

Re: Is it Lyme disease?

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kl101510@yahoo.com wrote:

- > *Hello everyone and anyone. My best friend was diagnosed as having Lyme*
- > *disease back in Nov 2004 but for some reason I can not accept that this*
- >
- > *is what he actually has.*

Why can you not accept that? What is your hesitation?

- >*Just to give you all a brief description of*
- > *what is going on. Last Nov 2004 my friend came home from work one day*
- > *with a very swollen knee, and I told him he needed to see a doctor*
- > *right away just in case it was a blood clot and he put it off for a few*
- > *days to the point he could not walk on his leg so I had brought him to*
- > *the emergency room and the doctors found a lump behind his knee cap*
- > *they called it a Bakers Cyst and they also took x-rays and referred him*
- > *to an Orthopedic surgen to drain the fluid from his knee, he did go the*
- > *Orthopedic surgeon and they requested for him to have an MRI which was*
- > *done and then the fluid was drained from his knee and the fluid was*
- > *also sent off to be tested which whatever tests were performed came*
- > *back with nothing to be concerned of.*

So you don't know whether or not the fluid was tested for Lyme antibodies or by PCR for *Borrelia Burgdorferi* (the etiologic agent which causes Lyme Disease).

Results of unspecified "testing" even totally negative/normal results certainly don't rule out Lyme disease.

Even testing for Lyme itself is VERY unreliable with a lot of false negatives (the patient actually has Lyme but the test doesn't show it).

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There are lots of reasons for false negatives, including prior treatment with antibiotics (whether or not for Lyme) and timing—late stage Lyme disease one might not see a positive result—early (first few weeks) is problematic too. Also the tests are just totally unreliable.

> *My friends knee was feeling*
> *better but then a few days after the 1st drainage the knee swelled up*
> *again and he went back and had it drained, and then we went through*
> *this several times until the surgeon referred him to a Rheumatologist*
> *and this doctor had blood tests done and stated that my friend had*
Lyme
> *disease and the doctor explained to us what Lyme disease was and so*
on,
> *so again the knee was drained and the this doctor put him on*
> *antibiotics for 4 weeks which made my friend very ill,*

COULD be a "herxheimer LIKE reaction."

And though the "standard course" is four weeks, many patients require MUCH longer term treatment.

Particularly when there has been delay in diagnosis and initiation of treatment.

A swollen knee MIGHT well be Lyme disease, but when seen it is typically seen in the later stages of illness, months or YEARS after initial infection.

Lyme can lay dormant or latent for long periods (months, years, decades) similar to its bacterial cousin syphilis, and then reemerge.

Early infection might be mistaken for a cold or flu (often a summer flu), and be "self limited" or appear to be—maybe a patient is given a short course of antibiotics and SEEMS mostly better or all better but that has just driven the bacteria into latency or dormancy only to reemerge later.

An unusual characteristic of this disease is what is known as a Herxheimer reaction (named after a guy named Herxheimer who discovered the phenomenon).

When treatment begins, the antibiotics or other drugs start to kill the bacteria. As the bacteria die off, they release neurotoxins which will actually cause the infected person to have symptoms much worse than they did before they started treatment.

Lyme patients refer to this reaction as a "herx" or as "herxing."
Patients and doctors can use these reactions to determine how well a patient is responding to treatment.

A strong reaction says that the treatment is working well. Also, in cases where a diagnosis was made based on symptoms alone, with a negative test for the disease, a Herxheimer reaction can confirm that a person is actually infected with the disease.

A Jarisch–Herxheimer reaction (J–H reaction) is an exacerbation of a patient's Lyme disease symptoms shortly after the introduction of an antibiotic. The antibiotic kills off or "lyses" the bacteria and when it does, bacteria release toxins into the patient's system. This reaction is similar to that seen during treatment of the spirochetal illness, syphilis.

Once antibiotics are introduced, a patient with a J–H reaction will actually feel worse before feeling better.

*>this was on
> going for over a month and then all of a sudden he did not have any
> swelling until just this week his knee blew up like a balloon, so
here
> we go again, back to the doctor to have the knee drained again, in
> which the swelling had gone down and then a few hours later the knee
is
> swelled up again, what is going on, this is just a complete nuisance
> and is getting very aggravating for my friend.*

Does your friend have other symptoms? Fatigue? Swollen glands?
Neurological problems, cognitive problems etc?

Read Dr Burrascano's essay:

Joseph J. Burrascano Jr, MD:

Diagnostic Hints and Treatment Guidelines for Lyme and Other Tick Borne
Illnesses

November, 2002

http://ilads.org/burrascano_1102.html

*>I do know of a few
> people that have Lyme disease and none of them have had swelling of a
> joint, they have all had the flu like symptoms.*

Maybe he HAD flu symptoms when he was first infected. The swollen joint would tend to come months or years later. And it can be a classic sign but is not actually seen in a big percentage of patients.

*> And another reason I
> can not come to grips that this is Lyme disease is that my friend and
I*

sci.med.diseases.lyme: Re: Is it Lyme disease?

- > *have gone and thought about the last year and can not think of where he*
- > *could have been bitten by a deer tick, he has never been in any woods*
- > *or grassy areas, he is a workaholic and works in a paper factory, so he*
- > *never has time to even be outdoors.*

Geographically where do you live? You can get Lyme in your own backyard, at a picnic, a walk in the park. Your dog can bring in an infected tick.

And this might have happened long before the last year. Does he live in or vacation in or recreate in ANY area where Lyme occurs? It isn't just the woods or grassy areas (though it is found there). You can get it at the beach, some of the most endemic locales are beaches.

And it only takes one tick bite one time.

- > *My question is...is there anyone*
- > *out there that is going through joint swelling caused by this disease*
- > *and does this have to be a life changing this for him to have to go to*
- > *the doctors many times to have the fluid drawn.*

I know of a number of patients with similar stories. That said, no one can diagnose your friend via the internet. You've got to get him to a doctor knowledgeable about Lyme disease. Call a support group in your area.

As to whether this has to be life changing for him, well that remains to be seen. Delay in diagnosis and initiation of proper treatment is a big risk factor for morbidity but some people will do well once properly treated which may take months or longer, others don't have as much success.

Don't put the cart before the horse.

See a doctor knowledgeable about Lyme. If you tell us where you're at (geographically speaking, we don't need your address but a city and town or area is needed) and we can direct you to support groups and maybe individual doctors we'd recommend.

Good luck!

- > *If anyone has any info please let us know*
- > *Thanks*

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