LymeSig

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WELCOME .... from the Coordinator.

LymeSig is all about Lyme disease. The international term is Lyme Borreliosis. Currently debate rages among those involved with the disease. Those affected are patients, doctors, scientists, legal professionals, insurance professionals and governmental decision makers. Because Lyme disease is an emerging disease both in terms of epidemiology (we keep discovering new areas of the world where it exists) and in terms of our understanding of the effects of the disease on those afflicted, there is room for everyone to learn more about the disease.

Many victims, including Mensans I know, have already become disabled by Lyme disease. We know of people who have seen as many as forty-two doctors before being properly diagnosed as having Lyme disease. Often years go by before proper treatment is attempted, and more and more often I hear stories like that of my new son-in-law-to-be that it is too late to cure the disease. On the other hand, I have three grandchildren who have all been bitten by ticks in a highly endemic area, West Chester County, New York, who were treated immediately with antibiotics. Two of the three seem to me to be doing fine. The soon-to-be three year old boy is mixing his "D"s and "R"'s , "K"s and "T"s, stomps the floor rather dramatically when walking - sometimes for hours, and sometimes doesn't quite seem to hear me when I talk to him. I don't see him that very often, and so I notice things like that. I remember that when he was six months old he was treated for a prolonged period of time with antibiotics for his recurring earaches. I wonder.

continued, page 4

~ NOTICE ~

LymeSig is the publication of *LymeSig*, a Special Interest Group (SIG) of *American MENSA Ltd.* The publication serves as an international forum for sharing ideas, opinions, and information about Lyme disease. Opinions expressed in LymeSig are those of the individual contributors; American Mensa holds no opinions, nor does LymeSig as a group hold any opinions.

LETTERS AND STORIES...

From West Virginia...

Dear Dave,

You can not imagine the joy I felt when I saw the Lyme SIG announced in the Dec. Bulletin. There is so much I want to share that this letter may not make a great deal of sense.

My wife, my son and myself have been diagnosed by two different physicians and two separate labs as having contracted Lyme disease.

We live on top of a mountain in a very rural area; our nearest neighbor is a mile away. The area has a very high population of Whitetail Deer.

I have no idea when I first contracted Lyme.

My undergrad degree is in psychology and I was able to recognize the symptoms of clinical depression in myself about five years ago. I brought my fatigue and depression to the attention of our family physician, he referred me to a psychiatrist. With the many vague and various symptoms I had, I honestly thought I was going "crazy". The psychiatrist put me on Prozac for over three years until my diagnosis of Lyme. I am now on Wellbutrin at a low dosage.

My family's diagnosis of Lyme was by pure accident and luck. My wife works at a local hospital. She had developed Bell's Palsy with facial paralysis. One day a physician (who was familiar with Lyme) passed her nursing station, paused, looked at her an said, "Bell's Palsy, have you ever been tested for Lyme Dice?" This is how we found out; pure serependipity.

Unfortunately my body has sustained permanent damage, as you can see by the enclosed. On the bright side, Social Security does now recognize Lyme as a disability and will grant benefits. I am looking forward to the newsletter, as I have never met or even talked with anyone, outside of my family, who has contracted Lyme Disease.

Lyme has made my life a hell on earth, so please feel free to use any or all of the information enclosed as it may encourage or help others.

Pax,
E. Fred Moore

(Thanks, Fred. Fred tells me his doctor thinks he had LD maybe five or six years before being diagnosed. Info enclosed is in regards to his disabilities and social security battle- write if interested.) D.B.

From Connecticut...

Dear David,

Several years ago, my son David was very sick and it turned out to be Lyme disease. His doctor had suspected it, but never diagnosed it, because 6 tests (at several labs) over a 3 year period had all been negative. The doctor believed the tests more than the symptoms, history, and exposure in a hyper-endemic area. Anyhow, to make a very long story short, he missed a year of school, and had medical expenses of about $100,000, and now is now doing well.

Frank C. Demarest

NEWS BLURBS/SHORTS

Another doctor persecuted.... ?

Doctor Phil Watsky of Bristol Connecticut is currently being prosecuted by the State Department of Health and Addiction Services investigating a complaint that he overdiagnoses and overtreats Lyme disease.

Another doctor, not a patient, complained. The complaining doctor, Dr. Lawrence Zimel, did not even know the patient, but learned about it "second hand" according to an Article in the Courant, a New England Newspaper.

In New Jersey, another treating doctor, John D. Bleiweiss, committed suicide after that state's attorney generals office reopened a claim he had already successfully defended. The complaint was the same: overdiagnosis and overtreatment of Lyme disease. In my personal discussion with doctor Bleiweiss, he indicated both he and his wife suffered from Lyme disease.

Dr. Bleiweiss committed suicide on 12 August 1995. One death should be enough. If you want to write to Connecticut state officials, addresses and more information is available in LymeNet at http://www.lyment.org. LymeNet not associated with LymeSig.

Dave Bartholomew

Chronic Lyme Disease...

The Lyme Disease Foundation (LDF) is hosting a conference on chronic Lyme disease on April 19th and 20th 1996 in Boston. For more information and registration forms please contact the LDF at (860) 525-2000. Topics include Lab diagnosis, Clinical Diagnosis and Treatment for chronic Lyme disease.

WELCOME... continued...

My feeling is that we should all have a sense of wonder when it comes to Lyme disease. Scientific researchers are broaching many traditional concepts in their efforts to find the truth. In Switzerland, Doctor Judit Miklossy found coiled spirochetes in the brains of 14 out of 14 Alzheimer's disease victims
(NeuroReport 4, 841-848 (1993). In the first study of chronic LD, patient 12 died while under observation. Her CSF was negative, but spirochetes were isolated from her brain. She had received over the course of the years of her disease two short treatments of I.V. antibiotics - two weeks each course.

At the same time, controversy rages among doctors about diagnosis and treatment of Lyme disease. Because patients end up seeing many doctors before they find the right one for them, the "I had a doctor who.." stories tend to be quite interesting.

It is the intention of LymeSig to allow the freedom of expression of all opinions so long as they are not injurious, slander, or libel. Medical professionals would do well to remember John Stokes quoting the famous aphorism of Nonne "A neurasthenic with syphilis in his history suggests the paretic." Patients would do well to remember that doctors are human beings.

Because this Special Interest Group is new, it is still very small. Only one advertisement appeared in the Bulletin in December. The SIG's list in Spring will list this SIG. Also I have written to the publications officer to advertise in all the local groups' newsletters.
I have drafted a letter to British Mensa which will be dispatched soon. I could use some help from linguists fluent in German and Japanese.

As the SIG develops and grows I expect many interesting issues to come up. For instance; do we want to "show" at an RAG or the AG, do we want to only do the newsletter thing or do we want to become more involved in other ways. Some of my ideas and plans for the future appear on the last page of this newsletter.

I hope you enjoy this newsletter and find it interesting, thought provoking, and perhaps of some use. As always, your comments and criticism are invited. Write to LymeSig, 323 Chapel Avenue, Allentown, PA 18103.

David P. Bartholomew
Coordinator

PERSONAL STORY ARTICLE

by

Lava Irish
Doctor of Natrology

As someone who has been tortured by physicians all in the name of "curing" Lyme Tick Disease", I am "one who knows." I will begin by telling you OUR horror story, and then I will tell you how to cur, (yes CURE) yourself, once and for all of Lyme Tick Disease.

I was in Billboard Magazine, January 1985, in the back. My co-manager (I was a singer) was Sid Bernstein, of Laura Brannigan and the Beatles fame.

I went to Connecticut for a picnic, and got bit by a tick. I weighed (all of my life) 135. I am 5'10 1/2".

I began to swell up, get horrible rashes, and muscle spasms so severe that my legs locked, and I fell down the stairs, separated 7 fibs, and scoliosed my backbone. I went to a RCA appointment to talk about a contract in a back brace. My legs were so numb, that when I had put on my tight black spandex pants, there was a rip in the inside of one leg, and I sewed it while it was on. When I hot home, I had to be taken directly to the emergency room, and when they took my britches off, they found that I had SEWED MY PANTS TO MY MEAT!!! No lie.

Joseph, my husband, also go bit. He was a very famous photographer in New York, did all the Penny's, Wards, Hermanns catalogs, all the Photographs. Now he could hardly walk, got bit on a location shot. We were a mess, quite a couple!

We went to about twenty different doctors, begging them to see what was going on. I later read about Lyme's, and from the symptoms, I knew that we had both been bit, and again, begged doctors to help us.

We were given TONS of antibiotics, all the wrong kinds, and for the wrong durations, and became sicker and sicker. I had more and more muscle spasms, went blind for a half a day, bedridden for many days at a time, our abdomens swelled up like balloons, our joints became stiff, we wanted to sleep all of the time. It was Hell on earth...

But wait... it gets BETTER!!!

Then from the east coast, we moved to Kansas City, where we went to KU, and found we had in deed "Lyme's", Dr. Chien Lu decided to treat us (Joe showed a tritation, but like David, I didn't, I was just symptomatic) with 1 GRAM of Ceftriaxone intravenously for three weeks.

They put a pipe in our wrists, and had to change it every three days. If we hit it during the night (and we did) the pain was excruciating and hideous. Joseph and I soaked the bed with night sweats, and had to change sheets every day, and turn the mattress every day.

(Continued next page.)

I stopped urinating, and became uremic, and became totally incontinent because unbeknownst to me at that time, the antibiotics almost destroyed my liver, and I developed Erythropoetic protpporphyria. Now I weighed 275, and I was dying, completely swollen and deathly ill.

I was trying everything. Of course I lost my music career, no one wants to see a deathly ill blimp on stage.

I went to the Library to see if they had a book on the light therapy. No such luck. but all of a sudden, as I was turning to go, something made me ask, "by the way, do you have the book, "the Secret life of Plants"?

Now, I had never heard of that book but I was astonished to hear the guy at the desk say, "Oh, yes, we have that book, here it is", and see him pull it out from under the computer!!!

I checked it out, and read all about radionics, for the first time.

Radionics is the use of an instrument which can broadcast the opposite rate or the same rate as a disease germ or imbalance within a plant, mineral, human, or animal and eliminate that condition.

For years, physicians gave mercury for Syphilis, without actually knowing why, but Syphilis vibrates at the same exact rate as mercury, so they canceled each other out basically.

Everything in this world has its own vibratory rate. If a germ is hit with its own or a more powerful vibratory rate, it will explode.

I use my instrument, the SE-5 on our farm, our garden, all of our animals, ourselves, even the local Vet asks for my help if he gets stumped on a case. The instrument can find any hidden condition, tell you if an organ is functioning, can find and eliminate cancers, Leukemia, etc., etc., and alleviate Lymes, amongst other things.

It is immensely difficult to learn how to use, and effectiveness "depends upon the efficiency and talent of the user". I can tell you many stories a saving our animals' lives with the instrument, remote treating, the instrument does no work on time and space. No matter how far away the subject is, it will work.

Anyway, I first purchased an old fashioned model from the widow of the first inventor, (no names mentioned here), suffice it to say that there were many shortcuts taken, and Senility is involved, and it was a mess. I found the SE-5 makers, and a more sophisticated instrument, with no "hoodoo" involved, got rid of my old model, and purchased the SE-5, a computerized model. Works great.

In my rate book were homeopathic rates. I knew nothing about Homeopathy, but had used Shussler's cell salts before.

All of a sudden, I found myself getting a doctorate in this field, getting a highly advanced computer program exclusively for researching remedies, and using the SE-5, I could tell what remedy rates were "high", which I then researched the symptoms to tell if they matched, and the always did, and I began to heal us.

I subsequently found the CURE for Lyme Tick Disease. This WORKS.

(TEXT EDITED: Due to the recent legal attacks on Ld treating doctors, this portion of Alva’s article has been omitted pending legal clearance). D.B., Editor.

(deleted text)

After taking this regimen, I defy anyone to take another blood test and find a titration of Lyme's disease remaining.

That is all there is to it. An absolute cure is available and possible.

We subsequently in the meanwhile, had commissioned a plumber to put a furnace in downstairs because Joseph could not pick up wood for the fireplace, and the guy put the furnace in with the vent UNDERGROUND!!!, so that in ADDITION to being disabled from Lyme's and this porphyria, we were also poisoned by Carbon Monoxide. We lost two of our dogs, and we nearly died, except for the radionic instrument, and the homeopathics, which saved our lives.

We would be dead if we hadn't had these two things.

Well, this is all for now. Get well, all.

Much love,

(Thank you Alva, for sharing with us. For further contemplation along these lines I offer to readers this quote from Albert Einstein from Science, Washington, D.C. May 24, 1940: "In particular, Niels Bohr was able largely to understand the structure of the atom, on the assumption that atoms can have only discrete energy values, and that the discontinuous transitions between them are connected with the emission or absorption of such an energy quantum. This threw some light on the fact that in their gaseous state elements and their compounds radiate and absorb only light of certain sharply defined frequencies." Einstein's article was titled "The Fundaments of Theoretical Physics".) D.B.

About the Tests... a Clinical Relationship

by David P. Bartholomew

There is no test. NIH, CDC, and the LDF all agree that diagnosis of LD is clinical. So why do many doctors want positive tests before they treat LD? They don't know the symptoms well enough to make a clear clinical diagnosis. Or worse, there is interference by insurance companies, worries about reputation, and lately professional reprisal by litigation as in the New Jersey Complaint against John D. Bleiweiss - litigation based exclusively on treatment despite negative tests.

So what about the tests? The standard text Gel Electrophoresis of Proteins, Michael J. Dunn, ed., 1986, lists nineteen things that can go wrong with a Western Blot test for any disease. There are over 80 strains of Bb. Epidemiology is lagging. Direct observation is rumored to be nearly impossible. Ability to culture the organism is rumored to be next to impossible. "False Positives" are rumored to occur. So, what about the tests.

Let me offer for consideration an approach that is well founded in medical history - a clinical approach. The tests have long been known to be negative due to the clinical course of a spirochetal disease which has a four hundred year history: Syphilis. The symptomology is so similar in many respects that where the reader sees Syphilis in this article the reader may choose to substitute the term Lyme disease. Or better; just look at the following presentation as indicative of what may be going on in any spirochetal infection. I have seen no reference denying conjugation of spirochetes as of yet, nor have I seen studies on the evolutionary patterns of the species.

I refer hereafter to the knowledge of the relationship of tests to clinical presentations of the disease as documented by Herman Beerman, Chairman, Department of Dermatology, University of Pennsylvania, and John Henchman Stokes, Spokesman for the Penicillin Panel Group whose investigation of late syphilis comprised five cooperative clinics and drew on the experience of eight clinics, as co-authors of "Syphilis". I refer to knowledge documented by well known Neuropsychiatrist Roy R. Grinker, and Irving G. Sherman, Northwestern, as co-authors of "Syphilis of the Nervous System". My reference is Practice of Medicine, Tice and Sloan, eds., 1954, Volume 3 for syphilis and Volume 9 for neurosyphilis. For simplicity, page numbers are given after quotations. Grinker and Sherman numbers are above 700.

In comparison to toadies limited knowledge, after the Penicillin Panel Group, "observation of a large number of cases treated has now reached the tenth year or longer, and the serial examinations of cerebrospinal fluids and parallel clinical data give an impressive account

of what the antibiotic actually accomplished, not only of itself but in comparison with the methods of therapy hitherto available." 441. That tests were carefully considered by Beerman and Stokes is evident: "Without a presentation of the newer diagnostic technics, much of the practical significance and fundamental groundwork of the clinical side of syphilology, both early and late, is missed." 351.

My opinion is that the credibility of their opinions in terms of test interpretation in the clinical course of spirochetal disease is therefore valuable and may serve us today.

The basic reasoning of these two gentlemen which led them to advocate aggressive treatment as early as possible, which will become evident throughout this article, is founded in the following tragic consequence of nontreatment: "It should, moreover, be clearly realized that in the later years of a syphilitic infection, different tests, or the same test taken at different times, or even on successive days, give variable and often totally conflicting results. The seropositive landmark for late syphilis, comparable to secondary syphilis in the early stages of the disease, is general paresis." 362. By the time the test is positive, in other words, the damage has already been done. Therefore, instead of rehashing their own comments about controversial interpretation of tests at that time (1954) which included the same false positives, the same difference in quality of laboratory technics, and the same controversial arguments among doctors we have today, let me just say that the today's specialist is welcome to a copy of Beerman and Stokes's "Syphilis" from me.
Just write.

So, why not tests? One reason early is "apart from the possibility of occasionally identifying an individual who may tend to relapse, the frequent repetition of blood serologic tests during the management of early syphilis tends to overemphasize the importance of the procedure in the eyes of both patient and physician. If the serologic test is repeatedly negative, the patient will tend to regard himself as cured and the physician will tend to abate the vigor of his therapeutic measures. Instead... the patient should be trained to the knowledge that his blood test is no index whatever either of his infectiousness or his nearness to the goal of cure. The physician, in turn, should accustom himself to the practice of using an empiric scheme of treatment of maximum intensity absolutely without regard to the serologic findings." 366. As an exception, for a patient who's test was at first negative "it is desirable to repeat the blood serologic tests week after week for several occasions... to be sure that the test does not become positive soon after the patient was under treatment. When this does occur it indicates that the infection at the time treatment was begun was so near full-blown that the more favorable prognostic significance of the seronegative primary state does not apply." 366.

Concerning abnormal spinal fluids "in treated and more advanced untreated secondary syphilis, it falls to from 24 to 26 percent," 366, in terms of reliability as a test. Following a percentage analysis of spinal fluid tees reliability, a very important caveat is given: "It is important to note, for reemphasis later, that the spinal fluid does not invariably indicate the existence of a neurosyphilis, which

nonetheless is present. This is notably the case in certain types of tabes dorsalis, including those presenting Charcot joints and gastric crises, and in the comparatively isolated involvements of vascular neurosyphilis and solitary gumma." 367.

And indeed it was reemphasized: "Both active as well as arrested neurosyphilis may present completely and persistently negative spinal fluids to all four tests. This is particularly true of vascular neurosyphilis, of those forms of tabes dorsalis associated with gastric crises, Charcot joints and trophic ulcers, cerebral nerve palsies, cerebral gumma, syphilitic epilepsy, Erb's syphilitic spastic paraplegia and nonparetic syphilitic psychosis. As previously stated, it is even possible for the spinal fluid to contain Treponema pallidum and yet be entirely negative to all four tests." 373. Keep in mind that most of these patients were not treated with modern day corticosteroids by mistake prior to trying to get tests results. There were also some indications that paresis could be negative in the spinal fluid and yet be "active and symptomatically progressive." 373.

As a reminder of caution in interpretation of negative blood serology, Beerman and Stokes noted that a patient being treated with arsphenamine and a heavy metal "whose serologic reaction reverses to negative before the eighth week of his treatment, is showing a positively dangerous degree of serologic response and one which predicates a distinct tendency to relapse or to continuance of syphilitic process under cloak of negative serology." 365.

There are specific clinical syndromes in which the blood serology is known to be negative. "Cardiovascular disease probably furnishes the best examples of this slow progression of the degenerative process in spite of a persistently negative blood and reasonably energetic treatment. Patients may be observed for years with negative reactions who slowly progress to serious grades of cardiovascular, visceral and neurosyphilitic damage in spite of treatment and beneath an unruffled serologic surface." 384. Specific cases of thirteen and fourteen years duration are mentioned - with never a positive test. The authors conclude that "particularly in the later stages of the disease, each patient is a law unto himself and that observation at reasonably frequent intervals takes overwhelming precedence over merely serologic data." 384. It is this kind of statement that begs the academic community to consider strongly again the teaching of the symptomology of spirochetal infections: to include Tabes and Paresis. Just like Syphilis, treatment regimens from best to worst have failed in Lyme disease. The problems of Clinical latency, Serologic latency and Pathologic latency need to be reexamined. Hopefully, a simple method of direct detection will make this possible. In any case, there is a need for highly trained and dedicated specialists who treat Lyme disease. "Practically all the observed phenomena of the disease throughout the lifetimes of patients thus far studied could be satisfactorily explained, including the fact of a lifelong latency, by the discovery of a granular or ultramicroscopic stage in the life cycle of Treponema pallidum... there is today, so far as man is concerned, no proof of cure except observation." 381.

So what about negative tests indicating "cure?" Beerman and Stokes present numerous examples in which the tests are unreliable. They state that there is symptomatic progress in spite of seronegativity in cardiovascular syphilis, and they note that "neurosyphilis likewise affords a number of excellent examples of symptomatic progress due to isolated lesions which leave no indication in serologic positivity either in the blood or the spinal fluid." Of the patients in the first population based, controlled study of the long-term consequences of Lyme disease, in 1991, patient number 12, who had a negative spinal fluid, died. At autopsy "a spirochete was present in the cortex and another was exterior to a leptomeningeal vessel." So, what about the tests?

Tests can be negative. Specifically, "the blood serologic tests are distinctly unreliable in the identification of Charcot joints, for the type of tabes with which they are associated, like tabes with gastric crises, is the one most commonly associated with negative blood and negative spinal fluid." 401. "The commonest Charcot involvement are foot, ankle, knee, hip and shoulder. Multiple joints may be afected." 401. This sounds like I've read it somewhere before. As a word of caution to orthopedists and surgeons "apt to be the ones to first diagnose a Charcot joint... although the association with a negative blood and spinal fluid is frequent in these cases, the serologic findings do not mean that neurosyphilitic process is necessarily arrested." 401.

Gastric crises are commonly known to be accompanied by negative tests. "The negative serologic blood test and the negative spinal fluid do not by any means eliminate syphilis from the explanation of a gastric syndrome. This combination, as in the case of Charcot joint, occurs in the type of tabes in which gastric crises are most frequent and in which the diagnosis must be made practically entirely by neurologic signs plus the periodicity of recurrence of the gastric disturbance without other explaining factors." 409.
This was so little understood even then, at the zenith of our understanding of Syphilis, that "one third of the needless laparotomies performed on the writers' patients were done for gastric crises masquerading under other diagnoses." 409. And if by luck or by a physician's clinical awareness a patient was correctly treated "really amazing functional recoveries take place in syphilis of the stomach under appropriate systemic treatment." 409.

And because the tests were negative "even the earliest clinical recognition of vascular involvement in the disease is unhappily comparatively late. Generations of bowing at the shrine of the spectacular in physical diagnosis has tended to make it still later." 413. I hope the reader of this article is by now getting a feel for the need for expert clinical diagnosis. For educational purposes, the following was added: "It cannot be too vigorously impressed upon the physician in charge of a patient with syphilis that complete serologic negativity within the first 5 to 10 years, coincident with indubitable lesions, is entirely possible. The senior writer has himself watched patients develop cardiovascular syphilitic lesions even under fairly thorough modern treatment for syphilis and with practically continuously negative serologic tests. This emphasis on the untrustworthiness

of the negative, however, should be coupled with an emphasis on the very great importance of even slight degrees of positiveness in the serologic control of a patient between the second and fifth year of his infection." 413. It is interesting to note that my own slight degree of positiveness in standard blood tests repeatedly shows as the flagellar protein on my Western Blots (41KD protein). Those Western Blots are considered "non-supportive of a diagnosis of Lyme disease". My specialist diagnosed Lyme disease anyway. Again, the need for specialists should be becoming evident.

The need for clinical expertness as opposed to reliance on tests is further stated "while reaction shows itself in the spinal fluid examination in a large proportion of cases, there will always be some who will present true neurosyphilitic complication with negative spinal fluids and negative blood serologic tests. These will include especially the vascular accidents, preponderating early, and the slow, degenerative cord lesions and localized gummatous changes late in the disease." 418. This can be interpreted to mean that those who rely on tests alone put at risk of death patients with early cardiac involvement or late serious nervous system involvement: the two groups of people who suffer the most damage. Misdiagnoses in these situations make malingerers and alcoholics out of general practitioners: law suits have been know to produce this effect on doctors. There is no wonder why "vigorous reemphasis should be placed on the fact that negative blood serologic tests, no matter how often repeated, do not prove the absence of neurosyphilis in patients with early or late manifestations." 418. Sherman and Grinker echo the last statement "a positive finding in the blood is of great value in the diagnosis and treatment of neurosyphilis, while a negative finding is of little or no value." 749. Additionally, "in the later stages of neurosyphilis, the percentage of positive finding may fall to as low as 65 to 70 percent, while in latent syphilis the percentage of positive falls still lower, to 50 per cent or less." 749. Doctor John D. Bleiweiss, Lyme disease specialist (deceased, formerly in practice in Trenton), noted that many of his sicker patients repeatedly had negative tests. In interpretation of spinal taps, Sherman and Grinker also noted that in cortical meningitis "the exudate may be so well localized that there may be no increase of cells in the lumbar fluid and the Wasserman reaction may be negative." 777. This sounds like patient number 12 in the first chronic study for Lyme disease.

So, what about the tests? How much are modern day insurance companies going to want to pay for repeated tests when "in chronic meningeal syphilis the blood and spinal fluid Wassermann reactions are positive in 70 to 80 per cent of cases although one may be positive without the other. The spinal fluid may be negative on one examination and positive subsequently." 778. How many patients who recall their tick bites and subsequent rashes would want to put up with spinal taps just to satisfy the curiosity of treating physicians who do not know symptomology? The observation is tough, however, because "indeed the palsy may be so transient that, when looked for on the day following its appearance, every trace of it may have disappeared."

Perhaps instead of "tests" we should pay for prolonged periods of clinical observation recorded by camera. The neurological problems of Lyme disease are in many respects similar to syphilis. Why shouldn't the lab work be just as confusing: "In tabes dorsalis the laboratory findings are dependent upon the state of activity of the disease and not upon the presence or absence of clinical signs of neurologic involvement." 837. "...statistics have ignored the problem of activity and some have even made no attempt to distinguish between treated and untreated cases. In a study by the Cooperative Clinic Groups it was found that 32 per cent of 896 cases had a negative blood Wassermann reaction in the presence of a positive spinal fluid, but this too has been questioned as unreliable and reflecting only the status during a period when less sensitive tests were in use." 838.

Sherman and Grinker, because they were experts in symptomology, were able to state "The diagnosis of the clinical syndrome of tabes may be made in the presence of a completely negative spinal fluid even where there has been no therapy or inadequate therapy to reverse a previously positive spinal fluid." With signs and symptoms of ataxia, lightening pains, and crises "considerable relief can be expected ... Even more valuable than this is the prevention of progressive destruction of nerve tissue." 840.

Again in terms of neurosyphilis, under the heading "diagnosis" Sherman and Grinker say that "physicians rely too much upon the laboratory and too little upon their own diagnostic skill." 756. In neurosyphilis "the diagnosis must be made after a full consideration of symptomatology, course of the disease and laboratory findings." 757.

Even in early syphilis "serious neurorecurrences of the isolated vascular type involving the second, seventh and eighth nerves may develop even though a previous negative spinal fluid has seemed to indicate that the nervous system is free from involvement." 394.

To emphasize the clinical approach in favor of reliance on any test procedures, Beerman and Stokes note that the tabetic patient "cannot be discharged completely from observation throughout life. The principal reason for this is the undoubted occurrence of symptomatic unfavorable progress in the presence of completely negative serology, both in the blood and the spinal fluid." 424. So, what about the tests? There is controversy today about the tests for Lyme disease. We are reliving syphilis all over again: "The struggle between clinical and laboratory interpretation, the battle of syphilologist and serologist for supremacy, the war between specificity and sensitivity... - all have unmistakable hallmarks of drama." 354. That within the scenes of the play upon our current stage we still witness the unfolding of death and disability is a shame upon us.

And, so, about the tests, I prefer the discerning eye of specialist. There is a caveat to be considered. In their 127 page treatise, Beerman and Stokes say "the writers have tried to make it clear that the term 'cure' in connection with syphilis at the present day, despite the enormous advances in treatment control, is still an expression of faith rather than a statement of fact." 381.

- End -

LYMESIG ... the FUTURE.

~ is wide open ~

Good things coming up in the near future include the following:

@ LymeSig advertisement will be sent to all LocSecs by Mensa Sigs Publicity Officer very soon.

@ LymeSig ad should already be in the Connecticut/West Massachusetts local Newsletter.

@ Coordinator and Spouse will attend the LDF sponsored World Conference on Chronic Lyme disease in April - at their own expense.

@ This newsletter was late because the coordinator's old computer broke - a new one has been purchased and it broke too. Now that is fixed. I have built an efficient new office into one room of my house which will also facilitate and expedite matters.

@ Lymesig will com on-line www.com, probably with a 24 hour daily access - my cost not the Sig's.

@ Letter/Article to British Mensa to be completed and dispatched within days.

@ Letter/Article to Alzheimer Sig to be completed and dispatched within days.

Open topics for publication/discussion in our newsletter recommended:

@ Suggestions from members wanted!

@ Do we want to do any fund raising - to support research/education or to support public awareness or to support the LDF or support patients in need (some people, believe it or not, do not have any insurance.)

@ Do we want to sponsor MD degree candidates to become specialists in Ld? Why not - only should cost a couple hundred thousand each?

@ Let's use our imagination: if it can be conceived, it can be accomplished. If you look at the December 1931 cover of Popular Science, you will see Professor Goddard's original concept for the Space Shuttle!

A function of intelligence is survival.

d.b.