

UPDATE OF AN APPROACH TO THE TREATMENT OF CHRONIC LYME DISEASE

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The stimulus that prompted this essay is what seems to be a concerted attempt by well-thought of professional organizations in this country to denigrate a group of dedicated physicians who are involved in treating problem cases of chronic Lyme disease. This essay tries to show the other side of this coin by sharing with colleagues experiences obtained over some years in my trying to face up to helping patients who I think might have this vexing disease.

The epigrams upon which this presentation is based are as follows: where there is smoke there is fire; absence of proof is not proof of absence; when experienced observers think something is true it usually is (the basis of Bayesian statistics); hypotheses do not spring from the head of Athena but rather from the experiences of their author; when intelligent people disagree, no one knows for sure.

The building blocks for the approach that is being presented are as follows: The spirochete that cause Lyme disease can lurk undetected for many years in the tissues of individuals who have this disease; (This assumption is based on experiences with syphilis sufferers who respond to penicillin years after they got syphilis); Lyme disease often or perhaps usually is multifactorial due to co infections and the autoimmunity which is part of its spectrum; and the fact that the causative organism has a cystic phase that may be resistant to some antibiotic has to be taken in consideration in management.

THE SYSTEM USED TO APPROACH AND TREAT CHRONIC LYME DISEASE

First is the initial “face to face” interaction in which I try to use my clinical experience and intuition to decide, “Is this patient ‘for real’ in regard to having this disease?” Experienced clinicians will know what I mean by this. Then I try and determine if there is a reasonable possibility that the patient has ever been in an endemic area. Being possibly exposed is the sine qua non for serious consideration of the diagnosis. Having a rash, remembering a bite, and having a negative test for Lyme disease do not by any stretch of the imagination rule out the possibility of Lyme disease. A not unusual hint that helps is whether a patient’s dog has ever had Lyme disease. Veterinarians are often very savvy in this regard and seem to have access to very good diagnostic tests for Lyme disease. Hunters, fisherman, campers, hikers and bikers of course are candidates for this disease. The previous workup is important. Most patients that I see have had a workup that ruled out the more serious diseases that cause one to feel “lousy.” The existence of fever which rules out the chronic fatigue syndrome often is seen in Lyme disease. On the other hand, bizarre arthritis with little swelling catches my attention as an important finding. What most patients call “brain fog” that happens intermittently is another finding that suggests chronic Lyme disease. While Lyme disease patients have joint and muscle pain, they do not usually merit a clinical diagnosis of fibromyalgia in regard to tissue pressure points. A very important feature of the history is a history of Bell’s Palsy. This syndrome is well-documented as a presenting

symptom of Lyme disease. I was amazed to see a classic acute case of Bell's palsy melt away when intravenous treatment with ceftriaxone was administered. I have discussed elsewhere on this website demylenizing syndromes which surface in chronic Lyme disease. They often improve after treatment for chronic Lyme disease with antibiotics.

What has been called Bell's palsy of the gut has been reported and I can share that this syndrome has improved with antibiotic treatment. I have also heard patients describe symptoms that remind one of the celiac diseases. These symptoms sometimes disappear after treatment for Lyme disease (see case report on this website). These experiences suggest that when Lyme disease is under consideration that symptoms characteristic of Bell's Palsy, multiple sclerosis, celiac disease, and upper gastrointestinal pain should be asked about. It would take hundreds of cases to prove that these diseases respond to antibiotic treatment in some instances but that does not mean that it might not be reasonable for a physician to try them on a patient who was "going nowhere." This would be consistent with treating possibilities rather than probabilities which has also been discussed elsewhere on this website.

The physical examination of patients suspected of Lyme disease is usually negative. Joint soreness without the spindles of rheumatoid arthritis is the most constant finding. Findings that should alert one to Lyme disease are those often found with multiple sclerosis, i.e.: ataxia, parathesia, absent abdominal reflexes, and hyperreflexia. It should be pointed out that the MRI findings thought to be characteristic of multiple sclerosis have been reported in Lyme disease. A provocative finding that I have seen several times in Lyme disease is fasciculations of the type I have seen in amyotrophic lateral sclerosis. Skin rashes are often seen with chronic Lyme disease but I have been told that these usually are caused by co infection with Bartonella (cat scratch disease).

None of the things mentioned may be found on the physical examination in which case one must turn to the laboratory. Here I wish to share the opinion that in most cases of chronic Lyme disease the only benefit of the lab is to rule out other diseases and to sometimes establish co-infections. What follows is suggested laboratory work that should be considered. The studies that have been done in the near past usually do not have to be repeated if they have ruled out autoimmune disease, occult cancers, Hashimoto's disease, clinical hypothyroidism, and drug addiction, which in my experience is often caused by narcotic treatment for fibromyalgia and profound depression. Then antibody studies for Bartonella should be done. These bacteria are the most common co-factor in my experience. Other organisms may be co-factors and should be considered as part of the entire picture and treated as such. T cell studies occasionally turn up unexpected important factors as do determinations of immunoglobulins and complement levels.

As far as where it is best to get the Lyme tests I am going to "take a pass." Suffice it to say Immunex in California seems to have served me well whereas this has not been the case with other national laboratories. When the Western blots are markedly present along with antibodies the diagnosis is established but in most cases this does not happen. I pay attention if only one band of the Western blot is positive because if this occurs the blot concerned often disappears after treatment.

When one puts all of the above together what might be the next step? When I

decide that treatment for Lyme disease is worth trying I first institute a treatment program using oral antibiotics that in some cases seems to solve the patient's problems. They are: doxycycline 100 mg TID. Ketek or erythromycin or biaxin (this tastes awful), 500 mg tid, flagyl 500 mg po daily or diflucan 200 mg per day by mouth, and ceften 500 mg BID.

This oral program has helped some patients with chronic Lyme disease with improvement being noted in six weeks, and if it does, I keep it up for at least a year. If the oral program doesn't help I go over with the patient and his family the possibility that a course of intravenous antibiotics is a reasonable option. However if they do not live in my area in order to receive intravenous antibiotics patients have to find a doctor who will take the responsibility of the daily oversight of a homecare agency that will manage intravenous treatment with the antibiotic cephtriaxone. If and when their insurance carrier agrees to foot the bill I then lay out the following program for which their doctors will be responsible. We let the insurance carrier decide on a homecare agency which can institute a home-based intravenous program. When this is done I go over the following orders with the agency chosen and if it is out-of-town, with the doctor who has agreed to take the local responsibility for the program. When all concerned are on the "same page" the following orders are written. Interestingly, in spite of the negative publicity we have all heard regarding this subject, in the Milwaukee and Chicago area some third parties have been willing to fund the program that is being outlined when it is carefully explained to them.

THE SYSTEM BEING USED TO TREAT CHRONIC LYME DISEASE

1. Have a pic line placed for long-term IV therapy. I prefer to have this done at St. Mary's Hospital in Milwaukee which is my home hospital because they are experts in placing this line
2. Give the first infusion of 6 grams of ceftriaxone in 30 ml of saline with the infusion nurse or specialist standing by with an EpiPen and leave a supply of these pens with instructions with the patient. Teach the family member or friend who is willing and qualified how to prepare and give the IV generic ceftriaxone daily. Have the home care professional be present until he/she is satisfied that the family member or friend is comfortable and accurate with the infusion procedure.
3. Oral medications that are to be given concurrently with the intravenous antibiotic are in prescriptions counter-signed by the personal physician. They are in the patient's possession. They are erythromycin or ketek 500 mg po id daily, Flagyl 500 mg or diflucan 200 mg once daily
4. Weekly labs: metabolic panel, CBC, urine test. If any loose stools, get stool culture for staph and clostridium difficile. All lab reports are to be sent to the patient's personal physician weekly
5. Visits by a professional from the home care agency weekly or on request of patient or the family
6. After the IV program is completed, take out the pic line in the approved manner.

The daily intravenous infusions are for six or eight weeks. After they are completed, start the oral antibiotic, with the patient given prescriptions by the physician. They will be for: doxycycline 100 mg bid po, ceften 500 mg bid daily po, flagyl or diflucan 500 mg or

200 mg daily, po, per day. Note that the oral antibiotics may be up to the personal physician. We have had to compromise with some home care givers and give the ceftriaxone in only a four gram dose because the package insert of the drug says four grams. We have given ceftriaxone in six grams intravenously for many years for long periods without complications but our home care people have been so cooperative that we felt that they earned this compromise. However, there is no legal rule that the dosage on the package insert must be followed. There have never been any complications in my experience with this program.

FINALLY, I WANT TO EMPAHSIZE THAT THIS ESSAY IS TO SHARE EXPERIENCES WITH COLLEAGUES WHO MIGHT BE INTERESTED. ANY TREATMENTS MENTIONED HERE WILL HAVE TO BE GIVEN BY A PHYSICIAN WHO TAKES FULL RESPONSIBILI8TY FOR ITS OUTCOME.

It is my hope that the experiences mentioned here may result in some patients receiving more aggressive treatment for chronic Lyme disease and will perhaps raise the understanding of some in the “establishment” regarding how some physicians try to operate by thinking “outside the box” in their attempts to help problem patients.