etc. Stop wasting money with misdiagnoses especially when have a positive Lyme disease test, treat lynes first not waste appointments, etc. Realise Lumbar puncture tat most tropical disease places is not a test for Lyme disease. (Re cells borrellia bacteria in and out tissues so could be hidden so negative result in lumbar puncture regarding Lyme disease etc)
Monday, Feb 29th 6:44AM	Accurate blood tests.
	Trained Lyme specialist in every dr surgery.
	Recognition of private approved tests outside of UK.
	Clear guidelines of treatment on NHS. (Antibiotics etc)
	Recommend herbal protocols.
	Clear advice about detoxing.
	Financial support with beneficial therapies.
	Financial support from govt when unable to work/study.
	TO BE HEARD! FOR THE NHS TO TAKE THIS SERIOUSLY AND NOT BE AFRAID TO TAKE THE LEAD IN OPENING UP THE TABOO TOPIC THAT LYME DISEASE SEEMS TO BE. We are very fortunate to have an NHS but in this area the NHS have let down so many suffering. Mainly because of lack of knowledge, funding, legislations.
Sunday, Feb 28th 3:12PM	With immediate effect Educate all NHS employees about this devestating & disabling disease. This disease is a very serious & severely disabling disease & they need to know this if they are to help these desperate patients.
	Set up lyme disease specialist clinics throughout the uk, with lyme disease specials. I have asked repeatedly to be referred to a lyme disease specialist & repeatedly been informed there are no lyme disease specialists in the uk. If that was & is the case then i should have been referred to a lyme disease specialist overseas.
	Lyme disease testing is appalling in the uk. Namely the Elisa is not fit for purpose and misses most cases of lyme disease.
	It is widely acknowledged by ILADS that negative patients are often the sickest patients & this needs to be acknowledged & the Elisa needs to discontinued with immediate effect.
	To acknowledge that a EM rash (bullseye rash) is gold standard for diagnosis.
	To acknowledge a very clear tick history & symptoms & clinicallly diagnose & treat.

	To acknowledge that blood tests are in support of but do not decide not to diagnose & treat, this disease is primarily a clinical diagnosis as per CDC.
	Specialist labs in other countries are exactly that, specialist in tick born diseases and the nhs should not be allowed to discredit these labs, when the nhs does not have the answers or the expertese themselves. Instead they should be communicating with them, learning from them, working together in the common goal of finding a cure.
Sunday, Feb 28th 6:08PM	Teach Gps and consultants the facts about Lyme / Lyme testing / Lyme risks to eradicate the myths and misconceptions.
	Educate and give doctors the confidence to diagnose clinically.
	Revise the current guidelines on treatment of a few weeks of abx, to a long term treatment regime that acknowledges the persistence and chronic phase of the disease, as well as the possibility of future relapse. Also to include a broader range of available treatment ie. herbal treatment programmes.
	Discuss with patients the prevention of future relapse and maintain contact with patient for regular check ups.
	Be open minded about research already done re congenital and sexual contraction and include the patient's family in testing process where necessary.
	Roll out a public awareness campaign, similar to the AIDS campaign in the 80's
Sunday, Feb 28th 4:46PM	Please recognise this as a chronic illness.
	Please raise awareness.
	Please provide funding for further research into diagnosis and treatment, including diagnosis of co-infections.
Sunday, Feb 28th 4:20PM	Take them seriously
Sunday, Feb 28th 3:03PM	Scrap Elisa test in favour of Elispot/Dark Field tests and blood cultures. Train all GPs and staff in hospital about Lyme. Invest in research and real treatment using a mixed biotic/herbal and autonomic study approach. Treat chronic patients the same as Jemsek, Stram and Burroscano have in USA and offer Blood cleaning as done in Germany. Emphasis on treating a patient thoroughly rather than leaving it if symptoms are of Lyme but no other condition can be found. ALS and MS/ME are conditions with unknown causes ...Lyme is frequently the diagnosis.
Sunday, Feb 28th 9:35AM	Nhs may not have finances to invest on new tests- understandable given the demands
	In that case, be ethical and accept third party results- they're probably right and they re saving the nhs a fortune. Do The right thing by the patients
Sunday, Feb 28th 2:53AM	1. Don't fob us off with a diagnosis of ME - there is always a trigger for ME symptoms whether it is viral or bacterial. Tests should be undertaken.
	2. Most GP's are ignorant about Lyme and because they have to pay for the blood tests they don't want to do them plus they treat all teenage girls as if they are exaggerating. They need to follow a certain path of testing when symptoms are consistent with Lyme.
	3. Test for Lyme
	4. There are lots of auto immune diseases that certain people are more genetically disposed to - why is it assumed Lyme is only caused by tick bites and not transferred on in other ways?
Saturday, Feb 27th 9:57AM	I would like to NHS to accept the existence of chronic lyme disease; introduce more sensitive tests to aid diagnosis; send doctors to train with the excellent lyme specialists in other countries then have them return here and treat lyme/co-infections appropriately
Friday, Feb 26th 10:40PM	Acknowledge Chronic Lyme Disease & financially compensate those who have received false negative test results.

	Change the way tests are "read" & bring the accuracy of LD tests in line with IGENEX. Introduce yearly re-testing.
	Introduction of therapies proven to have been sucesseful in treating LD patients
	EDUCATE GPs & OTHER HEALTH PROFESSIONALS
	Introduce a public health campaign in line with other infectious diseases
	Set up /invest in research
	Compile a register of Lyme Disease patients
	Give both financial & practical support to LD sufferers & their families
Friday, Feb 26th 7:44PM	Simple accurate blood test and when a patient has a bite and they feel flu like put Lyme disease at the top of their checklist.
	Awareness like AIDS ads in the early 90's because Lyme is a ticking time bomb!
Friday, Feb 26th 4:54PM	Blood test done by eye specilist came back lyme. Referres to tropical diease expert how advised iv line antibotic for 2 weeks at home. No follow up appointments..expert became aggress with mother when asked could test be done again to see if it worked...now denying daughter had it in 1st place. Left confused as to why iv treatment given then in 1st place. Eye infection still on going after 3 years no explaination as to what it is. Daughter health not what it was self medicating. Would appricate more clarity and follow up appointments
Friday, Feb 26th 7:59AM	Yes. I feel completely abandoned by the NHS, none of my gps have any expertise and my consultant retired some time ago and I cannot find another Lyme literate doctor in England. My gp recently told me I needed to see my specialist when discussing my relapse. I didn't bother telling him. There is no point. General practitioners simply think it is outside their services. Fortunately I had the Bulls eye bruise, despite a negative blood test, it is difficult to deny it, however I am sure without that bruise, my condition would be put down to flakiness or exaggeration.
Thursday, Feb 25th 7:04PM	Employ people who care for the sick!
Thursday, Feb 25th 1:14PM	1. Get a test that works, the ELISA test is flawed
	2. Listen to patients with a history of a tick bite, and act on it.
	3. GP's in Lyme endemic areas need to made more aware of Lyme.
	4. Antibiotics first, not the ELISA test first.
	5. I had doctors and consultants tell me that Lyme is not in the UK, How can this be? Training/awareness must be minimal
	Lyme and it's co-infections are going to be a massive problem for the UK and globally, start dealing with it now in a professional manner or this disease will turn around and bite you.
Thursday, Feb 25th 9:02AM	Stop saying chronic Lyme does not exist
	Acknowledge the devastating effects it has on individuals and their families - that's the least they should do
Thursday, Feb 25th 8:33AM	Listen to patients, see what's clearly in front of you! If I am capable of research and learning about my disease, why aren't doctors? We first of all need a decent test. Second we need doctors to treat us clinically regardless of the test. Then we need legislation that allows doctors to be trained to the standard of the best US llmds, without the fear of prosecution. Most of all have an open mind and consider the role bacteria is clearly playing in hundreds of illnesses!

Thursday, Feb 25th 1:20AM	Doctors need to improve their understanding to give people a chance of full recovery with early treatment - due to the unreliability of testing a clinical diagnosis of an EM rash or feeling unwell after exposure to ticks should be enough; a few weeks of antibiotics could save a lifetime's misery and costly NHS drugs and appointments. The U.K. should become leaders in both creating a reliable test for Lyme and researching, why it causes the health problems it does and what is happening to the body in 'chronic' cases - too little is known.
Wednesday, Feb 24th 5:26PM	Take this devastating disease seriously! And offer both better testing and relevant treatment rather than pretending that it doesn't exist.
Wednesday, Feb 24th 3:24AM	Remove testing from such a secretive lab! Research research research!! Education amongst Doctors is appalling. I've heard the most ridiculous statements from the people who SHOULD know better but are so ignorant, it's frightening. Yet these same people are the one's responsible for my (fast failing) health. Stop treating the symptoms and sort the cause of the symptoms. It's exhausting attending all these appointments which do nothing for me. My osteoarthritis is not caused by being overweight -I'm barely 6stone! Why is there such a ridiculous one size fits all approach to such a complicated conditions?
Wednesday, Feb 24th 1:15AM	Like Cancer patient's are treated with dignity just to care and to take the severity of this illness seriously.
Tuesday, Feb 23rd 5:47PM	I think the NHS should use a direct test that does not rely on the creation of antibodies. They should also accept that chronic Lyme exists and that a few weeks of oral antibiotics is not always enough. They should rule out Lyme disease before labelling a patient with ME/CFS.
Tuesday, Feb 23rd 11:09AM	Open their eyes!!!
Tuesday, Feb 23rd 9:27AM	An official/criminal investigation should be conducted about the actions of Sue O'Connell.
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	NHS representatives "on the field" don't know (enough) about lyme disease, how to spell it, how serious it is, how badly the affected suffer with multiple signs and symptoms, affecting multiple systems. And then co-infections! and reactivated viruses!
	=> A team of specialist of different medical fields should further specialise on how lyme et al affect their field of medicine, and work together to help people holistically, or advice GPs and/or other specialists what to do and how to treat.
	***
	UK people travel, it is more than naive to think that UK cases are from UK origin only. Testing needs to reflect this.
	Above all, sick people need to be treated, and for as long as necessary, not blood tests, which should just support diagnosis. Take a good medical and travel history, GPs are very busy, so maybe a nurse or lay person could help to fill in a comprehensive questionnaire.
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	Surely an algorythm can be created to suss out the probabilities of someone having certain illnesses, to help with ruling out issues and diagnosing.
	***
	A dog is very ill, a vet takes a blood sample, sends it to a good lab. A particular parasite is detected, a diagnose and medication provided, the dog gets treated at home daily indeterminately to keep the parasitic load as low as possible.
	A person is very ill regularily with malaria like symptoms, some signs are similar to those of the dog, but a blood sample is not taken, nobody seems to know where to send a sample if one was taken, or to diagnoses anything anywhere. Suffering continues, NHS doesn't care to find out, learn, help or cure. But if the patient privately gets the bloods to be sent abroad and tested, the NHS doesn't accept the results or treat. Suffering continues.
	Could the UK vets to be allowed to help humans here too please?!
Tuesday, Feb 23rd 10:51AM	Open their eyes!!!
Monday, Feb 22nd 3:04PM	There needs to be proper research into this disease. First there needs to be proper tests, I had to go private to get my results costing over £1000. My NHS test which I had to beg for was of course negative. If I had of accepted that result I would only have got worse!
	It's scary being told you have Lyme Disease, whats worse is doctors know nothing! Every time I go to my GP why do I feel like they just want to get rid of me? You are very much alone when you have Lyme Disease, suffering and unsure where to turn.

	The NHS need proper Lyme literate doctors who will see patients and understand the disease in and out, who will help them every step of the way until they are much better. There needs to be support for all Lyme patients.
Monday, Feb 22nd 9:51AM	Actively and effectively recognise, diagnose and treat Lyme disease in all its forms. From newly acquired Lyme disease to those who have suffered undiagnosed and untreated for years.
Monday, Feb 22nd 7:25AM	1.Firstly, control by the biowarefare establishment at Porton Down needs to be removed. If Lyme and co is not a biowarfare issue then remove all control from Porton Down. British citizens need medical intervention, not nutty security forces trained scientists running the NHS/Lyme issue.
	2. Get accurate testing processes and get GP's to proactively refer for tests those showing signs of Lyme such as CFS. ME, MS, Alziemers, parkinsons, addicts, depressives..
	3. Set up regional centres across the UK specifically to deal with lyme and co.. Including viruses!! Viruses ignite Lyme and co
	4. Get Doctors (and nurses) trained (not ID consultants who report into Porton Down)!! We need trained medical doctors such as those in Germany and the US who can provide extensive antibiotic and alternative treatment such as ozone
	5. We need research scientists, who are independent and not controlled by Government security forces
	6. We need redress- compensation for our pain of long-term misdiagnosis and reimbursement of our private medical bills
	7. We need the Government to admit liability under the Human Rights Act we need protection afforded to us as the threat from catching lyme and co through many sources means the government have not afforded the British public the protection they are entitled to.
	8. We need to be provided with finances to help us cope and live a reasonable life
	Good Luck and thanks JC :-)
Monday, Feb 22nd 9:29AM	Listen to their patients !!! Stop prescribing anti depressions look into it I'm not a number I'm a person!! With children that need me
Monday, Feb 22nd 4:07AM	The government needs to listen, listen and listen again. How can NHS be an effective health system if it is not recognising, diagnosing and treating chronic Lyme and co-infections. Too many patients suffering for too long and on top of that they are traumatised as they seek help from a system that has no effective way of dealing with them.
	NHS needs to educate GP's in Lyme disease and it's co-infections.
	NHS needs give GP's enough time to listen and respond appropriately to patients with multiple symptoms.
	NHS should develop a questionnaire for symptoms of Lyme to help GP's in diagnosis.
	NHS needs the most up to date blood tests for Lyme and co-infections. i.e. blood tests which show if there was an infection, if there is an active infection, if there is an inflammatory response continuing after infection is gone. Blood tests which show a high rate of false negatives should be a thing of the past.
	NHS needs specialist clinic or clinics in UK with consultants trained in diagnosis and treatment of Lyme and co-infections. (A rheumatologist should not be giving opinions without scientific back up on something he isn't trained for)
	NHS needs to better inform the public re prevention and urgency of treatment if bitten by tics.
	There has been scientific research on borrellia spirochetes found in the brains of alzheimers patients and the spinal fluid of multiple sclerosis patients and the links between chlamydia pneumoniae and multiple sclerosis. The NHS needs to take Lyme and co-infections and their treatment very seriously so as to prevent the huge suffering of patients and the burdens on the NHS of leaving Lyme and co-infections untreated.
	If the NHS wishes to continue to keep it's head in the sand regarding Lyme and co-infections they should pay for patients to get treatment in other countries.
Sunday, Feb 21st 9:09AM	•PHE to agree to collaborate with scientists to develop a gold standard method of detecting Borreliosis in the UK.
	•PHE using LTT Elispot, Melissa, PCR, Microscopy and scrap 2 Tier test
	•Chief Medical Office to update public on true risks
	•Differential Diagnosis (MSIDS) diagnosis method (Horrowitz) to be adopted by all GP’s and made available on NHS website

	•Treatment based upon symptoms not unreliable tests
	•Doctors must be encouraged to use antibiotics based on clinical symptoms
	•NICE guidelines to be updated using ILADS
	•Private Tests to be accepted for NHS Treatment
	•IV Antibiotics to be given to Patients
	•Natural Remedies to be offered
	•Announce to press that Lyme Disease may be an STD
	•National Press & TV Advertising warning of Lyme Disease risks are increasing
	•New Treatment Protocol for UK – Patient Centred – Based on ILADS – Owned by new Centres not NICE
	•Doctors removed from Rigid guidelines preventing novel techniques
	•Treatment of Lyme by Antibiotics to be removed from Annual Appraisal monitoring
	•Better Surveillance & Statistics
	•3-4 National Treatment centres set-up
	•Specialists brought in from Abroad
	•Lyme Literate Doctor Training Scheme
	•New Professional Body set-up for Lyme Literate Doctors
	•RIPL role changed to Testing for Lyme and introducing new tests – Not medical advice to doctors
	•PHE Test results independently Audited and published every 6 months
	•GMC prevented from harassing doctors treating Lyme
	•Research Funding for Testing, Treatments & Prevention (relative to other major disease prevalence)
	•Funding for UK company IanXen to develop XRAPID microscopy tests for Borrelia and common co-infections
	•True survey of Lyme Patients to determine how many are suffering
	•Announcement that Lyme tests were inaccurate and retesting required (I.E Recall Notice)
	•Training for current GPs about Lyme (and other TBDs) diagnosis and treatment.
	•Prevention and awareness training for the general public, by government agencies.
	•All public Places warning Signs at entrances
	•Schools given warnings and teacher training
	•Public Inquiry
	•New Labs Independent Labs to set-up in UK under independent watchdog (Private/Public)
	•New independent Lyme & Co-infections Lab set-up (Private & Gov funded)
	•Suspicious deaths should be tested for Lyme bacteria and other tick born infections
Sunday, Feb 21st 6:11AM	1. READ and UNDERSTAND the over 700 peer reviewed articles via ILADS.
	2. Make up your OWN mind and not that of a select few at IDSA.
	3. Appreciate that a short course of antibiotics won't treat it. BUT, don't assume that because 2 weeks of Doxycycline didn't help, NO antibiotics will help.
	4. Ask doctors, consultants, specialists etc to remove their feeling of self importance from the equation. If we knew everything in medicine, we'd have no illness. Remember HIV/AIDS and Helicobacter Pylori?
	5. My own blood tests have consistently shown infection and inflammation, but with no known bacteria, I have been left for 14 years.
	6. Accept that people with these illnesses, while holding a sick bowl, are unable to eat, are/are not tired, have pain beyond your wildest dreams... do NOT want to undertake graded exercise until they KNOW and UNDERSTAND what is wrong with them.
	7. Accept NHS testing is not adequate and take the lead from companies who have successfully developed appropriate testing methods.
	8. It's ok to accept you got it wrong.

Sunday, Feb 21st 5:41AM	First and foremost there needs to be better more reliable testing- the NHS test is out of date and has a low efficacy.
	Secondly, recognise that even with a good test it is not always possible to obtain a positive result, despite a person having the disease. In this case there needs to be recognition of a clinical diagnosis
	Provide chronic sufferers, including those clinically diagnosed, with proper treatment along the guidelines set out by ILADS
	We have no truly qualified doctors in this country that specialise in this disease. Acutely it can be treated quite successfully but in its chronic form the prognosis and treatment is quite complex. We therefore need more specialists physicians. Collaboration with doctors on the continent and in th US, where they have the expertise
Sunday, Feb 21st 5:22AM	More effective testing, treatment and acknowledgment. Better trained health professionals. I.v treatment on nhs
Saturday, Feb 20th 9:11AM	The nhs need to sort out the Lyme testing procedure and need to update their testing methods. I was diognosed with Lyme three months ago and still not received any treatment. Since being tested posstive from armin labs my gp sent me for full blood count, nhs Lyme test which came back negative and Mri scan of the brain.
Friday, Feb 19th 7:44AM	I wish for the NHS to recognise the severity of this disease and in turn offer support, care, understanding and treatment. By treatment, I don't mean a quick few weeks worth of antibiotics and then shown the door. I mean continued treatment to get these desperate people well.
Thursday, Feb 18th 4:18PM	Use accurate tests and continue treatment until patient clinically well. Recognise the importance of supportive treatment for the liver (thioctacid and glutathione) the gut (probiotics) and biofilm breakers (bromelaine, nsk, stevia). Give clinicians the freedom to be flexible with treatments until improvement achieved. Educate physicians to competent level and stop accepting misdiagnoses such as CFS and ME which are caused by bacterial or viral infections such as Lyme.
Thursday, Feb 18th 2:35PM	Change the testing methods so that more strains are tested and use different methods of testing. Have more knowledge of the disease so that it can be diagnosed on symptoms in the early stages. Realise that a bulls eye rash is not always necessary. Realise that antibodies do not always show up in chronic lyme. Not rely on several bands to be present and learn that some bands are lyme specific and only one band is required in such instances. Be more open minded and learn about the disease and how it can affect bodily systems. Use improved lyme testing more frequently when unsure of a diagnosis instead of labelling a patient as chronically fatigued, fibro, depressed, stressed, anxiety disorder etc. Provide the proper treatment e.g. pulsing varied abx, cyst buster, biofilm breakers etc. Test for coinfections and treat.
Thursday, Feb 18th 9:28AM	1.stop sending our blood to a Military base. set up an independent Lyme centre for this. We no longer have trust and Faith in Porton Down
	Is RIPL at Porton Down the only lab in the UK which tests blood for Lyme disease by Western blot as part of NHS?
	2.If its already recognised that tests ARE NOT RELIABLE why are they continuing to use them? WE URGE FOR A NEW AND RELIABLE TEST IMMEDIATLY
	3. Enforce new training and modes of treatment for DRS so they MUST look at LYME even for "FLU" like symtoms and test as a priority for anyone presenting with viral or everyday symptoms we need a national screening programme
	3. recognition that it is sexually transmitable. Give advise and info
	3. Specialist Lyme centres that are trained by specialists from other countries to share knowledge on a wider scale
	4. signs to warn public. HOT SPOTS for tourists etc
	5. To take Lyme disease seriously for the real life threatening disease it is. stop minimising it and us.

	kiosks in public places advise and info how to remove ticks safely. links to what to do where to go 6. herbals as a free alternative and not seen as the lesser option 7. recognise that a one size fits all treatment does not work for Lyme patients 8. recognise it can kill you so take it more seriously and put on death cert. Make Drs and public aware 9. study brains more money for research recognise work of Eva Sapie and Alan McDonald who have studied brains etc where are his papers why are they not recognised as important evidence?? 10.that mothers can pass to unborn baby. My daughter has a heart defect she is yet to be tested for Lyme which can cause heart defects in babies I only learnt this recently 11.patients able to decide where they go for treatment in Europe UK or America 12. that ALL treatment for Lyme is recognised in the UK that infec diseases consultants and DRs do NOT see themselves as the experts that they currently claim to be and learn from outside of themselves to knew and more diverse modalities of treatment. 13. recognise that there are at least 16 types of ticks but only one antigen is looked for in our current test kit so if you went to Japan on business and got bit back in the UK got ill your test in UK likely will be negative. 14.RE. Coinfections the Uk does not yet recognise fully Babesia Bartonella etc I have tested positive and had to pay for these tests yet in UK it has been dismissed and told its highly unlikely yet it is already recognised as highly likely if you have tested positive for Lyme disease!! 15. the fact that many tests are ^lost^ at Porton Down or we don't get to see our tests results from Porton down. My results took over 7 months and that was after my MP wrote to Tim Brookes. I have never seen my actual results 16.discounts for dietry requirements and supplements vitamin injections etc 17. vets and animals to get more help and more advise and care to sick or potential sick animals 18.schools that take children on camping and outdoor pusuits everyone needs training and learn how to safely remove ticks and what to do following a bite or just an illness signs etc 19.is anyone in UK collecting data how are true statistics being compiled with to alert Public Health?
Thursday, Feb 18th 8:40AM	http://www.ilads.org/lyme/treatment-guideline.php
Thursday, Feb 18th 3:39AM	Our first contact mostly after been bitten is our GP's I like them to act immediately. Then follow up. Listen to the Pt's as health Sec TRANSPARENCY. Where is it.
Thursday, Feb 18th 3:20AM	Dna test asp.
Wednesday, Feb 17th 5:24PM	Treat each individual until they are well.
Wednesday, Feb 17th 1:35PM	I think that the first thing would be to suspect Lyme before anything else when people present with some of the emotional problems that seem to be common in sufferers. Not to be dismissive of patients, ensure that a valid and reliable test is carried out. Resist the temptation to prescibe psychotropic drugs (they make things worse) Extensive medical education re: Lyme so that all involved are singing from the same hymn book. Prompt treatment as per ILADS guidelines for newly infected patients, and treatment for as long as it takes, not time defined, but guided by symptoms and test results

Wednesday, Feb 17th 12:35PM	run the right tests and treat us! i reported a tick bite shortly after being bitten and was told i was fine. after 7 years of symptoms i was eventually given antidepressants for my low energy and sent to an NHS psychologist once every three months who told me it was all in my head
Wednesday, Feb 17th 8:56AM	make GP aware of lymes
	give you a test if you ask for one
	not to think it is in your head
	have full treatment how every long it takes
	to offer a blood test without going privatr
Wednesday, Feb 17th 8:23AM	DOCTORS TO BE TAUGHT TO LISTEN TO WHAT THE PATIENT IS SAYING-THEY NEED TRAINING HOW TO RECOGNISE IT AND SEND PATIENTS FOR THE RELEVANT TESTS-LEARN HOW TO TREAT LYME WITH ANTIBIOTICS
Wednesday, Feb 17th 5:43AM	RESERCH LYME DISEASE
Wednesday, Feb 17th 6:13AM	I would like the NHS to publicise the poor reliability of the current antibody testing to the practitioners who order the tests - usually ID consultants, general physicians and GPs. They are used to coping with low reliability of testing (e.g. syphilis antibody testing is not great) and if awareness was higher they would be more inclined make more clinical decisions based on patients presenting issues and history. Currently, many doctors rely on the unreliable available tests and make poor decisions that often neglect the patients experience, debility and reality.
	I would also the NHS labs to report all of the WB bands to the physicians. Let the doctors be informed and to take responsibility for the decisions regarding treatment/infection - not he lab.
	I would like the NHS to never declare on the back of an antibody test that 'this patients does not have Lyme' as this is scientifically not a credible thing to state.
	Introduce reliable culture testing for borrelia followed up by pcr/immuno-fluorescence testing to identify the strain of borrelia patients are infected with. Have repeat culture testing until the patient feels well and it cannot any longer be cultured.
	Develop and have available reliable co-infection tests e.g. babaesia and bartonella.
	Educate GPs and other doctors/healthcare professionals about Lyme.
	Discourage the psychologisation of people who are often desperately ill and in need of practical rather than psychological support. Provide appropriate supportive psychological care if necessary but not as a substitute for medical care.
Wednesday, Feb 17th 4:48AM	RESPOND IMEDIATELY TO POSSIBLE INFECTION. TICK BITE OR RASH OR KNOWN CFS TYPE SYMPTOMS.
	DO NOT RELY ON SERIOLOGY. WASTE OF TIME.
	PREVENTION IS BETTER THAN CURE. RESPOND WITH URGENCY.
	ONCE INFECTED THERE IS OFTEN NO CURE , ONLY REMISSION.
	STOP TREATING PATIENTS WITH GLIB DERISION AS A DISPLACEMENT ACTIVITY JUST BECAUSE YOU DON'T HAVE THE ANSWERS OR THE CURE.
	TREAT THE PATIENT WITH RESPECT AND COURTESY AND COMPASSION.
	REMEMBER THE PATIENT DID NOT CHOOSE THIS ILLNESS.

	LYME DESTROYS LIVES.
	LYME KILLS PATIENTS.
	LYME PATIENTS KILL THEMSELVES TO ESCAPE THE TORTURE OF NON TREATMENT.
Wednesday, Feb 17th 4:37AM	It is important that GPs do not treat Lymes disease solely on results of blood tests and recognise that Borrelia is a complex .debilitating bacteria which can affect many parts of the body.It is very difficult to eradicate,especially with Co-infections and needs long term treatment with regular patient check ups
Wednesday, Feb 17th 3:57AM	Raise awareness of Lyme Disease - prevention is better than cure.
	Better blood testing.
	We need recognised Lyme literate doctors like America and a few specialist centres throughout the country.
	Easier access to antibiotic cycles.
Wednesday, Feb 17th 2:55AM	Change the testing methods. The NHS test is inadequate. Other methods are recognised as accurate and it is beyond me why they don't adopt them and save sufferers not only money by having to go private but the anxiety and stress of finding someone that can help.
	Longer term antibiotics are also needed. Even if there usefulness is still in doubt. If a patient is seen to be benefiting from them, why stop?!?
Wednesday, Feb 17th 2:31AM	My GP referred me to a private functional medicine practitioner as he felt the NHS wouldn't be able to help. I've paid a lot of money for treatment. £1,500-2,000. I am trying herbal route first and will try antibiotics if that fails. My GP feels he doesn't know anyone on the NHS to refer me too.
Tuesday, Feb 16th 8:40PM	Yes. I would love to be a consultant and teach a creative writing course for suffered who are usually pretty traumatised in some way. They must be heard, before they can mend.
Tuesday, Feb 16th 6:39PM	We need to develop a coherent pathway for preventing, testing, and treating Lyme disease. GPs appear to hold little knowledge of Lyme disease. I spoke to 6 GPs before being tested for Lyme, despite.my rash and other symptoms. Despite being tested, the long term treatment plan for lyme has never been clear - it has simply been 3 weeks of doxycycline and nothing further. Upon a positive lyme test it would make sense to also test for coinfections. We need to research and review the best treatment options, looking at international research and treatment options and from this review develop pathways for treating patients.who have had Lyme, and coinfections, fo different lengths. Effective diagnosis may require educating GPs about symptoms and testing. It may also be beneficial to research better, more reliable tests.
Tuesday, Feb 16th 7:55PM	Recognise other tests
	Respect patient choice
	Give antibiotics appropriate and for enough time to destroy the Lyme disease.
	Accept that chronic Lyme exists.
Tuesday, Feb 16th 6:00PM	Open the minds of GPs and give them all the information they need to at least arouse their suspicions of possible LD infection. Referring possible LD patients to ID specialist should open up the chance of CORRECT diagnosis and NOT being fobbed off!
	They really need to send blood samples to laboratories that conduct thorough tests.
Tuesday, Feb 16th 6:18PM	To Recognise chronic Lyme exists, start with that admittance and to treat with appropriate amount and duration of antibiotics
Tuesday, Feb 16th 5:05PM	*Adequate testing.
	*Acceptance of overseas test results eg. Germany, USA
	*Long courses of ABs as recommended by LLMDs in US (including pulsing, combined ABs, changes to ABs etc)
	*Recognised alternative treatments available through the NHS to diminish suffering and support immune system. In many cases these are ESSENTIAL.
	*Referral by local GP to NHS specialist Lyme doctors who are able to diagnose and treat and agree treatment plan with GP.
	*Testing and treatment of co-infections.

	*Testing and treatment for the numerous side effects of *Lyme,the co-infections and secondary diseases resulting from *Lyme and longterm AB treatment.
	*Inpatient care as needed.
	*Home nursing/'GP visits as necessary
	*Never, ever to be told again by my GP that 'we don't have Lyme disease in Northamptonshire (or wherever in the UK or elsewhere in the world) and therefor ABs could not be prescribed. This doctor, whom I would be very willing to name in the right forum, condemned me to what is currently a decade of suffering and huge expense
	*NHS recognition of the extreme seriousness of Lyme: that it is chronic, is rarely cured and most significantly can be fatal.
	*Where appropriate Lyme disease to me mentioned on the death certificate even if the direct cause of death is a specific organ failure most likely due to Lyme.
Tuesday, Feb 16th 5:07PM	1. Diagnose it properly, using the most up-to-date testing protocols which test for the active infection rather than antibodies, which will not show in long-term chronic cases.
	2. Put some proper budget into potential treatment protocols.
	3. Classify it as a disability, because it is. That way employers would have to allow certain dispensations as they do with other serious chronic illnesses.
Tuesday, Feb 16th 5:06PM	Because it could e cured early so easily I was bittern in the new forest by a tick and had all the symptoms but still had to go the a and e for them to test me. The GP just wasn't interested and still isn't 6 years on .
Tuesday, Feb 16th 4:40PM	Accept tests from other labs.
	Develop better "DIRECT" detection methods for testing. Serology is not the way to go. I had 2 NHS western blots both negative. A western blot in Igenex was negative as well but in the same blood draw, the PCR was positive from Igenex.
	I was lucky.
	Listen to their patients and accept that their diagnosis of MS, ME, anxiety etc could be incorrect.
Tuesday, Feb 16th 4:24PM	I would like NHS ID consultants to be trained specifically in chronic Lyme and how it directly effects the immune system and it's abilities to produce antibodies. I would like NHS prepared to prescribe long term antibiotics and anti malarials if needed. I would like NHS to research into the benefits of multi antibiotic treatment. I'm on 2 antibiotics and 1 anti malarial and I'm seeing amazing improvements since on this regime. I would like more connection with other departments in treating the hormone disregation caused by Lyme, e.g. I became very hypothyroid but could not tolerate standard thyroid medication and had to have liothyronine. I'm having to self treat my low cortisol as NHS ranges are so large my adrenal disregulation wasn't recognised. Lyme literate doctors in the US recognise the need to treat adrenals and other hormones in conjunction with killing the bacteria.
	I would like the NHS to be proactive in talking the deficiencies in vitamins and minerals that often occur in Lyme. By dealing with mine I have reduced a number of debilitating symptoms.
Tuesday, Feb 16th 4:04PM	Diagnose, treat effectively, talk to us with respect, stop making us feel like neurotic hypochondriacs...
Tuesday, Feb 16th 3:56PM	I want them to get a blood test that gives the correct diagnosis. Also I want to be treated 100% on the NHS. Also I want everyone in the NHS to understand us and our awful fight!
Tuesday, Feb 16th 7:38AM	They must bring it up the priority of questions asked by the Doctors. I was in hospital for 4 weeks before the vital question " have you been bitten". Was previously told it was a mosquito bite.
Monday, Feb 15th 7:25PM	Take into account history of person - rural upbringing working with animals, living in area known to have high incidence of Lyme. No history of viral infection etc to suggest CFs. Diagnosis nothing to indicate this in bloods. Strange biochemistry results no one could explain but that we shouldn't be concerned about. Farmer whose fields played in helped with animals rode horses etc already had diagnosis of Lyme but despite fact he was willing to provide his test results etc as evidence nhs considered that to be irrelevant.

	History in area of people being diagnosed with CFs/me then years later receiving a positive Lyme test but by then have major damage ie heart, liver, arthritis despite telling Drs they think they have Lyme all are offered cbt & physio !
	Accept symptoms, for diagnosis - accept test results are not 100% and that not everyone will had a bull ring rash. In this area it looks more like ring worm.
	Do not insist cbt is answer to Lyme/cf/me .
	Do not insist physio is the cure when the person cannot even lift a glass.
	Do not tell parent to step back from this- if my mum had stepped back as told to I doubt if I would be alive today.
	Accept that when antibiotic makes an improvement it is not a placebo effect, the antibiotic my mum bullied dr into prescribing made me able to get to London for help and I have never gone back to the place I was before I had it so how can that be a placebo.
Monday, Feb 15th 4:52PM	- Review guidance for treatment including rolling out use of IV antibiotics to more patients and pulse dosing of antibiotics
	- Stop referring people who need physical treatment (either with antibiotics/ IV or herbals for example) to clinics around behaviour. Yes, pacing may help but it cannot cure someone with Lyme Disease or another co-infection. Yet, when I asked at the ME clinic (which sits within social care and mental health) they said they have a lot of referrals from people with possible Lyme Disease yet they knew nothing about it.
	- Put together a group of specialists, with leadership from Dr Richard Horowitz
	-Train nurse, GP's and Emergency services in how to remove ticks safely
	- Treat patients in an open, fair, caring and courteous manner.
	-Do not become offended if a patient happens to know more about an illness than you! Use it as an opportunity to go away and learn more.
	-Refer possible Lyme / coinfection patients (anyone with fibromyalgia, MS, ME for example for specialist testing at labs outside of UK - or change UK testing procedures to test for worldwide strains of vector borne illness)
	-Study vector borne illness and threat via pregnancy / sexual contact and advise people accordingly. Utilise specialists in your own service in this field such as Dr Sarah Chissell.
	-Set up a specialist Lyme and vector borne illness clinic with adequate staffing and knowledge and testing
Monday, Feb 15th 2:15PM	To have accurate tests available
	Where other guidelines state that Lyme Disease should be ruled out before a diagnosis is given (i.e. the ME/CFS guidelines for children) tests should be carried out before assuming that someone else has another condition
Monday, Feb 15th 1:14PM	I want to be properly treated for Lymes disease .
	I'm only 23 and my parents are planning to take me abroad for private treatment.
Monday, Feb 15th 11:03AM	TREAT IMEDIETLY IF SUSPECTED BY THE PATIENTS SYPTOMS ALONE BETTER SAFE THAN SORRY oR EM RASH IF THEY HAVE ONE iF NOT ON SYPTOMS nOT EFVERY ONES GETS THE EM RASH
	Better testing developed a culture test LOOKING FIR THE BORRELIA DOWN THE MISCROSCOPE aNTIBODTY TESTING ARE UNRELIABLE nOT EVERYONE GIVES A IMMUNE RESPONCE sO NO ANTIOBIES PRESENT .
	lONG COURCES OF COMBINATION OF ANTIBIOCS aS LONG AS SYPTOMS PERSIST AND 2 MONTHS BEYOND AS PER ILADS GUIDLINES
	bETTER gP ANND id training. on lymes and co diseases
	testing of all co diseasee
	listen the the patient they no there bodies best DO NOT JUMP TO THE EASIEST ANSWER YOUR SYPTOMS ARE ALL IN YOUR HEAD THIS IS CONDESENDING TO THOSE WHO ARE EXPERIANCING THESE SYPTOMS
Monday, Feb 15th 8:26AM	Relize is a disease.
Monday, Feb 15th 8:04AM	An accurate test leading to correct and prompt diagnosis.
	Effective and proven treatment options for patients.
	Understanding of the impact of this disease on individuals and families.

Monday, Feb 15th 7:53AM	Recognise that the UK blood tests are not accurate and start making clinical diagnosis.
	Recognise chronic Lyme as a disease not cured by 2 weeks of antibiotics.
	Provide a referral Lyme clinic in the UK with Lyme literate doctors who are able to help us.
	Train GP's to recognise signs of Lyme disease
Sunday, Feb 14th 5:34PM	Treat this illness seriously .
	Offer patients a proper recovery regimen.
	Stop telling people it is all ' in the head "
	Do u think people willingly want to be Ill and have physical symptoms ?
	I for one want to be physically well.
Sunday, Feb 14th 4:16PM	Do proper tests , listen to what the patient says . If the NHS doctors are not taught it , they will not think outside the box.
Sunday, Feb 14th 7:01AM	I think it is important for it to be a notifiable disease I kept reading how rare it is until I got it and as I live in the new forest and was diagnosed at my local hospital where they said they have loads of positive results each month and I now know a lot of local people who have had it. I think the fact that it may affect tourism may play a part! It was also very frustrating that there seemed to be no lymes specialists to speak to.
Saturday, Feb 13th 7:00PM	Develop a credible test but use combination of this and clinical diagnosis. Use an interactive tool like Isabel to help diagnosis often nebulous Lyme symptoms - early and late stages suggested Isabel diagnosis was Lyme. Be honest that the current PHE testing isn't effective - Dr Dryden told the registrar I saw at St George's, Tooting that the testing has problems - why not come out and be honest about it. Stop following like poodles the IDSA and start following ILADS immediately. Think about the biology of Borrelia - multiple forms, persistence to get to long term antibiotic protocols. Remember what the treatment of syphilis and TB entails. Unlikely big pharmacy is going to solve this anytime soon so work it out as I have said based on the biology.
Saturday, Feb 13th 10:03AM	I would like to see this disease acknowledged for the serious condition that it is.
	PLEASE take people's lives seriously, take people's pain and suffering seriously and don't disregard those suffering as 'fakers' and hypochondriacs just because a blood test that is known to be inaccurate doesn't return a positive result. There is no blood test for asthma, yet people are not told they are faking it, treat other diseases in the same way.
	I would like to see GP's become better informed and the ID specialists likewise.
	I would like to see actual healthcare, as in getting and keeping people healthy.
Saturday, Feb 13th 9:39AM	I want better research, much better testing, I want it to be believed (I am lucky mine does but his hands are tied regards treatment)
Saturday, Feb 13th 8:40AM	I would like this disease to be recognised and to be treated properly on the NHS. I would like for long term chronic disease to be recognised. I have no money left due to spending all my savings and inheritance on private medicine and no money left to carry on with any Lyme treatment which could/might help me get a better quality of life. It would be fantastic to be able to go to a NHS clinic or department and be able to be treated by someone who is experienced and knows what treatments to prescribe and then you can continue to try treatments until something works for the individual. I would like Lyme disease to be recognised and treated as any other illness would be on the NHS.
Saturday, Feb 13th 7:49AM	It is important to me that people are tested, monitored and given the antibiotics and supplements that will help them back to the best health they can get. It is not right to leave so many people feeling so ill and shoving them off to psychiatry to be drugged by harmful drugs that can make things a huge amount worse if they press for treatment and acceptance.

Saturday, Feb 13th 5:14AM	NHS should train their staff, GPs in the first instance to diagnose Lyme or other infections that may accompany Lyme (I have also several other viral infections.) This needs both clinical training and blood testing other than the one NHS uses currently. However, treatment trial according to recognised symptoms and clinical examination should take priority over any testing as these infections don't always show in the best of tests. There is enough information around the world to make this happen, and it would be common sense for the NHS to invest in this training (and allowing to treat properly) to reduce the costs downstream when people get really ill and are hospitalised, or unable to work and thus on benefits for the rest of their lives. Lyme is not going away by itself, so treatment is always necessary. It is very unfortunate that almost all GPs are either ignorant or not allowed to even try an appropriate treatment.
Saturday, Feb 13th 2:38AM	Start using a blood test that works. Educate all doctors on the existence of chronic Lyme disease and all the possible co-infections to give them the ability to make a clinical diagnosis. Change the treatment guidelines to make longer term antibiotics an allowable course of treatment.
Saturday, Feb 13th 2:37AM	Create a gold standard testing method (look into culture test available in America, do some research into international testing methods to try and standardize Lyme disease testing so one test can be accepted worldwide)
	Educate doctors to recognize Lyme disease and co-infections
	Stop jumping to the conclusion that people have ME and mental health problems before tick-borne infections have been rules out
	Create a Lyme disease clinic and send doctors to train with ILADS physicians who are getting patients better
	Do research into the most effective treatment protocols
	Recognize that chronic, persistent infection can occur
Friday, Feb 12th 6:27PM	I paid thousands and finally got recognition.
	I need antibiotics that are not licensed in the country, this is WRONG
Friday, Feb 12th 5:23PM	Like patients who have syphilis I would like open ended treatment based on how I am. Antibiotics pulsed and appropriate antibiotics to lyce the different forms borellia takes when under threat. All GPS need to be trained to recognise lyme disease and its symptoms and not treat us as blood test results, listen to what we are saying and not to be arrogant about something they know nothing about. Then once symptoms have stopped to continue treatment for a few months to hopefully prevent a relapse. Also there should be specialist llmds that can prescribe iv antibiotics as soon as a diagnosis is made. The NHS needs to research and find better tests for this disease that are accepted. Even the unreliable tests we have now the GP's don't even know how to decipher them so at one time there was one pathologist in South Hampton that was so arrogant that she told GPs that even when the test was positive they should not great because positive only meant you had been exposed to borellia at some point! I had multiple erythema migrans and still no consultant would agree with my GP that it was lyme disease.
Friday, Feb 12th 6:07PM	I want the NHS to start treating people with Lyme disease with the respect that those patients deserve, and also I would like the NHS to listen to the patients with Lyme disease and then they may learn how it effects each individual patient, I would also like the NHS to send their Gp's on training courses to educate the GP's about Lyme disease, and I would like the Gp's to do more regular testing for Lyme disease specifically on people who have already been diagnosed with it, instead of just leaving those patients to hang in Limbo with nothing offered to help those patients. also I would like to think that the NHS would bring more awareness to the public re Lyme disease, they need to spend some money on awareness campaigns through the media etc, to try and prevent more people suffering from Lyme disease, in general I would like the NHS to change their attitude towards Lyme disease and stop brushing it under the carpet as if it doesn't exist
Friday, Feb 12th 6:05PM	I want the NHS to provide Doctors who are trained and have in depth knowledge of Lyme Disease and all that comes along with it. It would be nice to speak to a qualified doctor who has actually dealt with Lyme Disease Patients and someone we can trust will understand and believe the symptoms you or your child are describing and be dedicated it treating you until

	they are satisfied you are completey 100% symptom free !
Friday, Feb 12th 5:32PM	I want the NHS to acknowledge that lymes exists in the UK and that they need to realise people are deteriarating right infront of their eyes. They cant go around misdiagnosing people and in some cases refusing to diagnose some patients. I want more money to be put into researching lymes disease, get a sufficient reliable test as the one currently being used doesnt test for all the strains of lymes and find treatment, not just one type of treatment, various treatments that will help people with different strains and at different stages as not every case is the same.
Friday, Feb 12th 4:32PM	Understand lymes is serious. It's not easily cured and you can help.
Friday, Feb 12th 4:33PM	recognise lyme disease and treat holistically
Friday, Feb 12th 4:19PM	Reliable testing
	Listen to patients
	Be willing to learn
	Provide a range of effective treatments (including herbal regimes).
	Support for our symptoms (care systems in place and mobility aids etc).
	Map geographical lyme and co infection data
	Research, research, research!
Friday, Feb 12th 3:33PM	The NHS needs to;
	Improve testing for Lyme disease, it is not accurate
	Liaise with experts in the field (not in the UK) and research best treatments.
	I am a walking example of failure by the NHS but success elsewhere.
	Educate GPs to suspect Lyme for many idiopathic illnesses and to diagnose based on history of exposure and clinical symptoms.
	Understand that this is a far greater problem than PHE realise and proper investigation and treatment will save billions of misspent prescriptions for people to manage symptoms rather than addressing the real cause, Lyme.
Friday, Feb 12th 3:16PM	Can the medical profession find some humility? Why do they espouse patient entered care and deny the reality of the lives of those with chronic Lyme? Why do they talk of evidence based medicine and ignore the medical journal papers that indicate inadequate serology testing, persistence of infection and involvement of co-infections? Do we have any clinicians left or can our medics only practise by lab testing everything?
Friday, Feb 12th 2:57PM	I want them to stop telling me that I don't have Lymes disease
	I want them to refrain from steering me towards some other illness.
Friday, Feb 12th 2:42PM	More research is needed on how to detect it and treat it , it should be made a recognisable illness
Friday, Feb 12th 2:16PM	I want the NHS to accept Lyme disease
	I want NHS Lyme blood tests to be more sensitive so our results are positive
	I want them to understand how Lyme affects their patients
	I want them to believe us
	I want them to accept other lab results on Lyme, from other countries until they have more sensitive testing
	I want them to research and learn from the US how to treat patients, then to treat them with long term antibiotics if that is required.
	I want them to stop humiliating patients telling us we are making it up and its all in our heads.
	I want them to stop spending money on treatments that are not going to help us
Friday, Feb 12th 1:29PM	Doctors need to be trained and know about it, there needs to be better tests and appropriate treatment, way too many patients are being diagnosed with the wrong things.
Friday, Feb 12th 1:28PM	Apply the science, not opinions (honest or dishonestly held)
Friday, Feb 12th 12:59PM	Testing to be improved
	GP knowledge of Lyme.
	Recognition of chronic & neuro Lyme

	Most importantly recognition of co infections and treatment with multiple drugs/pulsed regimes, and more natural routes
Friday, Feb 12th 10:52AM	Please adopt the ILAD (International Lyme and Associated Diseases) Protocol as it works. Two weeks antibiotics will only work if you catch the disease within a couple of weeks, after that the disease will return as a chronic condition attacking the immune system, the nervous system, the brain, muscle tissue and lots of other nasty things. The Elisa test also only seems to work within a few weeks after being bitten, there is a lot of information the government are ignoring. I am not a shirker but my life has been ruined by this disease, I gave up with NHS, as they gave up on me.
Friday, Feb 12th 10:31AM	GP's should be taught to recognise Lyme Disease, people don't always have a rash and many do not remember a tick bite. It is the second great imitator the first being Syphilis.
	The ELISA test is not fit for purpose, it should be changed for a more accurate diagnosis.
	The NHS should recognise that chronic Lyme Disease exists and realise that the bacteria persist and are not eradicated by two weeks of Doxycycline.
	GP's should learn that Lyme can present in unusual ways, with neurological or psychiatric symptoms.
	Doctors should be taught more about Lyme Disease so that they know it is not rare and it is actually in people's parks and back gardens.
	The NHS should ensure that Consultants who know how to treat Lyme Disease are available to patients.
	The NHS should recognise that people with Lyme and Coinfections are mostly very ill and unable to travel far or at all.
	The NHS should be compassionate towards chronically ill people and not be patronising or dismissive towards them.
Friday, Feb 12th 9:50AM	Find a cure
	Develope accurate diagnostic tests
	Educate doctors properly
	Have Insurance cover Lyme disease and chronic Lyme disease
	Admit Chronic Lyme disease is real
	700 peer-reviewed studies prove it according to ilads.org
	It is a pandemic, therefore treat it as such
Friday, Feb 12th 9:08AM	Wake up and recognise it and start helping people and being kind
Friday, Feb 12th 8:18AM	Listen to the patients and work with thier needs and admit that a standard dose of antibiotics isn't enough when the patient has shown signs of this disease longer than just being treated as just bitten!
	Also better training into Lyme's and its persistence!
	A longer and stronger baseline treatment time period!!!
	And if needed a constant treatment based on the patient's needs and not the needs of the NHS to keep costs down!
	Also recognizing relapses without having to beg for medication!(judged by the fact you are positive either now or past and not treat it as if you were infected at some point!.
Friday, Feb 12th 7:14AM	The general approach needs to change. Drs that understand and acknowledge Lyme disease as possible diagnosis for patients. (No raised eyebrows when patients mention the disease!) Funding and resources put into research.
Friday, Feb 12th 8:05AM	Recognise this often becomes a chronic long-term condition if not diagnosed and treated agressively early on. Spread more awareness of this fact among doctors. Offer long-term antibiotic trials, and if people improve don't tell them they've had enough antibiotics. I have been told by several NHS "specialists" antibiotics won't help me anymore, and there is no proof for chronic infection (yet there is in about every animal & lab study ever conducted..), yet got myself back to being able to work full-time in a demanding job again by self-treating. So I basically wasted 10+ years of my life (and narrowly avoided killing myself) when I could have recovered ages ago.
Friday, Feb 12th 7:24AM	proper testing and treatment
Friday, Feb 12th 5:55AM	provide a diagnosis and treatment
Friday, Feb 12th 6:28AM	Please treat your patients. I am proof that you can get better and get back to work but now symptoms have started again, please continue to treat if symptoms return. I don't want to not work. Please help us!!

Friday, Feb 12th 6:10AM	Please treat your patients. I am proof that you can get better and get back to work but now symptoms have started again, please continue to treat if symptoms return. I don't want to not work. Please help us!!
Friday, Feb 12th 6:20AM	A good reliable blood test and treatment that works to begin with plus recognition of late stage Lyme, differentiated from chronic Lyme which has been treated been symptoms persist
Friday, Feb 12th 6:09AM	Come up with a proper accurate testing programme to first of all check for Lyme disease and then choose an appropriate way to treat it and provide support for those who need and are entitled to it. We pay are taxes to the government for services such as NHS and yet we are being denied a service we are entitled to.
Friday, Feb 12th 5:44AM	Quicker off the mark to do the tests as the longer it's left, the harder to clear up and longer lasting damage.
	More accurate tests.
	If tests are requested and blood is taken, run the tests - mine were not run and then I was told they were normal. But they were not run and this has been confirmed.
	Develop better protocols for administering antibiotics as it is known that the multiple forms are needed to clear up the infection.
	Less emphasis on trying to pass the 'blame' for symptoms on to mental health. Keep focused on the cause.
Friday, Feb 12th 5:39AM	I want them firstly to accept it is a disease ..to start treating one as a person instead of thinking and treating us if we were all got head issues ,, where they think and tell you its all in your head ... to be honest and tell you they don't know much about lyme ,, instead of brushing you off or passing the buck and tells you to see a therapist ...
Friday, Feb 12th 3:01AM	Recognise this illness and treat it effectively
Friday, Feb 12th 2:41AM	I think there should be better testing and all people presenting with ME symptoms should be tested for Lyme disease. Doctors need to be educated regarding Lyme and co infections. There should be better more comprehensive testing.
	4 weeks antibiotics is not always the treatment required and they should understand that people can have chronic Lyme as well as co infections.
Friday, Feb 12th 1:34AM	- Make it clear to all GPs that if someone presents with the classic bullseye rash that they must be given antibiotics straight away.
	- Develop a more reliable test for Lyme
	- Develop a treatment for Lyme patients who have had Lyme for many months or even years (so a short course of antibiotics won't be effective enough)
Friday, Feb 12th 12:59AM	Listen to Lyme experts. My ID specialist NHS says I have more knowledge. Private dr suggested meds but can't pay for them.
Thursday, Feb 11th 7:36PM	Be more open minded and less judgmental when a patient suspects Lyme Disease
Thursday, Feb 11th 5:56PM	GET EDUCATED ....
Thursday, Feb 11th 5:10PM	Completely overhaul all vector-borne disease research, and the education of doctors. Stop thinking that Tropical Diseases so called, exist only in the Tropics. There are parasites in temperate countries too.
	Appoint a Lyme Czar, or a vector-borne disease czar, and go back to basic diagnostics. Use microscopy. Use the mouse infectivity test even, which is a type of culture test, or follow the already-designed culture tests and set them up in regional hospitals.
	Do whatever it takes to diagnose which people are infected, and to what degree, and give them the best treatment. After all, billions of animals are being dosed with antibiotics each year, so why not humans?
	Recognise that this illness is like TB and Syphilis, and like the latter, it's a danger to the spouses and children of infected patients. And also, like Syphilis, it can cause dementia.
	Investigate properly the pathology of all brain diseases, ME. MS Alzheimer's, etc, and stop ignoring the latest research. Get your heads out of the sand, and protect the population, as is your duty to your country and your profession, be you a doctor, MP or military officer - this needs your full attention and full transparency.

Thursday, Feb 11th 5:38PM	More research is needed into chronic lyme. Private treatment is expensive and I cannot work. Doctors have observed what works, long term antibiotic combinations with other therapy. However, this has not been proven in the right kind if studies hence is not known or believed by many.
Thursday, Feb 11th 5:29PM	Support us. Help get us well. More research is needed. Its been a nightmare thats gone on and on too long and never feeling well. My condition and treatment is not adequate.
Thursday, Feb 11th 4:56PM	The NHS need to recognise that their refusal to acknowledge Lyme is causing people to suffer in an enormous number of ways and to varying sometimes terrible extents. For some their lives are still acceptable and sustainable. For others, their lives are totally destroyed on every level, and some victims ultimately die. It is a humanitarian issue, one of basic human rights, that the NHS educates itself on what is already known about Lyme, that understanding is furthered, that GPs et al. are trained to recognise it and everything that goes along with it, that correct accurate diagnostic tests are used, and that proper treatment is given. News flash: 2 weeks of doxycycline does not, has not and never will treat Chronic Lyme. The more doctors have a complete and systemic understanding of Lyme in the broader sense, including co-infections, viruses, how the gut, the heart, the brain, the mind and the immune systems can be compromised, the better they will be as doctors and the more useful in every way to their patients, Lyme infected or not.
Thursday, Feb 11th 4:52PM	Acknowledge that this isn't acceptable. Offer specialist expertise and guidance on best route forward.
Thursday, Feb 11th 4:29PM	We need to see specialists, I don't want a GP to prescribe to me. Every GP i have seen knows little or nothing about Lyme D and can mess people up. For example, I have been sick following a tick bite 20 years ago. I was prescribed Doxycycline by my GP, which is no good for a chronic Lyme infection. It only helped temporarily. I think we need much much more than Antibiotics. They have actually done more harm to me than good. We need to be supported with herbal and high strength vitamins and minerals, which actually cost more than Antibiotics, I cannot afford to buy them on benefits. Prescription strength probiotics should be prescribed for those on ABX. I would NOT trust a NHS doctor to treat me for Lyme Disease currently.
Thursday, Feb 11th 2:54PM	The NHS need to research and get fully trained and start to get people better FAST!!!! And use better testing so all us suffering can get on the right treatment and have trust in the doctors.
Thursday, Feb 11th 3:32PM	Please give us support, medications, home services when needed, referrals etc. We don't want to be dismissed.
Thursday, Feb 11th 3:20PM	More awareness and research to finding proper treatment. Let patients make their own decision on treatment. We shouldn't have to leave the country for treatment. Classify lyme disease as chronic and have insurance companys pay for treatment. Make every doctor aware that lyme affects the entire body and mind.
Thursday, Feb 11th 3:24PM	Yes - more understanding of condition and its effects on the sufferer
Thursday, Feb 11th 11:21AM	National Health England and N.I.C.E should allow G.Ps to use clinical diagnosis accompanied by classic symptoms for antibiotic long term treatment in Chronic Lymes Disease
Thursday, Feb 11th 12:24PM	- more reliable and improved Lyme testing
	- prescription of ABX for longer duration, immediately Lyme is suspected.
	- specialist Lyme advice, similar to Breakspear Clinic
	- more Lyme research
	- provide NHS prescriptions for the various supplements that help Chronic Lyme patients
Thursday, Feb 11th 1:41PM	Firstly have a proper test and all of the after care ready
	Recognise Lymes and linked conditions as cricical conditions to then get financial help as conditions can stop you right in your tracks
Thursday, Feb 11th 1:36PM	I would like the NHS to wake up to the fact that Lyme disease is not a rare condition, nor is it treatable with a few weeks of antibiotics. If someone like myself who was fit and healthy and a productive member of society, presents a classic bulls eye rash and a host of bizarre largely neurological symptoms...then diagnose clinically even if the NHS test says 'borderline/equivicol'. Stop misdiagnosing people with 'M.E' and look at why this person has these symptoms.
Thursday, Feb 11th 12:12PM	Take them seriously, retreat with antibiotics if required at a dose and length higher than a couple of week and use other treatments taylored to individual needs, not one size fits all.
	Educate Drs/nurses with new information on whats known, that lyme is increasing, not rare.

	Check routinely (but with better tests or microscopy) anyone presenting with RA, ME, FMS, MS, Alzhiemers/dementia etc especially those who have other inconcludive test results and all those not responding or poorly responding to meds for the diagnisis they have.
	Ie if diagnosed with RA and still getting sicker or no relief, check for lyme
	Also check for other, co-infections of anyone presenting with Lyne especially severe symptoms or slow improvement or relaspe after treatment.
	ME is meant to be a diagnosis of exclusion, you can't exclude lyme, just because the patient can't remember a tick bite!
	But above all take Lyme disease seriously.
Thursday, Feb 11th 1:06PM	The nhs need to take this more seriously and be more clued up on treatment plans and symptoms etc as they don't know enough about who the desease works or affect people long term unless treated straight away but if people are late they need another plan to go by. Also they need to treat people with more compassion as its soul destroying having your fitness and wellness taken from you and them telling you it's in your head.
Thursday, Feb 11th 1:02PM	Better testing, better knowledge and understanding by dr's. Realisation that 2 weeks antibiotics isn't enough. I was tested by the NHS for Lyme and it came back negative after years of illness. So that was that, in their eyes I didn't have it and still haven't!! In truth I am still suffering from chronic Lyme disease and live with the realisation I could relapse at any time.
	I was fortunate enough that my parents could afford for me to be tested and treated privately by The Breakspear Medical Group. The NHS have agreed they have failed me and have only offered me pain management and antidepressants over more than 15 years of illness. I would be in a wheelchair or dead if it wasn't for my private help! But how many people suffering do not have the opportunity to pay for their health care, and in this country they shouldn't need to. I think it's disgusting they way people with Lyme disease are treated.
	Thank you John for all you are doing to help, it is so greatly appreciated to those suffering. Lymies feel they don't have a voice.
Thursday, Feb 11th 1:18PM	recognition of labs in Germany America and holland stop covering lyme up recognise lyme for the serious illness it is and treat accordingly
Thursday, Feb 11th 1:15PM	I would love the NHS to be more aware of Lyme and co infections. I wish they would use better tests and train gps to understand that chronic infections won't show antibodies on current tests. I would love to see them offer longer treatment than they currently do.
Thursday, Feb 11th 12:03PM	Listen to patients. Learn about it . Be open minded . Test at prop labs and be open minded to the right treatment Learn from top lymes specialist like horovitz
Thursday, Feb 11th 11:21AM	I want the NHS consultants to be trained in Lyme and all associated conditions with Lyme, to carry out their own research.
	I would like to be able to receive multiple classes of antibiotics which help improve my health.
	Look at chronically sick patients blood under a darkfield microscope and treat accordingly.
Thursday, Feb 11th 10:17AM	I live in Belgium but similar situation as in Uk: doctors dont believe in chronic lyme. I paid 3000 euro for a dIagnosis: a treatment is 10.000 euros a year! I want lyme to be recognized, especially chronic lyme. NHS in Belgium and other authorities see it as a new name for cfs so they dont have to pay for it. They think you are crazy and put you in psychiatric hospitals!
Thursday, Feb 11th 11:23AM	Stop the lies...start a world wide educational awareness. Hire, support, lyme literate doctors. Research, train all medical nurses, labs, gps, staff on lyme disease and co infections, open millions of free lyme clinics world wide. Don't force vaccination on immune suppressed lyme patients or their families. Free metal testing for all lyme patients. Free chelation for all lyme patients. Awareness, acceptance and change the way our medical society ignores lyme disease. Recommended punishment to anyone who hides the truth or harms a lyme patient, which prolongs their suffering or death. Their must be consequences for the lives lost and there must be change in helping in all areas of awareness, research, treatment and education and support.
Thursday, Feb 11th 11:47AM	I would like the Nhs to have a more reliable blood test for lymes disease and then give the appropriate treatment.
Thursday, Feb 11th 11:11AM	Believe us, support us and treat us. Nothing more and nothing less.

Thursday, Feb 11th 11:06AM	Even if the NHS test comes back negative accept other tests or at least treat the symptoms, especially if other diseases have been ruled out. Proper dosage of antibiotics not just 3 weeks and ideally for chronic patients intravenous antibiotics should be used. My vet said if they had an animal showing signs of Lyme they would treat for 3 months not 3 weeks
Thursday, Feb 11th 11:05AM	Test more widely, use a more sensitive test, diagnose clinically, and treat more agressively. Accept the existence of Lyme in its chronic form.
Thursday, Feb 11th 11:03AM	Enlist a quality testing protocol and adequate response
Thursday, Feb 11th 10:37AM	Not wait for a possible positive blood result act on the rash its so important to get early diagnosis.
Thursday, Feb 11th 10:23AM	I need help to continue treatment. I am in the US. I know you are all suffering too. My prayer is for all to receive help. I pray to not die before I can help someone else not live this nightmare.
Thursday, Feb 11th 10:04AM	An "legalized" LTT Test or other parameter !
	More engineering with "open access" for all!
	longterm Antibiotics if nobody now what helps whey cant the Doc give long term antibiotics and no "after Lyme Syndrom".
	If Prof. Erbguth postulat that 3-4 % of the people had pos. ELISA and Westernblot test without Symptoms then i want to made a Bloodtransfer with these Guy, in her opinion it isnt dangerous only max 4 Weeks Antibiotics. No Test as comparison with "healthy" people !! Whow can say which people is healthy when the Test are so bad. The only solution i think is to compare the Test with other Test !
Thursday, Feb 11th 9:42AM	Have sympathy for patients and believe them.
	Provide information to GP's.
	Provide reliable and accurate international testing which recognises chronic Lyme.
	Provide treatment for Lymes and coinfections.
	Provide treatment of viral load and coinfections ASAP.
Thursday, Feb 11th 10:13AM	Get proper testing so no one has to go through this and also help the people who are suffering! We need help!
Thursday, Feb 11th 9:56AM	Listen to the patient They have a very real story to tell you.
	Look at the patient..they often may actually look sick.
	Don't label the patient as depressed etc..since that just sticks to the file.
	Decide on a gold standard that actually can diagnose Lyme correctly. Have Medical Dr who have knowledge re Lyme .
	Develop a center of Excellence for treatment , with qualified staff.
	Financial support is necessary ..many have gone bankrupt finding a solution and many have no treatment because the can't afford to pay the inflated Medical fees charged to them.
Thursday, Feb 11th 10:06AM	Get proper accurate testing. Offer long term antibiotic treatment. Actually educate NHS doctors about the disease.
Thursday, Feb 11th 10:05AM	I wrote the complaint letter to my GP,after 6 years of being bad treated.It didn't change anything.
Thursday, Feb 11th 9:30AM	Recognised in the UK as a notifiable disease
	Correct testing
	Treatment centres
	Protection to medics that are prepared to accept patients with Lyme and coinfections
	Stop labelling a cluster of sx as M.E

	Identity how Lyme can be gained I.e tick bite, mother to child
	Screening with the blood service should include testing for Lyme
Thursday, Feb 11th 9:49AM	Proper testing (I contracted Lyme in the US and they don't test for this species), proper treatment and understanding of the related conditions. My daughter has PANDAS, CFD, Autism, other auto antibodies causing seizures and neuro symptoms. Not one NHS consultant understands it. We are treated in the US at a cost of more than I take home every year. It's a disgrace.
Thursday, Feb 11th 9:47AM	I've been tested positive three timess by the NHS but they still refuse any long term treatment. I'd like to have more treatment and I'd like all doctors and consultants to know about the illness. So far I have yet to meet any doctors or consultants who understand it at all !
Thursday, Feb 11th 9:38AM	Be aware of it and do the proper tests that are accurate. They would save themselves money in the long run. Also you can diagnose Lyme from looking at symptoms. I had the bullseye rash but doctors ignored it.
Thursday, Feb 11th 9:42AM	Be lyme literate for starters and able to recognize the symptoms rather than pass them off as depression or worse.
Thursday, Feb 11th 9:34AM	Not Diss us but help us. Take away the fear of gps and a&e where we're not taken serious. Etc!!!
Thursday, Feb 11th 9:33AM	Primary Care Physicians should have education of Lyme Dr. on staff!
	Better blood testing.
	Insurance benefits for testing and medicine, even alternative methods!
Thursday, Feb 11th 9:22AM	Correctly test
	Test for old infections and new
	Provide treatment and support
	Give adequate info to be accepted by dwp
	Just help us in the we need
Thursday, Feb 11th 9:21AM	We need better treatment and a cure . Idsa needs to stop denying that chronic lyme don't exist . I can see the spirochetes in my blood using a dark field microscope how can they denied this .
Thursday, Feb 11th 9:20AM	Take us seriously.
Wednesday, Feb 10th 3:44AM	1. The NHS and Public Health England need to publicly acknowledge that Lyme disease is here and becoming ever more rife in the UK and to understand just how many people are suffering in this country. But I suspect this won't happen until the US, whose health authorities are still sitting on a very wide fence, start treating their Lyme patients.
	2. Acknowledge that the testing is far from adequate in the UK. So many receive a negative test result but positive from Germany or the US. I know of people who are routinely told they cannot have a test "as its winter or as there are no infected ticks in this or that part of the country.
	3. There needs to be fast track training of front line staff - GPs; A&E doctors; all specialists in particularly as I know from experience and that of others that ID specialists do not take Lyme seriously at all.
	4. Set up clinics around the country where GPs can refer patients who think they may have Lyme. However, at the moment there is little expertise and the one clinic which was opened in Winchester wasn't open for very long as the anticipated trickle of patients turned into a veritable flood and the clinic was closed because the funding authority said they could no longer afford the funding.
	(Although Tim Brookes of NHS England is well aware of this as he has attended several recent Lyme Disease Action conferences).
Tuesday, Feb 9th 7:22PM	Listen to patients recognise em rashes and the symptoms drs are so terrified now of prescribing antibotics even for my constant utis they keep on retesting they will not listen why on earth would anyone make up having these things the nhs guidelines tie them up in red tape to the point where they fear to do anything .

Tuesday, Feb 9th 4:38PM	Research.
	Improve testing.
	Educate doctors/ specialists.
	Accept testing from accredited labs abroad.
	Give correct ongoing treatment.
Tuesday, Feb 9th 6:00AM	To wise up and become more Lyme literate. To accept the chronic condition and offer patients the Elispot test as opposed to the Elisa test. Refer patients to natural health practitioners for treatment as an alternative.
Monday, Feb 8th 6:20PM	Try and diagnose symptoms earlier and treat accordingly.
Monday, Feb 8th 6:00PM	Believe.. research...treat....acknowledge...help....offer as much support as necessary for ever long as needed and MORE PLEASE!!!
Monday, Feb 8th 1:19PM	Yes. There should be more research and education or the medical profession. Many NHS professionals are either dismissive of the Lyme diagnosis or do not know how to deal with it.
Monday, Feb 8th 7:09AM	Acknowledge the problem and the scale of it!! Look at all the evidence and form an objective opinion, one not coloured by political or economical concerns.
	Improve testing
	Educate GPs
	Treat people, not leave them to develop a chronic extremely debilitating illness.
	Educate the public - awareness and prevention
	Do everything they can to prevent such large scale negligence as is currently occurring.
Monday, Feb 8th 10:11AM	Research better Lyme disease tests and treatment. Test all patients who present with meningitis for Lyme disease, as this is often an indicator of Lyme neuroborreliosis (when borrelia crosses the blood brain barrier and goes into the brain).
Monday, Feb 8th 10:18AM	Give me a professional that will help me cope with this terrible disease. Better testing and a GP that knows how to treat me
Monday, Feb 8th 9:18AM	I would like to see better testing as when I originally was under a specialist at the hospital for tinnitus and hearing loss they did tests and picked up nothing. They wanted to fit me with hearing aids...... My wife had an ear operation many years ago and pushed for a second opinion with the same doctor........ In the meantime I was at A and E as I had facial palsy. I went to see this other doctor and he re started assuring me he would get to the bottom of it. He did and diagnosed me with Lymes....... He had suggested I v treatment but when I saw the foreign disease specialist she put me on antibiotics........
	I want them to be more thorough and medication needs to be longer....... As I am now feeling worse than 2 years ago..... The specialist basically says " oh you got chronic fatigue, it's totally different.
	I think it's disgusting that I have paid my stamp all my life and worked full time and the nhs doesn't look after us better, so many lyme patients go abroad and pay, they are selling there houses to get funds, it's disgusting
Monday, Feb 8th 8:29AM	Recognise the symptoms as a serious and debilitating illness. Try to help to treat instead of denying that there is actually anything wrong with the person just because your tests and diagnostic skills are sub standard. It is hard enough living with an illness like this without having to battle with the people who should be supporting you.
Monday, Feb 8th 7:45AM	1. Have awareness of what an EM rash looks like - mine was really quite horrific looking and was missed by so many doctors and consultants including dermatologists and rheumatologists.
	2. have the GP in a position where they can make decisions themselves - mine sought 'advice' from an ID consultant who told them categorically that I could not possibly have lyme - despite tick exposure, the EM rash and positive lyme results.
	3. Challenge the ID consultant views and things they say. i.e. lyme is easy to diagnose and easy to treat. They are dangerous in the way they approach lyme - really very inappropriate.
	4. Have a lyme expert available as a consultant across the UK for medics to call for advice - one that is not dismissive of lyme.

Monday, Feb 8th 6:46AM	Development of better tests to be available of the NHS. Full review of Antibiotic regimes to treat Lymes disease. Raise awareness among Medical practitioners of the long term consequences of inadequate treatment of Lymes disease.
Monday, Feb 8th 7:03AM	Better diagnostic testing, the NHS test is useless
	More awareness of the life cycle of Bb, which will affect the testing outcomes
	Diagnosis on clinical symptoms as well as testing
	More awareness within the medical profession.
	My GP told me that Lyme was rare, yet when I went for a blood test at the same surgery the phlebotomist told me that more and more people were asking for testing.
Monday, Feb 8th 6:43AM	Offer better treatment and make doctors aware of. Lyme disease. I wouldn't have been diagnosed under the NHS as nobody even considered testing me for Lyme. Instead I was fobbed off with Valium as nobody believed me that I felt so unwell.
Monday, Feb 8th 6:30AM	It's too late for me. But they need to educate the Dr's and the patients. Lyme should be a clinical diagnosis but the use of specialist labs like igenx should be encouraged as well as other testing methods. The Elisa is useless and the Western blot is flawed. The NHS is as usual nearly 20 years behind the US and is making Britain look foolish. Patients need to be given a choice after initial treatment to continue long term or to try other methods by educating them on the pros and cons of long term antibiotic use. Also secondary infections need to be addressed as well as other physiological changes that can occur. It is a long process and there is much to learn. They need to import experts like Dr Harold Smith and Dr. Robert Bransford and learn from their experience as well as research and study. Rather than holding back treatment, Britain should be funding research. Over 200 countries are affected, instead of being a laughing stock just once I'd like to see the UK leading global research and development. Maybe we could find a cure .
Monday, Feb 8th 5:59AM	Recognition. It is not recognised that is can become chronic, nor that it is epidemic in our country. Treatment. Is not up to date nor adaqate. GP's are not trained in dealing with symptoms or realise how fast it must be treated for what length of time etc. Testing is out of date. We need to be up to speed with current capabilities and research. Awareness that Lyme comes with co-infections which are extremely hard to treat. Support for a disease which at the chronic stage can be and feel like life and death. Protection for our children for everyone. Which involves campaigns to Schools and public notices showing warnings etc.
Monday, Feb 8th 5:35AM	Invest in and implement Lyme Disease centres that offer reliable blood tests, treatment and support protocols to address the illness with a view to cure.
	1. Reliable bloodtests for early diagnosis of not only Lyme Disease, but full bacterial, to identify any co-infections which often are neglected and not treated.
	2. Acknowledge that when a person was active before and suddenly becomes bed-bound to accept something more serious is the matter and refer to 1.
	3. Look at the symptoms on a whole and not in isolation, ie stomach flu that lasts for several months to be investigated further and if nothing wrong, to refer to 1.
	4. A treatment protocol that are not only killing and stifling bacterial growth, but also a support protocol that helps the body to cope with the bacterial die-off and symptoms experienced. For example, understanding the meaning of low iron and high cholesterol and re-evaluate when other bacterial related symptoms are present.
Monday, Feb 8th 6:09AM	Get educated go to see LLMD in US and get the right treatment protocols this disease and its co infections require personalized treatment .. One dude does not fit all everyone will tolerate and get results at different dose levels increasing over the days and months ... Much education is needed to much denial
	I was lucky I went to see a LLMD in the USA he gave me my life back
Monday, Feb 8th 5:53AM	1) Diagnose clinically where there is a clear clinical picture but negative serology.
	2) Develop better testing methods and educate doctors/consultants about the fact that current testing lacks sensitivity and that a negative doesn't mean the patient is clear of lyme disease.
	3) Liaise with leading doctors like Dr Jemsek in the USA to help find better treatment methods.
	4) Look into possible contamination of blood with Lyme and other tick borne diseases.

	5) Take a more cautious approach with maternal transmission - i.e. it's not proven that it can't happen to all should be done to clarify this and preventative measures put in place for pregnant women with Lyme in the meantime.
Monday, Feb 8th 5:48AM	To stop lying and denying it, and refusing to test, treat or research it properly (and that applies to many other illnesses as well as Lyme eg B12 deficiency, anaemia, cognitive deficiencies, etc ...
Monday, Feb 8th 4:12AM	Give better blood tests especially for Lyme and co infections and then give the treatment they need including supplements and the necessary treatment to support the body. When you get Lyme the body can develop all sorts of problems like thyroid and adrenal issues, poor mitochondria function, chemical sensitivity, food intolerances, bacterial overgrowths, sleep issues, gut issues - ALL of these need to be looked at with better testing from the NHS. If a person has Lyme then all of these areas need to be properly checked and then treatment given to help repair. There would be no point just treating the Lyme because that would be like fixing a car but leaving it on flat tires. The whole body needs the right care, doctors need to understanding hoe diet change can help, hoe supplements will support the body, how detoxing needs to be carried out - their is a serious lack of understanding on HOW to treat Lyme and all it does to the body. If you want to get an idea then go to a Lyme Facebook forum. You'll soon see what we go through. And if doctor don't get it then ask them this - what would they do if the person asking for help were your son or daughter?
Monday, Feb 8th 4:44AM	I want them to have a clear action plan for when people are diagnosed with Chronic Lymes, my doctor spent too much time hesitating - I'm still waiting for some form of treatment now
Monday, Feb 8th 4:11AM	Have a better understanding and knowledge of the disease to treat accordingly and in time to treat successfully.
	Our Dr said that my son's EM rash was a normal bite and she sent him away with some anti histamine cream. It was only 3 months later when we heard something about Lyme on the radio did we go back to the DR with evidence that it was Lyme that anti biotics were prescribed - probably too late!
Monday, Feb 8th 4:00AM	1st - admit that Lyme is not rare & that you can catch it in the UK.
	2nd - recognise Chronic Lyme Disease as an illness, when symptoms persist after initial treatment.
	3rd - listen to the patient, they know their own bodies & treat the symptoms.
	4th - find better ways to treat - mainly look at the whole person, not be sent off to different specialists that only understand their chosen subject & who don't understand the connection with other parts of the body, with a multi-system infectious disease. Dedicated Lyme Disease Experts who can study the whole body?
Friday, Feb 5th 5:09AM	1) Accept that the ELISA test is not definitive and offer Western Blot testing as standard. Also the NHS should release full details of the test results including all band results to the ordering physician and patient as standard.
	By way of example, I have a PCR positive result from a laboratory in the USA yet I have not been offered a Western Blot test. The ELISAs I have had only report back IgG negative and so I suspect that they are IgM positive but that information has not been given.
	2) Accept results from foreign laboratories
	3) Remove the restrictions on prescribing antibiotic treatment for lyme disease patients. As one GP shared with me... it is ridiculous that patients with acne can be treated with antibiotics continuously for years, yet patients with a proven or suspected systemic bacterial infection can be treated for no longer than 2-4 weeks.
	4) Explore chronic infection (including lyme) as an underlying cause of other medical conditions. The NHS is divided into specialisms and there are a lot of consultants who look at a single aspect of the body or a discrete set of symptoms without looking to the rest of the body to identify interactions and underlying causes. There is a sticking-plaster approach to treating NHS diagnosed conditions by concentrating on managing symptoms, rather than a desire to identify causative factors and help the body heal. The NHS would be well advised to have a couple of general medicine practitioners in each hospital who are capable of looking at the whole body-mind presenting to them rather than the individual body part(s). This approach is

	likely to identify infective causes much more successfully. Essentially, the NHS needs a "House M.D." in every hospital!
Sunday, Feb 7th 3:37PM	Look out for the signs
	Be polite to Lyme patients
	The blood test needs to be reliable
	And give out the correct care eg antibiotics
Sunday, Feb 7th 2:52PM	Treat it more seriously and admit the scale of the problem
Sunday, Feb 7th 7:51AM	Treat sufficiently with pulsed and combination antibiotics which address the cysts and biofilms as well as the bacteria itself. Treat each patient as an individual case. Recognise that the associated health conditions could be caused by Lyme and not dismiss this possibility.
Sunday, Feb 7th 6:07AM	Treat us effectively, long term and most importantly recognise this disease and the complexities it presents. It's soul destroying fighting for recognition and being made to feel humiliated and insane by doctors when life with Lyme is difficult enough.
Sunday, Feb 7th 4:50AM	The guidelines for treating / diagnosing should change to take into account clinical history & not rely slee on an inadequate & notoriously reliable blood test. Their is still a tendency to diagnose 'depression' when an obvious cause isn't available. ME / CFS should not be diagnosed until other causes - Lyme / tick borne diseases , HIV, MS, Lupus etc have been ruled out. It took 4yrs and threatening my PCT with legal action to get any investigations & a referral to an .infectious ?Diseases Clinic. Where after extensive testing a German Immmunologist said *off the record* that he felt I had Lyme & if I was presenting in .germany would admit me to hospital for intravenous antibiotics, but as I didn't meet NHS criteria he could not treat me and could lose his job for suggesting it. He said goodbye and good luck... That was devasting.
Saturday, Feb 6th 1:56PM	Please educate doctors, other health professionals and government bodies (NHS, HPE etc) about the reality and seriousness of untreated tick bites and remind doctors that the EM is diagnostic, so NO further tests are required if this rash is observed.
	Please continue to warn the public of the risks of acquiring a tick-borne infection and the potentially life-threatening consequences of delaying treatment.
	Please research and disseminate widely new treatments for tick-borne diseases.
	Please develop rapid, reliable screening tests for borrelia and for the other common co-infections.
	Please please PLEASE! - tell doctors to stop using the USELESS IDSA/CDC guidelines and use the ILADS guidelines instead!
Saturday, Feb 6th 2:55PM	Accept that this disease does indeed exist in the chronic form and is not the figment of our imagination. Nobody wants to live in pain. We are not looking for attention. We need real medical help and understanding. All NHS medical staff need training on how to identify, treat, and manage Lyme disease.
Saturday, Feb 6th 12:32PM	The NHS should do in depth investigation for Lyme and not rely on the antibody test for confirmation. The NHS needs to research treatment plans for anybody showing any signs of Lyme. The NHS need to educate GP's into the complexities of Lyme so that they are equipped (and I purposely missed out better equipped as they seem to be totally ignorant of symptoms)to diagnose symptoms being presented to them by patients.
Saturday, Feb 6th 10:21AM	I would like the NHS to create a support unit for Lyme, learning from perhaps LLDMs in America. A team of Lyme literate doctors would be a dream come through. The guidelines for treating Lyme and the blood tests must change as they are to non specific and not up to date.
Saturday, Feb 6th 9:53AM	I think the NHS should undertake and improve their method of detection of this disease in line with other countries such as Germany and the USA. Also to realise how it affects many other bodily systems such as endocrine, cardiovascular, neurological , gastronomical etc and treat accordingly.
Saturday, Feb 6th 8:56AM	Provide ACCURATE testing, support for people who are suffering with it, as well as the correct medication. AWARENESS would be fantastic and be better educated at how the disease works and for them to stop sniggering at Lyme payients makin us feel small and like we are a waste of time etc
Saturday, Feb 6th 7:28AM	1. Stop denial & stop ignoring the many accurate research findings.
	2. Test using blood microscopy.
	3. Train all medics with the full facts including all possible symptoms.
	4. After onset re-test at appropriate intervals to ensure full recovery.

	5. Have individualised & multi-disciplinary treatments, including complementary and alternative, when disease becomes chronic.
	6. Teach medics to be kind, caring & respectful even when tests come back negative (often because the tests are not sensitive enough) and when they don't understand why a patient remains ill.
	Being treated with scorn & mistrust by most medics is almost worse than the devastation of NeuroBorreliosis and the many opportunist and co-infections.
Saturday, Feb 6th 8:11AM	See above
Saturday, Feb 6th 7:49AM	-Recognition of this as an increasing health problem in some areas
	- Immediate and in depth investigations into diagnosis and appropriate treatment regimes
	- Immediate and significantly increased compulsory training for GP's and other medical staff to identify, treat and understand this illness
	-Investment into more targeted and specific treatment
	-Significant improvement into recognition of, and treatment for, ongoing health problems after initial treatments when these have failed.
Saturday, Feb 6th 7:22AM	Start working decently and properly. YUbfortunately the agenda is to kill people. The know about Lyme disease and otheri nfective multisystemic disease but they do no want to treat them.
Saturday, Feb 6th 5:50AM	Treat them! With long term antibiotics. Don't fob them off telling them they have depression, chronic fatigue, fibromyalgia, arthritis, MS etc. Actually learn from the US ILADS doctors and treat long term accordingly.
Saturday, Feb 6th 3:32AM	They need to be aware of it and train gp's to recognise symptoms.
	They need proper testing
	They need to take it seriously and Gps need tostart listening to the patients. Really listening and taking them seriously
Saturday, Feb 6th 2:38AM	First they need sensitive tests and even microscopy to discover the infection. GPs have to able to recognize an EM rash and not diagnosed as a ringworm rush. Infection diseases Drs need to learn more about the complexity of Lyme and coinfections and treat it with long term antibiotics when chronic.
Friday, Feb 5th 6:50PM	Acknowledge that chronic Lyme disease exists.
	Educate nhs doctors.
	More research into Lyme disease.
	Lyme literate doctors in the nhs.
Friday, Feb 5th 7:07PM	NHS guidelines for accurate diagnosis and treatment made available for Lyme disease. Specialist Lyme clinics set up in all cities throughout England ,Scotland and Wales. Drs too be fully supported in treating Lyme even when it's a clinical diagnosis.
	All student Drs too be fully trained in multisystemic infectious diseases and how they can be treated rather than the focus being just on symptom management.
Friday, Feb 5th 6:46PM	Investigate thoroughly all cases of unexplained illness, instead of sending patients away with the dustbin diagnosis of CFS / ME, and with nothing further in the way of "treatment" except for CBT and GET, which are nothing more than coping techniques, not treatment of symptoms or cure.
	Start using reliable blood tests as have been developed in Europe and the USA, Diagnose Lyme clinically, not just relying on the inadequate blood tests that are currently being used by the NHS. But also to diagnose clinically, rather than relying on the blood test results alone.
	Treat Lyme Disease and its co-infections adequately, with long-term antibiotics, oral and intravenous, if necessary. Treat all the resulting conditions that Lyme disease causes adequately and in a comprehensive, holistic manner, looking at the patient as a whole.
Friday, Feb 5th 6:02PM	Training GPs about Lyme Disease and coinfections. Introduce more reliable testing. Prescribe antibiotics for much longer than 2-3 weeks.
Friday, Feb 5th 3:27PM	I would like to see Lyme disease taken seriously, more research done, more public awareness, specialist GP's in areas of high incidence of the disease, better understanding of LD in the NHS.
Friday, Feb 5th 2:44PM	Investigate better tests, realise the danger of this disease, treat and acknowledge people whilst providing the care and support we need.

Friday, Feb 5th 3:28PM	There needs to be a review of new evidence both scientific re persistence of this disease. There needs to be an education program for Drs of clinical practices used successfully in the US. Research into accurate tests needs to be done urgently. Meanwhile overseas tests need to be accepted. Diagnosis however should be made on a clinical basis, and Drs need to be educated how to do this. Lyme disease and also co-infections need to be at the top of the list for differential diagnosis for symptoms that are curently given the name CFS ME and Fibromylagia. Any disease with neurological symptoms especially Alzheimers MS and ALS should be investigated for a bacterial infection. Supportive therapies need to be provided for ongoing care to Manage symptoms.
	Further reseach also needs to be undertaken to determine both persistence
	Of the Bacteria and also immune dysfunction as a result of the infection. As these are both factors. Specilist centres need to be set up immediately. Drs need to not work in Silos. This is a systemic disease that cannot be treated by indiviual consultants looking at one body part.
Friday, Feb 5th 3:12PM	Educate GPs and consultants especially rheumatologists and neurologists
	Fda approved European blood testing eg borellia Ltt elispot or even better approved by nhs
	Approval of long term antibiotics - there are by far worse drugs to be taking as a result of untreated infections
Friday, Feb 5th 3:13PM	I told doctor I had bullseye rash, as I didn't have proof I had to wait until nearly 4 mths to get antibiotics and then not nearly enough with all the neurological symptoms. If they had just treated immediately I might not have been in this situation.
	If doctor had signed me off ill with Lyme disease it would help. Instead of exhaustion, depression, anxiety, stress, folliculitis.
	Co infections not even mentioned.. I think I have bartonella and that is why I can't get better and ongoing skin symptoms. Why is this test no longer available?
Friday, Feb 5th 2:37PM	Listen to patients and treat them with respect.
	Learn from ILADS how to treat this disease.
Friday, Feb 5th 2:14PM	Please start recognizing Lyme as a real disease that needs to be treated differently in people based on how long they have had it before they were diagnosed, symptom progression, and lifestyle.
	Covering a percentage of the doctor visits, treatments chosen based on the information listed in the paragraph above, and making it impossible to be denied help simply because of a Lyme diagnosis would be life changing for many people suffering from Lyme-related pain and fatigue.
	Educating doctors and medical professionals on Lyme, what it can look like in different people, the different ways to test for it, treat it, and the possibility that it can become a chronic illness if left untreated for too long.
	Offering nationally funded Lyme support groups would be extremely helpful in offering people knowledge on what Lyme Disease is, how to get tested, life-style changes that would compliment treatment, and emotional support as they see their life affected by a disease. Groups like these would also be able to spread the importance of why people with Lyme symptoms should get tested early.
	Thank you.
Friday, Feb 5th 1:41PM	Listen and help stop the denial
Friday, Feb 5th 9:05AM	Learn from experienced vector-borne infections doctors from the US, France, Scandinavia and Germany.
	Use the best tests available (not the insensitive ELISA, as a back up to clinical diagnosis.
	Train doctors using the ILADS guidelines.
	Listen to patients and them get better. This may sound odd, but many of us have been written off and given no help at all. Many others have been referred for psychiatric or psychological therapy, when they have chronic, treatable infections.
Friday, Feb 5th 11:22AM	1. BELIEVE THE PATIENT

	2. Diagnose Lyme disease and co-infections using the clinical presentation of the patient – do not delay treatment.
	3. Bull's eye rash is diagnostic for Lyme requiring no further testing, triggering immediate treatment
	4. Use the ILADS or German guidelines for antibiotic therapy. 200mg pd Doxycycline for 2 to 3 weeks is not enough if the symptoms remain. Pulsed multiple antibiotic therapy with an understanding of encysted forms and biofilms seems to work best.
	5. Treat the infections until there is remission - then monitor for relapse and continue treatment where required.
	6. Best results from blood tests come when a suite of tests are used (See Dr Horowitz) to decrease the likelihood of false negatives, to pick up different strains of Borrelia, Babesia etc and to overcome some of the problems of reduced antibody production. – dark field microscopy (Dr Macdonald), elispot, culture test (Dr Eva Sapi)
	7. Run tests for co-infections such as Babesia, Bartonella etc (see point no. 6), but still treat clinically even if tests come back negative.
	8. Set up Tick-borne diseases clinics as centres for excellence with consultants trained to use the most uptodate research - bearing in mind the paucity of knowledge, how very new this disease is to main-stream medicine and that we are still very much in an experimental phase. This is like the early days of AIDS .
	9. Create an open forum for Lyme Literate doctors with International dissemination and discussion of current treatment techniques, diagnostics, conferences, journal etc.
	10. All GPs and health care providers should receive training in proper recognition, diagnosis and treatment of Borrelia and co-infections.
	11. Medical training at university must be updated to include proper recognition, diagnosis and treatment of Borrelia and co-infections.
	12. Neurology consultants need to retrain in proper recognition and treatment of neuroborreliosis following ILADS/German guidelines.
	13. Infectious diseases consultants need to retrain in proper recognition and treatment of Borrelia and co-infections following ILADS/German guidelines.
	12. Provide rehabilitation and support for people who are house-bound, bed-bound, isolated or newly diagnosed - give them support to gain financial aid (PIP etc) and to counteract the physical and mental stresses of the disorder (acupuncture, massage, physio etc).
	13. Investigate the possibility of Borrelia in other disorders e.g. ME, fibromyalgia, Alzhiemer's, MS, Parkinson's, schizophrenia etc.
Friday, Feb 5th 1:20PM	Treat it.
	Understand it, more knowledgable and more training.
	Lyme specialist
Friday, Feb 5th 1:05PM	I want this problem for me rectified by what ever means, surely by not trying alternative therapies or treatment regimen, they are going against the hipocratic oath not to harm a human being.

Friday, Feb 5th 1:08PM	I want the NHS to recognise that Lyme Disease exists in this country and to give their Doctors the training needed to help patients with all forms of their illness. I would like to see the ILADS guidelines adopted in this country. Patients may need long term antibiotics and many kinds at once, also herbal treatments should be considered.
Friday, Feb 5th 1:11PM	Treat them thoroughly, with a long enough course of antibiotics to eradicate the disease. Listen to them when they say that they still feel ill and allow them to continue with treatment until they feel well.
Friday, Feb 5th 1:11PM	Find a way that Lyme disease can be treated effectively. I'm fortunate that the NHS tests worked for me… As I've actually got Lyme disease. I think some people think they have and it's making real lymies look like cranks.
Friday, Feb 5th 12:48PM	Tests for Babesia, bartonella, etc Find out how to tx lyme disease, but not to attempt this and get it wrong. Understand acute and get it right Understand their own guidelines and tx just on a bulls eye Understand that they do not understand chronic lyme and that they need to leave it to a specialist or support and pay for the patients own tx. Recognise that lyme mimics many other conditions, so that those illnesses can be rediagnosed and then tx'ed. BUT - I have no confidence that any of this will happen, and if the nhs attempt it, they will fail. With ME, they opened clinics. These were not good, they became just places for CBT and there was no proper treatment and no knowledge built up. Probably more harm than good. If they could just get one proper LLMD in one place to start, they could learn.
Friday, Feb 5th 1:04PM	belive us, treat us, dont send us away, we need help reliable tests, not just told we do nt have something, we need support orm the goverment like in my case, it wouldhelp if i couod get a few quid to get by i want to work its n my blood to graft, im a girl who was brought up to belie if u cant aford it go withoout, its hard to keep going, with working, but i do, i work i come home im shattered, i survue another week, i exsist i do not live i have very little quality of liie,
Friday, Feb 5th 11:42AM	Stop pretending an EM rash does not confirm infection. Treat suspected infection immediately with antibiotics at the acute stage. Do not wait for symptoms or a rash to developers. Prescribe appropriately. Strength of abx and length. Continue to treat NHS patients with chronic/ post Lyme with dignity and compassion. Stop treating them with derission and disrespect just because you can't CURE them. Adopt treatment protocols that show results in other countries. Stop being so pompous and insular to the extent that vulnerable people are abandoned to suffer in a hostile NHS environment. Remember your Hippocratic Oath. Remember your position gives you rights but it also gives you responsibilities.
Friday, Feb 5th 10:17AM	1. Accurate testing for Lyme disease. As recently outlined in a BMJ article current testing is not accurate. 2. Doctors educated to give a clinical diagnosis regardless of test result. This is currently done with rheumatoid arthritis. 3. "Chronic Lyme Disease" recognised as a persistent infection of Borrelia and co infections.

	4. Adequate treatment developed with resolution of symptoms.
Friday, Feb 5th 12:43PM	There should better and more reliable testing, more understanding of the problem, a better way to identify and diagnose Lyme and more treatment available.
Friday, Feb 5th 12:24PM	The main one is getting a test in place that is fit for purpose.
	After that, better education - high ALT, low testosterone and low blood count and CD57 were all pieces of the jigsaw no one could put together.
Friday, Feb 5th 12:32PM	Better diagnostics, better training of specialists, and a change in political approach. The patient is no fool and knows their body better than anyone, and what could be going wrong. Medical profession need to recognise this important fact.
Friday, Feb 5th 12:33PM	Treat and diganosise. Belief in chronic Lyme.
Friday, Feb 5th 12:27PM	Better testing that is accurate, more than 1 weeks worth of antibitics and open minded gps who understand that each patient and Lyme disease case is unique therefore more in depth treatment may be required.
Friday, Feb 5th 11:09AM	The first change would be to acknowledge that there are superior tests to the ones used by the NHS and to make them freely available. The second change would be to employ an open mind and be prepared to embrace the wisdom and knowledge of people who have explored and treated Lyme privately. More humility than the medical profession is renowned for will be required to do this, particularly as many private practitioners (some of them sufferers themselves) are medically trained and would seem to be targeted by the BMA with particular venom as a result. Lastly, they will need to work closely with the DWP so as to ensure that people who have tested positive for Lyme (with an improved test) are dealt with sympathetically. It needs to be understood that suggesting CBT or light work to someone who would give their eye teeth to be able to work or play the piano as they once did but is now devoid of energy is unbelievably hurtful, as well as practically useless.
Friday, Feb 5th 12:09PM	Research!!! Take the signs and symptoms seriously. Early recognition rather than denial or lack of education at GP level. Flexibility in treatment (length of and depth) particularly for long term misdiagnosed patients. Look at other European guidelines and see where the uk guidelines fall short.
Friday, Feb 5th 12:03PM	Treat each person like an individual don't put everyone in the same box ....to take note of what Lyme patients are telling them ...to have an open mind ...and to sort out testing methods ...
Friday, Feb 5th 11:52AM	To accept lyme, to not treat me and others like neurotics , to develop sensitive accurate tests and to treat properly and not just give 2 or 3 weeks of antibiotics and tell you that you are cured
Friday, Feb 5th 11:52AM	Believe symptoms presented rather than call me an attention seeking teenager. Counselling to give me the tools to deal with this illness. Information about my prognosis. Support and strategies. Training for GPs who openly say they know nothing about Lyme.
Friday, Feb 5th 11:50AM	Get Lyme literate doctors to educate NHS doctors & nurses so they treat based on symptoms and get better testing.
Friday, Feb 5th 11:04AM	Be much more aware of lyme disease and to lose the belief it's hard to catch and easy to treat when the opposite is often true. To recognise the bullseye rash and treat according to symptoms present. To accept lyme can be present without the diagnostic rash which highlights the need for a better diagnostic test. My many nhs elisas are negative despite the rash and ongoing neurological symptoms. To put money into research to show this bacteria can persist after weeks of treatment and to look into possible modes of transmission to try and rule them in or out e.g. sexual /saliva /in utero. To provide ongoing treatment for symptomatic people and not just manage the symptoms without addressing the cause.
Friday, Feb 5th 11:12AM	LIsten to patients.
	Show more compassion and empathy.
	Realise that this is a physical disease, not a flight of fancy!
	Create a more accurate means of testing.
	EDUCATE EDUCATE EDUCATE - doctors in training, GPs, hospitals, nurses, consultants, dentists, all health related workers.
	Set up Lyme referral units.
Friday, Feb 5th 11:29AM	Listen to the patient and treat on symptoms, and to please please stop treating us all as if we are going mad with mental health issues
Friday, Feb 5th 11:03AM	Train GP's so they know what symptoms to look out for, to stop so many cases becoming chronic and difficult to treat.

	Develop better diagnostic tests.
	Acknowledge that there can be persistence of infection after a course of antibiotics.
	Set up specialist clinics to help treat patients, with doctors trained according to ILADS guidelines.
	Try and ascertain the true prevalence of the disease, by targeting and testing a specific illness group like CFS or fibromyalgia.
Friday, Feb 5th 10:24AM	Introduce testing for borellia garinii as part of a standard panel of Lyme tests - I have tested positive for this in private tests but my NHS Scotland testing has not included this. Because of negative NHS serology I have been refused treatment and a second opinion despite a documented erythma migrans rash.
	Develop reliable testing for a wide range of borrelia species and co-infections.
	Develop UK guidelines for treatment that cover all borrelia species and co-infections - not just borrelia burgdorferi.
	Undertake research into the mechanisms for borrelia persistence - including biofilm formation.
	Allow consultants to use experimental treatments on patients without legal comeback when there is controversy on a subject and where patient consent is given
Friday, Feb 5th 10:01AM	Fund testing to improve detection of the bacteria and co-infections. Educate the doctors to the truth that 2-4 weeks of Abx is not acceptable to kill off the bacteria, (see dyoxcycline UK website) and that lyme can cause the likes of arthritis. Etc Instead of saying these things can happen to woman over 30. Yet they do not know why...... And fund the finding of a CURE. Stop doctors from being scared to treat this disease.
Friday, Feb 5th 10:15AM	Firstly, the tests should be updated.
	GP's could be trained and not afraid of consequences if they choose to diagnose clinically and treat from that.
	I believe that most of us could benefit from having a therapist of sorts to talk to, but as a support, not made/feel pressurised to go because 'it's in our head'
Friday, Feb 5th 9:03AM	First of all, I believe that doctors should listen to patients with respect, rather than with scepticism... and occasionally, even with barely-veiled contempt. My health records show two and a half years of going to and from to doctors surgeries sharing what I realise in retrospect amounts to a pretty comprehensive list of Lyme disease symptoms, but I felt their minds were closed and impenetrable. One doctor just kept reiterating how remarkably well I looked - one of the classic frustrations of Lyme Disease. When I asked another doctor why my liver tests were poor, she answered glibly 'drinking too much'... I didn't drink because of the fear of bringing on a migraine!
	Secondly - ditch the ELISA tests and use a culture test like Armin Labs!
	Thirdly - what is it with anti-depressants that they are so routinely offered for symptoms the doctors don't understand? Stop it!
	Fourthly, help doctors -especially those in classic tick areas - to catch up with the approaches of those who work with some success in this area. Bring over experts from BCA and other places to train in holistic approaches of IV antibiotics, herbs, supplements, diet and other treatments to help patients with Lyme. In fact, I think one of the keys lies in doctors being trained to treat holistically rather than keying in on individual symptoms.
	And fifth... My strong belief is that the NHS needs to completely change its approach from pharmaceutical-based symptom alleviation to finding the root of the problem and restoring health. The NY doctor who spoke to my daughter took only a few minutes to establish that her immune system was compromised by a serious kidney infection in her childhood (she has tended to get urine infections ever since) and that this together with Lyme Disease is most likely what has laid the foundation for the Sarcoidosis. Over here, her health issue has been thrown into the long grass with steroids rather than been unraveled as I believe it should have been.

Friday, Feb 5th 10:16AM	Listen to patients and take them seriously, actually make some effort to help. Do consultants really think they know more about a patient who they've seen for 20 minutes than the patient who's lived with the condition every day for years? I have very obvious identifiable symptoms yet I feel no effort is made to investigate or help because consultants quickly label me as "one of those crazy Lyme-disease people". Do they think I attend medical appointments for fun?
Friday, Feb 5th 10:05AM	The NHS needs to adopt a scientific attitude towards Lyme disease, rather than one which is castrated by the politics of healthcare in the US (and the medically-illiterate response of IDSA). The NHS also needs to address the fact that thousands of people with this disease are being treated as second class citizens in this country: denied the healthcare they need just as people with AIDs were 30 years ago. The NHS needs to work with Lyme experts from abroad in order to treat people who have become extremely ill through delayed and incorrected diagnoses. The NHS needs to raise awareness and train all GPs to recognise the signs and symptoms of Lyme Disease. The NHS needs to reform its testing protocols which a scientifically flawed. The NHS needs to reimburse the patients who have had to pay privately for treatment which should have been provided by the National Health Service, unless it is the case the 'free at the point of need' only applies to some people in this country, while other people face extreme financial discrimination.
Friday, Feb 5th 9:28AM	1. Education re Identification of EM rash and the importance/need to treat immediately if suspected, rather than wait to do blood tests after a few weeks time. This happened to me, sadly and with great regret, I wouldn't be in the turmoil I am now if I would have been given antibiotics at the time of em rash identification in my GP surgery four years ago. 2. Accurate, reliable new testing for Lyme disease and co-infections. 3. The understanding and acceptance that Lyme disease actually exists. 4. For the NHS to recognise clinical symptoms, if no em rash is/has been present. 5. Research into chronic Lyme disease and length/strength of treatments. 6. For those that are lucky enough to get treatment, a specific follow up blood test to see the effects of the treatment. 7. To be treated humanely, just like people with AIDS/cancer, Lyme disease destroys healthy cells and is a physical, mental and emotional degenerative disease which can be fatal. 8. Research and studies carried out into the links with Lyme disease leading/contributing to Alzheimer's, motor neurone disease (ALS), MS. 9. For Lyme disease in humans to no longer be swept under the carpet and ignored. Dogs are treated rapidly and effectively, surely humans could be treated in the same way. I believe that with global warming and the warmer winters, the increase in Lyme disease will increase indefinitely, so this disease is not going to go away. 10. For the NHS to provide any Lyme Patient with the opportunity to get better, to recover and to stop the suffering experienced by so many. For quality of life and humanity to be at the forefront of the diagnosis and treatment of Lyme disease in this country. For the NHS to become the pinnacle of Lyme testing, treatment and research for today and for all of our future generations.
Friday, Feb 5th 10:13AM	Open a REAL Lyme clinic. Offer 'alternative' treatments. Homeopath, herbalism, rife, bee venom, energy medicine, acupuncture etc. Scrap the US guidelines! Were in the UK not in the big pharma controlled US!
Friday, Feb 5th 8:33AM	The NHS need to rely on a better standard of testing (start accepting foreign positive test results) and stop relying on their current Elisa and Western Blot which has been show to be a poor testing system. They also need to accept Borrelia in its chronic form, put funding into research and train GP's, infectious disease doctors, rheumatologists, neurologists, immunologists, to acknowledge Lyme symptoms clinically, both acute and chronic and support their patients and citizens who pay for the service. The emotional trauma the NHS is giving those afflicted with Chronic Lyme is disgraceful. There needs to be better awareness of clinical symptoms and how the disease can manifest itself and mimic over 300 other conditions and research also needs to go into this, the neuro-degenerative diseases associated with Lyme and other chronic infections, as well as some form of NHS available treatment. We need to focus on obtaining a cure, but at the moment many Lyme literate doctors abroad can get patients into remission. The UK should be listening to these knowledgable doctors and treating their patients under their guidance as currently the NHS cannot do anything to help their patients. Lyme clinics which practice proper treatment of ongoing symptoms would be a start, or in the meanwhile the NHS could foot the bill for their patients having to go overseas to obtain medical care because at current there are no available satisfactory options through their own country's system.
	It dreads me to think how many are suffering with Borrelia or other ongoing chronic infections and being harmed by the NHS and treated with misdiagnosis. The NHS has the death and disablement of thousands on their hands and are being given the chance to act. Act now.

Friday, Feb 5th 7:05AM	Research! I have avoided NHS "Hospitals" because I've read enough newspaper/web articles sharing patient experiences to know how people are being treated. Complete treatment is needed on the NHS for this disease so that it doesn't re-appear. Don't fob us off with psychological talk therapy unless it's coping strategies to deal with our loss of function!
Friday, Feb 5th 9:43AM	yes
	but I want to help the NHS too understand better the conditions linked to chronic Lyme
Friday, Feb 5th 8:48AM	Sort out proper testing NOT antibody testing as chronic lymies are so immunocompromised they don't make them see dr Jemseks research!!! Dark field microscopy / culture is the way forward in my eyes or Armin labs tests like the Elispot..
	We need regcognition of collective symptoms (what the NHS tries to call diagnoses) and we need clinicians to clinically diagnose on symptoms like the DOH Jane Ellison said can happen in all reality this NEVER happens here in U.K. (Dr Horowitz - MSIDS questions for example)
	Need proper structured public health campaign with ILADS guidelines NOT IDSA!
	LDA and other bodies so said to be there for patients actually represent us properly!!!!! LDA in my eyes are NOT doing their job properly at all!! They fail to do anything constructive unless it's someone with new infection with antibodies!
	We need a balance/mix of holistic medicine / supps / herbals and pharmaceuticals to help fight this disease more attention needs to be given to building the person up properly with nutrition/supps/lipids/etc before embarking on treatments! So that patients strong enough! Dr Jess Armine is fantastic at this element he looks at genetic weaknesses/susceptabilities of the individual and works to fix that ie MTHFR - abnormalities issues with detoxing. Those need fixing first before embarking on treatment or more often the patient will get even sicker, treatment fail and in some cases treatment kills them!
	My dear friend from teen yrs got dx by Augsburg 12 yrs plus ago had to go to Cali for treatment and continued with picc line here he died last month of Lyme carditis caused heart attack!!!!!! He was only 44..
	Sort out regular blood tests for chronically sick patients ie thyroid, b12, vitamin / mineral levels, full blood counts my GP won't do them even though I'm symptomatic. Last bloods 3 yrs ago!!!! Not good enough!
	Acceptance of other labs testing like Armin labs, igenex, etc etc - these are accepted in Europe & the states why not here??? We need to incorporate all borrelia complex strains in testing and we MUST have a decent babesia & bartonella test here also! Plus rest of co-infections need to be tested for and taken seriously!
	The blood bank all donors should be mandatory screened as should the blood supply the USA & EU are doing this now and recognise it's an issue!
	More transparency with DOH, Govt & PHE & NICE regarding everything Lyme and patient consultation group before they change policy that effects our lives so much.
	Retraining of GP's, Consultants in Lyme disease still most patients told you can't get Lyme here it's rare and easy to treat! Wow! Like really!!!! Open minds needed here and clinical diagnoses if symptomatic.
	The option for guidelines to be flexible for example if a patient would like to trial a treatment it should be allowed ie extreme disabiling fatigue for 23 yrs last 6 been the unimaginable my b12 levels were 250 I should be allowed to have a trial of b12 injections why not if it will help and have the potential to make a huge difference to my life? Informed choice!?

	I feel all infectious disease should hold a mandatory education module for all clinicians in the uk as infectious disease is forever changing and emerging, that has one of the biggest impacts on human health and human life, particularly with undiagnosed, unrecognised & untreated or undertreated chronic infections are a major cause of systemic inflammation and chronic disease pathologies. We need to listen to the research of Alan MacDonald, Eva Sapi, Ernie Murakami and Thomas Grier along with the findings of Armin labs with testing!
	Patient engagement at all times & stages with this process by means of say a steering group etc is IMPERATIVE.
Friday, Feb 5th 9:30AM	Diagnose with appropriate tests as soon as patient has symptoms provide info and antibiotics
	Use both natural I.e homeopathic & allopathic treatment
	Listen to the patient
	Respect the patient
	Believe the patient
	Refrain from prescribing antidepressants for everything!!
	Actually check the patient
	Give a damn
Friday, Feb 5th 8:27AM	1. Training for GP's NOT by PHE or LDA (uk). But by ilads trained LLMD's.
	2. A better Lyme test & clinical evaluation.
	3. Removing Dr Brooks & Dr Dryden as Specialists in Lyme & Co-Infections, as they are determined to follow IDSA guidelines. We cannot move forward with old mentality. Dr Burgdorferi himself said that.
	4. A Lyme Disease hospital full of ilads trained specialists.
	5. Access to IV antibx for longer than 4 weeks, if you hit the jack pot & actually get IV antibx.
	5. More detailed results from Porton Down, than just 1 word on your test result; "Negative." Show the bands.
	6. Easier access to test results from
	Porton Down & also for them to lose tests less!! Quite a common occurance. Never happens in any other labs for other illnesses around the country.
	7. Have a separate lab for Lyme Disease & Co Infections, away from Porton Down & not connected. This will help with the losing of tests. This lab to be trained by ilads & Dr Armin.
	8. More accurate documentaries on TV, to educate the public, like "Under Our Skin."
	9. More charity & help set up for patients of Lyme like there is for cancer. We suffer alone, with no support network.
Friday, Feb 5th 8:32AM	I want them to start using a decent and reliable test, and stop relying 100% on their current test. My own GP told me that we could "rule out" Lyme disease on the basis of my negative result. Neither he nor my consultant neurologist was interested in even looking at my positive test from Igenex, where I had had a reaction (positive or IND) on all six of the lyme-specific bands. This arrogance has to stop. They don't even seem interested in learning about lyme.
	They have to recognise the bullseye rash, and treat immediately with abx - not wait around for blood test results to prove it. They must be made aware that EM rash = Lyme disease! No blood test necessary! They must also prescribe adequate doses of abx in these early stages, and for at least 4-6 weeks. 200mg of doxycycline for two weeks is not going to cut it!
	I would like them to actually consider Lyme disease as a diagnosis. I had many classic symptoms, but they only did a test months later, when I brought it up and asked for it. They are not going to find something if hey don't look for it, and it will remain a "rare disease" if they never diagnose it!
	We need properly trained (ILADS) specialist lyme doctors available on the NHS, with the knowledge to diagnose and the freedom to treat with long term abx if necessary. They need to learn about the complexities of chronic Lyme disease, as well as consider all of the probably co infections.

	We should not have to be bankrupting ourselves to pay for private treatment, just because there is no NHS alternative . . . the situation is absolutely scandalous, and changes need to be made in attitudes and training.
Friday, Feb 5th 8:51AM	Acknowledge the persistence of the bacteria.
	Acknowledge the complexities of treatment required.
	Acknowledge the multi systemic damage and therefore functional support needed for the body to recover.
	Treat Lyme patients with compassion not contempt. Acknowledge the suffering.
	Acknowledge new and emerging science.
	Learn from global leaders in Lyme disease within the medical profession.
	Accept that UK 'experts' have had their own vested interests in maintaining the status quo and acknowledge that this is unacceptable.
	Carry out reliable studies on tick populations and the illnesses carried by the vector within the UK.
	LEARN, LEARN, LEARN! EDUCATE, EDUCATE, EDUCATE!
Friday, Feb 5th 8:56AM	NHS should develop better test, also should accept private tests from abroad, especially from the European Union.
	Public should be aware that not only ticks spreading the disease, there are ways of preventing the disease by protection against insects bites.
	Education and awareness is the key to prevent this devastating condition.
Friday, Feb 5th 9:10AM	Give them a real diagnosis and ongoing proper treatment. Constant monitoring. Also check for damage to body organs and systems.
	Currently they just send you home to die if they cannot explain the illness
Friday, Feb 5th 9:14AM	Yes. They should test any one with symptoms of Lyme. They need to firstly learn what the symptoms of Lyme are to recognise it. Also the tests need to be improved as they only pick up some of the cases. Those who do test positive are not being treated aggressively enough or for long enough. Treatment needs to continue until or symptoms have gone. If symptoms come back treatment needs to be restarted. It is not good enough to say there is nothing they can do to help us !
Friday, Feb 5th 9:02AM	Yes. They should test any one with symptoms of Lyme. They need to firstly learn what the symptoms of Lyme are to recognise it. Also the tests need to be improved as they only pick up some of the cases. Those who do test positive are not being treated aggressively enough or for long enough. Treatment needs to continue until or symptoms have gone. If symptoms come back treatment needs to be restarted. It is not good enough to say there is nothing they can do to help us !
Friday, Feb 5th 9:03AM	More awareness of co infections and politeness from ID consult who was rude and dismissive.
	Also I would have liked to try different antibiotics for shorter periods.
Friday, Feb 5th 5:58AM	Recognition of chronic Lyme, better testing and acknowledgement of Armin and other private labs. have a specialist team dedicated to Lyme, improve dr's understanding of the disease, and stop prescribing anti depressants and referral to councillors as this issue is not being believed, I'm not crazy!
Friday, Feb 5th 8:40AM	Ideally set up Lyme disease clinics, at least train doctors about the real facts of Lyme as we know it, not the one day course that leaves them thinking they know everything there is to know.
	Inform GPs that NHS tests are NOT 100% reliable
Friday, Feb 5th 8:54AM	Recognise the diagnosis, listen to patient testimony. So many people with this illness have the same issues and difficulties. They cannot all be making it up. Listen before it is too late and investigate whether this could be sexually transmitted or transmitted during pregnancy. People suffering with chronic lyme deserve a chance to be treated, teenagers with acne get a year prescribed antibiotics so why not give people with a bacterial infection the same opportunity when it could change their quality of life. Lyme sufferers need better support and the link between ME and lyme needs to be established.

Friday, Feb 5th 8:42AM	The NHS should adopt guidelines on diagnosing/treating Lyme disease according to current scientific evidence from the likes of Dr Alan MacDonald, not according to so called "scientists" of IDSA who clearly have vested interests and have more to gain from letting patients rot than actually lifting a finger to fight this pandemic.
Friday, Feb 5th 8:34AM	Not punish doctors for treating Lyme with long term antibiotics. Doctors aren't allowed to practice medicine anymore. Give freedom back to doctors to make choice like In US. Acknowledge the research that supports chronic Lyme and antibiotic usage not just the opposite like on then have website. Nhs website quotes further symptoms are unlikely to be due to persistent infection? Evidence is coming out to prove that it is yet it seems to not filter through although readily available for the sufferers.
	Testing for Lyme should be done via multiple things/checklist to look for evidence of Lyme and co. Never just a blood test.
	Starter IV antibiotics need to be standard for chronic Lyme before progressing to orals it needs to be recognised for the seriousness it is.
Friday, Feb 5th 8:27AM	Reliable tests, not just for lyme, but for all co-infections and for other spirochetal disease- such as B. Miyamotoi, that don't show up on lyme tests but cause similar symptoms to Borrelia Burgdorferi and similar strains of the bacteria.
	Proper treatment and recognition of the disease- recognition that if caught late, it is a chronic condition and not easily treatable, like most think.
	Not treating patients like second-class citizens.
Friday, Feb 5th 8:49AM	Better blood tests, better GP education, availability of specialist consultants. The one I saw privately was pressured into early retirement from the NHS.
Friday, Feb 5th 7:40AM	Listen to the patient..
	believe the patient....
	Correct and proper education of the doctors...
	Tell the truth... Acknowledge Lyme as a pandemic....
	Use dark field microscopy to help diagnose,
	acknowledge Lyme is a Clinically diagnosed disease... And inform the gps
	stop mis diagnosing as other syndromes that are actually Lyme but not allowed to be called Lyme by the NHS .
	Research and develope accurate tests....STOP using inaccurate ones as being accurate.
	Acknowledge that Lyme is spread by many vectors....
Friday, Feb 5th 8:25AM	Use better tests.
	It is possible to inject a patient's blood into a few mice, then look at the mouse blood about 3 to 5 days later - it will be very obvious that borrelia are there, visible in the mouse blood (and tissues if you need to confirm it further)
	Its called the mouse infectivity test. Too simple and non-tech for anyone to make any money out of..just a few hundred mice per hospital. Im not joking, this is a scientific method.
	Microscopy plus culture (using the mice is a form of culture really) plus specific FITC stains - that should be enough, without DNA really. DNA shopuld be there for maybe keeping an eye on the other method, like a quality control, e.g. for every 1000 samples, double check with DNA PCR ..
	Make all doctors aware, and make it compulsory that they are aware - borreliosis is a public health threat, and they should label it as such.
	if TB and Syphilis are notifiable, why not Lyme?
	Treat patients properly, by listening to them. make all the psychiatrists in the UK go back to med school, and learn about microbial infections causing mental illness, and do the same with neurologists too.
Friday, Feb 5th 8:33AM	Doctors need to be fully trained. If they choose not to, I believe they must be deformed. My GP surgery is still failing to train and we have to educated the doctors on Lyme, even though they have a duty of care and they are aware I have it.

	Testing must be perfected and a halt called to the use of inaccurate commercial testing. testing from other countries must be accepted by the NHS, as it has been acknowledged that ours is more inaccurate that those tests conducted abroad.
	Treatment must be given for a suitable amount of time and the denial which is inherent within the medical field must be stopped.
Friday, Feb 5th 8:34AM	Abolish the NHS or put in place adequate checks on doctors.
Friday, Feb 5th 8:19AM	Recognise the illness for what it is, offer proper testing inline with other countries that have more experience with this illness and treat appropriately.
Friday, Feb 5th 7:07AM	1.Educate doctors to open their minds to the possibility of Lyme disease as a diagnosis and actively encourage them to treat on suspicion without the need for serological evidence
	2.Stop using the unreliable ELISA test:
	I had a positive IgM lyme antibody test from Chelsea and Westminster Hospital. The same sample was sent to Porton Down for further confirmation and produced a negative Elisa. No Western Blot was done and I consequently I was discharged with the recommendation to take antidepressants for IBS. If I had been diagnosed after this test I would not have given steroids at a later date which have left me unable to work for the past 6 months and for the foreseeable future.
	3.Change the comments on Western Blot results:
	A positive IgM WB comes back with 'Not diagnostic of Lyme' if chronic illness is suspected. Doctors trust Porton Down's interpretation of results and discharge patients on the basis of them.
	4.Be willing to learn and introduce combined antibiotics protocols that are showing good results for Lyme patients attending clinics in Europe, USA:
	I am appalled that I have to travel to the US for what is essentially a long course of inexpensive antibiotics. Why is this treatment not available in the U.K.?
Friday, Feb 5th 8:05AM	Improve testing
	Accept CE accredited private tests
	Traim gps to recognised clinical signs and join up symptoms
	Listen to global Lyme specialists and realise their treatment is inadequate
Friday, Feb 5th 5:41AM	1. Immediately review medical degree course content and enforce training for all medical professionals to include far more detail about all tick infections. My GP did not know what a tick was. She has just come out if medical school. Promote the understanding testing is limited and tick infections are a clinical diagnosis with at least 3 months treatment trials and ideally longer to back up diagnosis. Spread awareness about the usefulness of a herxheimer response to help confirm diagnosis.
	2. Use a panel of Lyme tests to get an overall picture and have standardised symptom check lists to aid clinical diagnosis. GPs should have access to these questionnaires as prompt diagnosis is vital. Liaise with experied overseas professionals and employ them in the UK to run a dedicated Lyme service that can also supply treatment advice to others. Porton Down has not succeeded at this. The info they give out is flawed.
	3. Recognise that anyone can have tick infections so don't assume they need to have been in endemic areas, the woods, gardening etc. Spread awareness that tick infections are in every UK county.

	4. Understand many people do not get the rash or develop symptoms for weeks, months or years. Understand the tick does not need to be attached for longer than a few hours to spread infection. Recognise that other vectors may spread infection, especially mosquitos. See recent German studies.
	5. Treat early before testing and do not stop until patients are asymptomatic for 2 months. Recognise the illness may come back later and retreat.
	6. Assess for coinfections at the beginning using symptom questionnaires and testing but understand testing is limited and treat on a clinical basis.
	7. Utilise dark field microscopy.
	8. Recognise that Bartonella and Babesia are the most common co infections and as testing is poor diagnose clinically.
	9. Train GPs and furnish them guidelines so they can treat urgently.
	10. Treat this as a POSSIBLE epidemic...don't worry about creating public alarm. Just give clear concise advice in all the normal places. People would rather that than just not be told much about it.
	11. Educate schools. Children are at risk especially.
	12. Do public awareness on how to safely remove a tick.
	13. Encourage safe sex just in case. You can do this in a way as not to spread panic. Come up with a treatment strategy for those that may be affected and are pregnant.
	14. Follow ILADS treatment guidelines or at least remove penalties for doctors wishing to do so.
	15. Review CFS, fibro, MS, Alzheimers, Parkinson's cases. Spread awareness of possible misdiagnosis amongst doctors especially in the CFS, Fibro and MS groups when it may be early enough to do something meaningful about it. Not negating the other groups of course. Also reconsider mental health cases.
	16. Ensure all consultants in all related departments are aware of the varied symptoms of Lyme and allow them to fastrack for appropriate treatment.
	17. Work from the standpoint that treatment of tick infections may actually be one of the most useful developments yet discovered in understanding many conditions that medicine is stumped with. This is a huge opportunity not just some illness to be disputed and ignored as too complex or misunderstood. Remove the stigma.
	18. Stop anyone donating blood if they have had Lyme or associated illnesses. Screen the blood for all tick infections.
	19. Develop dedicated tick infection services at key locations but allow doctors from other areas to start to treat if cases are suspected whilst people are being referred to specialist centres

	20. Promote awareness of alternative treatments for tick infections amongst medical professionals and due to concerns with using long term antibiotics consider the use of herbs for some. At the very least ensure doctors are aware that if a patient has herxheimer reactions on well known herbs used for tick infections then their case likely needs further investigation as they may be positive. Where testing is inconclusive then this kind of challenge testing can be useful. The same with rife applies.
	21. Ensure doctors give advice on how to control the herxheimer response.
	22. Ensure the benefits agency accept that tick infections are long term conditions varying in intensity at different times and that treatment can render people unable to work for a time.
	23. Run a public awareness campaign and ensure organisations and councils display signage about risk of ticks borne illness in parks, National Trust sites, woods etc. This should include advice on how to remove a tick.
	24. Confirm with all A&E doctors how to remove a tick.
	25. Consider treating prophylactically. I know this is difficult but consider the guidelines.
	26. Promote John Caudwell's charity as a source of info for the public. Lyme Disease Action have been giving out misleading info although they have also helped many.
Friday, Feb 5th 4:55AM	In the last 3 years (so not covered by this survey) I have had 5 MRIs, lumber puncture, evoke testing, bladder scan, bladder camera investigation, 3 days IV steroids, ultrasounds and multiple trips to my GP and A&E. I also had 8 consultantations with 4 different consultants (2 neurologists, uro-gynaeocologist, microbiologist). All of this was paid for by my husband's private medical insurance, which had we not had, the NHS would have paid for eventually. I was unable to work for 18 months, but now working again. Had our financial situation been different I believe I would now be at home, bedridden and claiming benefits. Our insurance would not stretch to outside UK treatment. The NHS may be short of cash, but that comes from the Treasury who also pay welfare state benefits and they would have wasted over £10,000 on NHS testing and treatment for me which did nothing to improve my health. It makes financial sense to embrace the German testing and treatment protocols to end human misery and get people off sick benefits and contributing to the economy. To say nothing of the huge cost saving of mis-diagnosing people. My own diagnosis was neurological that might one day prove to be MS. An accurate blood test 3 years ago would have saved so much heart ache and worry for me and my family and if I'd been an NHS patient, potentially tens of thousands in wasted testing, treatments and appointments.
Friday, Feb 5th 8:05AM	Accept tests from abroad from labs such as Igenex and Armin labs. Research every aspect of the disease co infections etc. We need a cure! To be heard and not left to rot away in silence. This disease has taken away my life. It is horrific the suffering we have to go through and on top of it all not being believed.
Friday, Feb 5th 7:52AM	To recognise or at least explore the possibility that ongoing issues starting within weeks of positive Lyme NHS blood tests and Bell's palsy, that did not resolve after 2 weeks antibiotic treatment and have continued for 10 years, plus 2nd positive NHS western blot in 2014, may mean the infection is still active.
Friday, Feb 5th 7:13AM	Accurate testing, Lyme educated and informed clinicians, recognition of Late stage Lyme, pathways for recognised treatments, understanding & compassion for Lyme patients, creation of Lyme consultants/specialists. I would like to be treated the same as other patients who have a chronic disease :with dignity, with compassion, with understanding, with kindness.
Friday, Feb 5th 7:25AM	BELIEVE THAT PATIENTS ARE ILL.
	READ THE RESEARCH ON THIS ILLNESS AND TAKE NOTICE OF DOCTORS THAT HAVE STUDIED THIS DISEASE FOR YEARS
	PROPER TESTING
	AND TREATMENT
Friday, Feb 5th 7:39AM	Educate our GPS:
	Recognise that Lyme Disease can be caught anywhere in the UK.

	Recognise the symptoms.
	Stop relying on useless tests.
	Recognise and treat co-infections
	Allow GPs to prescribe sufficient antibiotics.
	Employ Infectious Disease specialists who know how to properly treat LD.
	The best my GP could come up with initially was "Try drinking more water".
	There is a wildlife area within the grounds of my local GP surgery where I have found questing ticks. 8 out of 8 GPs I saw at this surgery discounted Lyme Disease as a possibility. One even said "You cannot POSSIBLY have it, because it's quite rare"
Friday, Feb 5th 7:28AM	To take it seriously, look at a patients medical history because we know the tests aren't reliable. Take a leap of faith and diagnose based on the symptoms. Don't be scared of issuing antibiotics. My SA doctor told me that the UK GP's now get a financial insentive if the DON'T refer patients for X-rays, blood tests etc. How scary is that. My childhood GP did one consultation with me and did a through exam and said it was Lyme (without fancy blood tests) just a proper diagnostics.
Friday, Feb 5th 7:16AM	Listen to your Patients and be there as a doctor ! Get your tools out more often instead of asking questions and see them off . Stop making us feel that we are all crazy . You are the reason why no one can carry on with their life because if you took us seriously we won't b where we are today !!!
Friday, Feb 5th 6:44AM	Firstly, the NHS needs to educate itself and all GPs about the illness and its coinfections, making sure that alarm bells ring for doctors when they are given a list of non-specific symptoms. It must be recognised as a potential cause of them, even if there is no rash or the patient is unaware of having been bitten. There needs to be much more publicity in general so that the public too are more aware of protection from ticks, safe tick removal etc. We need a fast acting, more reliable test, sensitive to all known strains of borrelia, so that diagnosis is not already rather late in terms of a good outcome. Tests also need to developed for the growing list of coinfections. If there is known history of tick bite, doctors should be prepared to use their clinical judgement and prescribe antibiotics. Ther needs to be a longer course of antibiotics than is offered at present and dctors should be much more open-minded about the possibilty of the illness not being cured after a relatively short course. Many doctors need to pay attention, not only to their knowledge of Lyme and its presence in the UK, but to their bedside manner with Lyme patients: many people have been told things that are either ignorant or untrue about the illness, its prevalence and its treatment and have been spoken to arrogantly and unsympathetically. It is a terrible thing to suffer a horrible illness and to have the nightmare compounded by ignorant rudeness and disbelief. They must be regularly updated about current research into this emerging illness.
Friday, Feb 5th 5:56AM	NHS testing is inadequate. Overseas test results should be accepted. Diagnosis should be available based on clinical symptoms and overseas test results. Treatment should be available in accordance with ILADS/Burrascano guidelines.
Friday, Feb 5th 7:16AM	The NHS need to know up to date information and research, in order to be able to correctly diagnose and treat Lyme disease. And offer the necessary treatments, including long term antibiotics. And doctors should not belittle sufferers problems
Friday, Feb 5th 7:07AM	All GPs need to recognise the symptoms. I went in with a bite and within a few days developed symtoms but many GPS dont relay the symptoms to a bite. Should give people at least 6 weeks high dose of antibiotics at the early stages to avoid it being chronic. For us chronic patients, I would the NHS to make it as recognisable as asthma, diabetes and then I would not have to travel abroad to see a knowledgeable and qualified consultant. To be treated as a patient!!!!
Friday, Feb 5th 5:44AM	1.Doctors to accept that current NHS testing is poor
	2. Doctors to accept that Chronic Lyme is a condition and needs treating
	3. Doctors to be aware of need to treat acute Lyme urgently with antibiotics
	4. A more symphatetic approach by doctors to people with Lyme, ME/CFS etc
Friday, Feb 5th 7:00AM	Give longer term treatment (ie. antibiotics)
	Offer psychological support for a proper illness, not just fob it off and blame the symptoms on anxiety.

	Improve current testing/enable to diagnose clinically. There seems to be an old boys club, especially amoungst the infectious disease consulatants who read from the same script. Time and time I've been told the lyme testing is accurate and they would not even accept results from columbia University in NY!!! Foreign lab results should be considered and not all just written off as rubbish!
Friday, Feb 5th 6:42AM	NHS GP s should be made aware of the occurrence of Lyme disease, its symptoms and the fact that a diagnosis is a clinical one, as existing tests are unreliable.
	Research should be funded into the development of a reliable test.
	Horizons should be widened as to treatment options and duration. Two weeks of antibiotics is not enough, as they should cover at least the full life cycle of the infection, which is four weeks!
Friday, Feb 5th 7:00AM	Recognising the illness and being able to properly test it. GPs should be educated. I had a massive bite on my hand in 1986. I consider the GP was negligient in not prescribing antbiotics.
	So early detection and treatment is paramount.
Friday, Feb 5th 6:48AM	As an emergency interim measure the NHS should make the LDA RCGP training module compulsory with immediate effect.
	I then want the NHS to research, study & correspond with Lyme patients as I have had to do to stay alive.
	I also want consultants & GP to recognise patients as their clients who pay their salaries and stop behaving like psychopaths in denigrating Lyme sufferers.
	I think that the NHS should strive to set up regional tick borne disease and insect bite clinics, walk-in one-stop shops for information, testing, fast-track treatment and support. This may possibly be more achievable as a joint initiative with a charitable organisation.
Friday, Feb 5th 6:31AM	The NHS need to listen to their patients properly and actively investigate patients symptoms. They need to be efficient in referring patients to the correct specialists and those specialists need to be efficient in doing tests and getting results. In terms of Lyme disease, the NHS needs to be able to clinically diagnose and treat Lyme disease and not rely so heavily on tests tests that are not reliable. The NHS is not efficient enough. They move too slowly and don't bother checking up on patients. Fast diagnosis and treatment is key to preventing people becoming chronically ill and becoming a drain on the NHS. NHS doctors need to lose their arrogance and be able to have the time to listen to their patients (who know their bodies better than doctors do) in order for them to be able to diagnose more effectively. And if doctors are not entirely sure what the problem is, they need to refer the patient to someone who does instead of being passed back to the GP all the time. There needs to be more collaboration between specialists. Patients deserve to be treated with more respect.
	All patients presenting symptoms of Lyme disease who know they were bitten by something and who doesn't have a rash should be treated with a long course of at least two antibiotics as a precaution at the very least. But only after blood tests have been taken for Lyme disease which should be arranged through a GP if necessary to avoid waiting for referrals to other specialists.
Friday, Feb 5th 6:48AM	Use an elispot test to diagnose and have the ability to prescribe long term antibiotics. Why can they prescribe them for acne and not a life threatening bacterial disease?
Friday, Feb 5th 6:38AM	I WANT THEM TO RECOGNISE IT!!!! LISTEN, LISTEN, LISTEN AND BELIEVE US!!!!
	I truly believe that there is something going on at Porton Down too. Both of my NHS results were worded in a way that clearly baffled my GP and in fact he said that he simply didn't know what they meant. The first was "indeterminate" and the 2nd was "mildly positive with no evidence of Lyme" ??????? It was only when I requested clarity, under the freedom of information, that I was clearly told that I had Lyme disease. Why oh why do they cover it all up? There surely has to be a definitive test or blood transfusions/transplants etc couldnt go ahead? There is a massive cloud over Porton Down and I don't mind if my comments go public. It's like MMR, like Mad Cow Disease........... The lid needs taking off!
Friday, Feb 5th 6:28AM	I want the NHS to develop a test which will diagnose Lyme quickly and more effectively than the current one.

	I want GPs to not automatically jump to ME and fibromyalgia diagnoses when faced with patients who don't fit in any other 'boxes' also those who may have been exposed to Lyme Disease but have a current negative NHS result.
	The NHS need to take advice from the health authorities and research from other countries and accept that the current 2 weeks of Doxycycline is not an effective treatment for either a new infection or late stage Lyme.
	The NHS need to accept that their current tests, diagnosis and treatment advice is not effective and importantly not helping 000's of patients who are costing the economy £000's yearly.
Friday, Feb 5th 6:27AM	Develop accurate tests for Lyme as well as serious co infections like bartonella and babesia and use them on patients presenting with early unexplainable illness so that early treatment can be administered.
	Dedicated regional centres should be installed to treat, monitor, and learn from patients with long term vector borne infections, longitudinal studies and a wealth of information could be gained and then used as the basis of best practice guidelines.
Friday, Feb 5th 6:26AM	Just do their job really. To learn enough about the disease to be able to treat patients respectfully, even if they can't cure them. Also it is shameful that they refuse to analyse blood samples under the microscope when even my internet friends can see spirochetes in their own blood. There is no excuse for not looking and for not using normal diagnostic methods that are already at their disposal. Nothing short of a paradigm shift will change things though, I fear, so if what it takes is for them to develop a better test, that they themselves believe, then let them do that ..and quickly.
Friday, Feb 5th 5:56AM	Educate GPs to be Lyme aware so that early infected do not slip through the net & become chronic. Create more accurate tests, particularly ones that do not rely on antibody responses so can pick up later stage infections. Create a dedicated service for Lyme & coinfections. Stop persecuting the few UK doctors who have tried to help. Acknowledge that chronic Lyme (or whatever they want to call it!) does exist & to devise strategies to treat it rather than the current climate of denial & blame.
Friday, Feb 5th 6:06AM	Have an open mind and treat empirically if the patient doesn't benefit from longer courses of antibiotics most patients will not continue with the treatment, but if it helps then patients need to be given the option to treat with longer courses of antibiotics plus suitable pain and symptomatic relief.
Friday, Feb 5th 5:37AM	Provide an accurate test which is 100% accurate and quick turnaround
	gps to be educated in recognising the symptoms of lyme disease whether it be when bitten or later. To always provide a test as a matter of procedure
	To treat it as urgent if suspect lyme and not wait for blood test to come back
	If need be to refer to a lyme literate expert
	To urgently invest in looking for a cure and not just remission via research
	Not just educate gps but also other specialists eg psychologists, psychiatrists, neurologists
	until a cure is found to provide a protocol based on individual symptoms
	Not label patients with Depression and Anxiety and treat with respect as the cause is bacterial which is causing the mental health symptoms
Friday, Feb 5th 5:35AM	To accept lyme results that have been done elsewhere.
	I have a CDC positive lyme test through IGENEX but it wasn't accepted by the NHS. The NHS did do a lumbar puncture on me around 8 years ago but it turns out that the cerebral spinal fluid was put in an NHS lyme test meant for blood so need less to say it came back negative. I have had no other lyme tests offered by the NHS.
	To stop ridiculing those who have lyme.
	To be supportive and helpful rather than negative and patronising.

Friday, Feb 5th 5:48AM	Clinical diagnosis
	Referrals to alternative practitioners with the skills to treat Lyme. In my research and experience antibiotics alone WILL NOT get Lyme to the point that the person is fully functioning - particularly not 4 weeks worth for a bacteria with a 6 week cycle!
	More awareness of GPs as to what are the symptoms of Lyme.
	Recognition of testing used outside the UK, particularly Armin Labs, which seem to be the most reliable, however testing should be secondary to clinical diagnosis as even the best testing can be unreliable.
	Public campaigns (like with AIDS) to make everyone more aware of the dangers of Lyme like the ones used in Germany where Lyme is understood and recognised more.
	Take responsibility NHS - you are failing us.
Friday, Feb 5th 5:57AM	Recognise it as a condition. Raise awareness and treat at acute stage on clinical diagnosis with follow up. Introduce a reliable test..and fund research.Test and investigate other similar conditions for Lyme.
Friday, Feb 5th 6:13AM	Take the disease seriously rather than laughing in our faces (literally) more research needs to be done and better testing has to be available.
Friday, Feb 5th 6:01AM	1
Friday, Feb 5th 5:14AM	Doctors acknowledge Lyme but do not want to help or assist in treatment. They all claim not to know about this and will only write a referal letter, if you can find a specialist. It's a tiresome waste of time and energy speaking with them, they look at you like you are mad, it is demoralising, it's like someone is lying here and it's not me. I can not bear to talk to doctors that are not ILADS trained , the sheer ignorance is unbelievable.
	Doctors need to be trained and specialists appointed , treatment should last as long as symptoms persist. People are not text book, two weeks of antibiotics is not a cure.
Friday, Feb 5th 5:52AM	Greater awareness, better testing and acknowledgement of the need for pulsed rotated abx by the NHS.
Friday, Feb 5th 5:41AM	To recognise Lymes does exit, to develop a much better test here in uk as the NHS will not accept overseas positive test results and to have Lymes literature specialists in every county here in uk. Vets know more than our GPs why?
Friday, Feb 5th 5:33AM	Better ,sensitive , more accurate testing
	Acceptance of chronic Lyme disease. Proper diagnosis and treatment in the UK.
Friday, Feb 5th 5:43AM	research ! and offer testing more widely Educate GPs and develop protocol for treatment learn from Germany an the Netherlands
Friday, Feb 5th 5:04AM	Based on my research on Lyme disease including personal experience I see the following needs:
	Better GP knowledge of Lyme disease, it's prevelence, symptoms etc.
	Better testing. Current commercial serology tests are poor. Independent studies indicate sensitivity of about 60% when used with samples that are from patients with EM or already are seropositive.
	Better treatment: Needs research for treatment for neuroborreliosis and post treatment persistent disease.
Friday, Feb 5th 5:21AM	I would like a sea change in NHS attitude. To listen to patients and understand that many complex illness have an underlying infectious cause.
	I would also like them to move away from the pharmaceutical model of treatment. For many it is not necessary to take antibiotics especially if, like me, they've been ill for many years. Alternative protocols can work well and address underlying issues. Antibiotics do one thing only - kill infections. They don't address underlying causes and won't help if the underlying cause of illness has a viral element. You can read on a daily basis on forums stories of people who regress as soon as they stop taking them.

	I would also like the NHS to look further than the one diagnosis, one treatment model. Many people with Lyme and/or co-infections have resulting damage/deficiencies that need addressing, as I do. I believe a multi-faceted approach is necessary to detect and treat each issue to give individual patients the best chance of improvement.
Friday, Feb 5th 4:58AM	Get better testing. Recognise the existence of Chronic Lyme and a few weeks of abx is not enough. Train Doctors betterto
	Recognise theEM rash and symptoms. Send Doctors to train under top Lyme Doctors in USA. Reimburse all Lyme patients the money they have had to spend from their own pockets on treatment.
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	Recognise theEM rash and symptoms. Send Doctors to train under top Lyme Doctors in USA. Reimburse all Lyme patients the money they have had to spend from their own pockets on treatment.
Friday, Feb 5th 4:48AM	We would like government health advisers to take this illness seriously.
	We would like doctors to be better informed/trained by those who really understand, and not those who 'think' they understand.
	We would like all medical ego's put to one side, and the focus to be on 'fit for purpose' testing, and not 'perceived to be adequate' testing.
	We would like to be heard in a respectful and proactive manner, enabling us to contribute in a useful and purposeful way.
	If the previous comments had been taken on board as requested many years ago, we would not be in this mess today - it certainly isn't for want of trying.
	The 'WE' comments are because there is more than one family member with this illness.
Friday, Feb 5th 5:08AM	Accept that Chronic Lyme exists.
	Treat with antibiotics either orally or IV for however long it takes.
	Recruit and train specialist doctors specifically for Lyme.
	Set up clinics nationwide
	Have reliable tests
	Realise that co infections come with Lyme
Friday, Feb 5th 5:16AM	Improve testing, look into the validity of overseas testing and create a specialised Lyme disease clinic with trained doctors knowledgeable in Lyme disease, co-infections and other complicating factors. Improve awareness and education and develop more effective treatment protocols with the option of longer term treatment if symptoms persist. Transmission needs to be studied so Lyme patients know the truth about sexual and congenital transmission and microscopy and culturing testing methods need to be looked into.
Friday, Feb 5th 5:13AM	A reliable blood test is essential.
	Proper antibiotic and herbal treatments to last if necessary for a few years.
	The same support that an AIDS or cancer patient recieves.
Friday, Feb 5th 5:15AM	Acknowledge chronic Lyme dieses and co infections and have the most advanced blood testing. Also to acknowledge herbal and homeopathic protocols work.
Friday, Feb 5th 5:21AM	I want doctors to able to treat with longer courses of antibiotics if symptoms are still present at the end of the recommended 2-3 weeks course.
	I want doctors to be up to date that Lyme bacteria can change into cyst and other forms and that often different antibiotics taken together and pulsed could be beneficial.
	I want doctors to not make references to Susan O'Connell head of the Lyme lab in Southampton who retired in March 2012 who states 'she'd never had a case that 3 weeks of doxcycline hadn't cured' even though medicine and research has moved on since then.
	I would also like doctors to take Lyme more seriously without comments like "get off the antibiotics and get some dirt into your system" and "I've had Lyme disease and so has my son and we are both fine" - both these comments have been made to me by 2 different doctors in the last 4 weeks.

	I want doctors to know about co-infections and where they can be tested.
	I want the Elisa scrapped. I had an 11 inch EM which my doctor saw - but I still have not got a positive Elisa after two tests six months apart (1 month and 6 months post bite)
	I want a better test that isn't based on antibodies and a test that will tell me that my body is rid of the Lyme bacteria
Friday, Feb 5th 5:09AM	It's all about testing and clinical diagnosis, as well as, we need an NHS specialist clinic in the uk. The NHS test misses around two thirds of cases but gps are not educated enough to know this. Even infectious disease specialists don't seem to know enough and seem to think one month of doxycycline is enough which, when looking at how foreign countries treat Lyme, one month is not enough. The NHS seems to be behind a few decades on how to treat Lyme and its co infections. The NHS doesn't have all the tests available to even check for all of the co infections.
Friday, Feb 5th 4:55AM	I want doctors to able to treat with longer courses of antibiotics if symptoms are still present at the end of the recommended 2-3 weeks course.
	I want doctors to be up to date that Lyme bacteria can change into cyst and other forms and that often different antibiotics taken together and pulsed could be beneficial.
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Friday, Feb 5th 4:53AM	Test everyone with chornic fatigue etc
	offer appropriate treatment including IV antibtiotics
	set up centres of excellence for treating and testing Lyme and co.
	make home visits available for housebound/bedbound patients
	Listen to top Lyme specialists from around the world (not IDSA) IN HOW TO TREAT
	recognise that long term patients will not be positive on NHS tests due to lack of immune response.
	train all GPs in spotting Lyme and in clinical diagnosis
Friday, Feb 5th 5:02AM	Change your testing, it is so inaccurate
	Training for GPs to understand Lyme, use Arwmin and Dr McDonald's expertise,
	Catch early to stop others suffering as I am
Friday, Feb 5th 5:06AM	More research, awareness and acknowledgment.
Friday, Feb 5th 4:59AM	To find and implement an effective and accurate test. To recognise the severity of the disease and its prognosis if untreated. To support the patients instead of victimising them.
Friday, Feb 5th 5:06AM	We need more doctors to recognise this treatment and have more knowledge about early treatment and chronic treatment
Friday, Feb 5th 4:57AM	Diagnose and treat the same as any other infectious disease
Friday, Feb 5th 4:47AM	There are very few clinical trials which give details of the best way to treat Lyme. So solid, best practice, evidence-based treatment protocols have yet to be established. In view of this I would ask a small cohort of open minded, motivated NHS infectious diseases specialists to speak to and learn from those doctors worldwide who are successfully treating patients and returning them to health. I appreciate that this means not following a strictly 'evidence based' route- but we do not have the high quality trials and this disease is too variable for trials to be easily done. There are doctors in the USA using complex, tailored treatments such as combination antibiotics, anti protozoals and other medications that are having very high success rates at getting patients into remission. I would ask that the NHS send a small group of doctors to train under these experienced physicians so that they may establish centres of true expertise in the uk on the NHS.
	I would also ask that the NHS re examine microscopy and culture as direct test methods which should be helpful in elucidating the cause of persistent, Lyme-like illness in chronic 'lyme' patients.
Friday, Feb 5th 4:56AM	Develop better testing and treat adequately. Provide more information and health warnings about lyme disease.
Friday, Feb 5th 4:52AM	Learn about the reality of it for patients.
	Teach doctors how to recognise it and treat it. Allow doctors to treat it properly. Prevent doctors from dismissing our illness as "all in the head" and being rude and dismissive. Set up a centre of excellence for treatment, including co-infections.
Wednesday, Feb 3rd 12:56PM	Warn, accept, diagnose, treat, support, etc.
Wednesday, Feb 3rd 12:08PM	Accurate testing and clinical diagnisis based on patient history and symptoms. Lyme literacy amongst medical professionals. Specialist regional clinics and patient support
Wednesday, Feb 3rd 11:58AM	The NHS must take responsibility that their tests are not sufficient, and put pressure on the powers that have the ability to research this. Doctors must also accept that clinical diagnosis is far more than being reliant on a single serology test. whole body presentation, symptoms and better quality tests. "Unexplained symptoms" is not a diagnosis we should ever be using in 2016. More funding, more research, better quality tests and long term abx therapy
Wednesday, Feb 3rd 11:42AM	because personally i belive they are told not to, because i think it has been messed with by men as a bio wepon, or something like this, and also i belive it is a disease that is a good way of dumming down the population, keepps us all unwell, and out of the way,

Wednesday, Feb 3rd 11:05AM	I want the NHS to treat Lyme as a serious medical topic and all that entails. Adequate testing, patient support, treatment where effective and help with wider issues. They should stop the stranglehold of the ID consultants and the Wessely school which is all underpinned by the pharmaceutical industry. There should be a parliamentary commission on the influence of pharmaceutical industry on medicine today, it doesn't just affect Lyme disease. Consultants and advisors who are paid by pharmaceuticals should have their evidence disallowed. The NHS should use tried and tested methods from across the world in treating Lyme without question.
Wednesday, Feb 3rd 10:52AM	Better testing, education, awareness and treatment protocols