

Re: IV ABX Study for Psychosis

Source: <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2008-02/msg01852.html>

- *From:* cowabungabarty@xxxxxxxxxx
 - *Date:* Fri, 22 Feb 2008 09:55:11 -0800 (PST)
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On Feb 22, 11:37 am, itsybitsy...@xxxxxxxxxx wrote:

Listening? Were you dancing? Did you have an indian print skirt on?
Sleeveless little something top?

I have no idea what I wore. Probably jeans but if I was a skirt it probably would have been ankle length. I may have been dancing. At some point.

However, my greatest memory of the event was my friend. I went with 3 people but the friend and I got separated from the others. She kept grabbing my arm and sinking her fingernails in and saying, "DID YOU SEE THAT?!?" I had marks for a week.

I saw Jethro Tull at the garden too. Maybe 92-93? I remember it was November. I don't remember what year. That was a good concert. Ian had a sore throat but he still was great on that flute. I remember him looking like Pan, dancing around playing that thing. It was a sight to behold. I was always a big fan of Rush. I have seen them many times.

I saw Jethro Tull too, but I think it was at boston garden, maybe in new haven or hartford too.

Good show.

I've seen a lot of shows. Tons of dead shows (and JGB, Jerry alone) and lots of other bands too. In the progressive rock era, Yes and Genesis (even with Peter Gabriel). The who, the stones, pink floyd!!!!, god hard to remember all the bands I've seen.

I still have most of my ticket stubs.

Yes. Sad that jerry died.

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Very sad.

Indeed. A great loss. It amazes me how Keith Richards can be alive but Jerry isn't.

Seeing the stones in recent years, Keith Richards always says "Great to be here in (wherever the show is)" then he says " Great to be anywhere"

Still Jerry lived on the edge. Sort of amazing he made it through when so many others didn't (Janis, Jim Morrison and how many dead Grateful Dead keyboard players?).

Remember Jerry went into a coma in the mid 90s and then came out again and played a coupla years before he died?

I met Dee Dee Ramone at a show in E. Rutherford, NJ when the Undead were playing for a WNEW halloween show (a friend of mine played with them for a while)...and it was weird when he died, too...I was like...HEY I KNEW HIM. I guess the older I get, the more will go.

The Ramones were awesome! Funny songs, decent musicians. Did a lot of producing too. I liked the clash too.

Well we are all a few years older. I'm not any more mature though still young at heart and stupid too.

Attractive qualities huh?

LOL. We all have our quirks, trust me, I am aware of that. I suffer from arrested development, too. No worries.

I also like dating younger women (why not?). When people ask how can you date a girl in her 20s I always ask "What's your point?" People assume that younger women have to be immature, what could we have in common? Again, what's their point? Also I don't rule out younger women being old souls. At least I give them a chance. And I am at least as immature as they are if they're not. In fact, I'd say most are more mature than me just not in age.

I do make exceptions. The woman I'm dating now is older than me. Unfortunately she's an emotional vampire and I just happen to be

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pathologically attracted to her. We've dated off and on for about ten years, there was a serious relationship for each of us in the interim.

Increasingly many psychiatrists have found infectious disease (not just lyme) as a cause of psychiatric problems. Psychiatrists are medical doctors with a speciality in psychiatry. In order to make accurate diagnoses (or diagnosi) they are supposed to consider and rule out physical causes. If they don't rule them out they are supposed to consider their role.

Well...they are SUPPOSED to anyway. I think even regular medical doctors are more likely to say "Stress" or "depression" when they don't have an answer, rather than take the time to scratch the surface.

Yes the tendency is to call the patient crazy when they can't figure out what is wrong. Usually because they haven't really tried.

At least when you go in and are female.

Probably a little more so than men but doctors do the same thing to men.

One thing I would like to point out to females everywhere is that if you go into the doctor with long lists of symptoms or upset, you will get nowhere.

Doctors HATE long symptom lists. They also HATE if you've been on the internet learning about what is or might be wrong with you. They also HATE to answer questions.

If you go in confident and mention the worst symptoms, the stuff you cannot live with...like the crushing migraine (and go in during one so they can SEE what you look like when you have a full on migraine) or something measurable...you'll get attention

Of course, ideally they would listen to ALL symptoms. The last one you mention might just be the one that is the key to diagnosis. If you get that far.

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. If you go in with fatigue, weight loss, generalized pain, and crying...you will be handed an antidepressant and sent home.

And most of them are very inexpert in prescribing and monitoring antidepressants and are not qualified to make psychiatric diagnoses. A good psychiatrist would actually rule out or consider the role of real disease. Antidepressants are actually quite dangerous especially when improperly prescribed dose adjusted and monitored including when it is time to withdraw the patient.

Of course everyone hands them out like candy on Halloween now.

To kids too. Sometimes with Ritalin Adderall etc sometimes without. Sometimes just Ritalin etc. Hard to find kids these days who aren't medicated most of them improperly.

Girls complain a LOT that they cannot get help and doctors will not listen. This is true, but a lot has to do with how you approach it. I learned the hard way. Is it sexist? Maybe. But it doesn't make it any less true simply because it isn't fair.

Shouldn't be that the patient has to plan their approach to the doctor. Unfortunately doctors don't have and don't take the time anymore. Nor do they listen to their patients. Study after study shows that when they ask a question they cut the patient off in 8-15 seconds. Old adage: "Listen to the patient they will tell you what is wrong with them" Doctors don't bother anymore.

People in general want to say, "That's not fair!"...

That's not fair!

Actually not only is it not fair, but it is just bad medicine.

you hear it a lot on Lymanut with little red emoticons shaking their little red fists. BUT because we do not live in a perfect world, we have to live and do things with what we have. If you diagnose yourself or let people on a message board diagnose you, and go into a doctor with a packet of stuff you printed out on the internet, you are surely going to be seen as a hypochondriac. If you think you know what you have, you have to gently lead a doctor to that direction and make him or her think it was their idea. No matter how you approach it, you must always keep

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your cool and maintain respect at all times.

Shouldn't be that way but I hear you. What ever happened to forming a therapeutic alliance with your doctor? (Oh hmos I forgot) (also medical schools tend to turn out cookie cutter robots with no emotions rather than emphasizing the human side of medicine, many doctors go to school with an idea of how they might want to practice but it gets educated out of them, independent thinking and old fashioned approaches are not rewarded, the ability to regurgitate information is and an overemphasis on technology has replaced the art of practicing medicine—guess what though? It is an ART not a science and very few doctors are artists, there is a tendency to reward salieris and punish mozarts).

I had several diagnosi...after being sent to well-meaning a rhumetologist, pulminologist, endocrinologist, and going through several GP/PCP's due to moving and insurance changes. What started it was when the hypothyroidism was discovered in the ER when I had inflammation in my shoulder and it was pushing on a nerve and it was so intense it took my breath away. I was in agony and my mom took me. I hadn't bothered with doctors in YEARS when this took place. ANY time before that, other than pregnancy, when I complained of pain I was x-rayed and told I had stress. Honestly...when I was told I had stress by doctors I trusted when I was younger, I didn't question it, though at that age I don't think I even knew what stress was!! I found out I had the fibroids or scarring in the lungs and the hypothyroidism and the anemia (well, I knew I was anemic, because I'd ALWAYS been anemic since I was like 11 or 12.). That's what started the whole "What the heck is wrong with me" quest. When I was interviewed by the ER doc about how long I'd had this or that problem...and couldn't remember a time when I didn't...and he looked so grave, started saying he thought it was sarcoidosis, he scared the crap out of me.

Hard to make a sarcoid dx on a first visit. Sarcoidosis tends to reveal itself only over time. Sounds like an unfortunately too common Lyme nightmare quest for dx though.

However, when I was sent back to the PCP, they went another direction... again I was hearing stress and depression and fibromyalgia and CFS and anorexia. Because me being mental scarred my lungs, apparently.

Yes lung scarring from mental problems happens all the time % rolling eyes

Of course who knows, maybe you smoked too many bong hits?

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Answer: How can you smoke too many bong hits? ;--)

I got really mad and really upset. They had me on too high of a dose of thyroid replacement for almost a year (and I was already underweight and this ended up having me emaciated...thus, I'm weathered). The OD of thyroid meds had me all ramped up and emotionally liable and stressed out is NOT even the word for it...my resting heartbeat was over 120 and I walked around sweating and shaking...and they said it wasn't the meds.

Of course not. Thyroid meds never affect anyone adversely % rolling eyes

After a while, I started to not trust them anymore,

Good instinct.

and This pegged me as a hysteric for a while. I was right, and if I listened to my gut, I would have stopped taking them sooner. However, I switched to a low dose of Armour through a local D.O. and while this was BETTER, I eventually stopped taking thyroid meds completely. I walked around with untreated hypothyroidism for a few years. With abx this year my TSH is down to 4 and a half, my T's are fine, and while I am SLIGHTLY subclinical, there is no need for replacement anymore. My TSH was 36 or 38 when they found it. It was obviously all late term infection related.

It is fairly common for lyme to affect the thyroid. Bb seems to love thyroid tissue for some reason. If I had to guess the bacteria has evolved to make the body as comfortable an environment for itself as it can and the thyroid is one place to go to help affect the global environment of the body. (Again I am NOT saying the bacteria is engaged in conscious though, I am saying that evolution has selected traits favorable to survival and thriving).

A rhumetologist dx'ed me with Primary Sjogren's with 'multiple connective tissue disorder'...clinically. That was right before I kicked the thyroid meds, and gave up looking for an answer for a few years. Because I don't test positive for the antibodies, I always thought it was only part of the picture...but eventually I gave up trying to find out and just lived day to day.

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Did you have dry eyes?

The Lyme dx was clearly by chance. It only happened because I'd been seeing a neuro because my GP was concerned about some of my neurological stuff and if my headaches were related to the arthritis in my neck. Neuro thought I had narcolepsy (and I guess clinically I did, but abx has cured that, no more sleep paralysis, no more cataplexy). I got really sick and wasn't getting better, so I asked him to run an arthritis profile. I figured with that way I was feeling, if it had been lupus or RA or Sjogren's...it would show up in a flare up. But no, he happens to run an ELISA as part of his arthritis screening...and that was first step of the wake -up call that started me down this path. I got a voice mail saying , "Itchy, looks like you have Lyme disease, call me back, we need to start you on antibiotics and do some more tests".

Wow he called you itchy? I thought I was the first!

Took me a few months to get into an LLMD, who was recommended to me by my pharmacist right after I got the dx, before I ever went online. He actually got me in to see her because she wasn't taking on noobs at the time. She takes new Lyme patients right now, but she also does GP stuff, and woman's gyn stuff, and a clinic, and isn't taking new patients other than Lymies.

Interesting.

And here I am. That's the reader's digest version.

There's a really good llmd and nurse in hermitage pa. They do advocate a lot of alt med, the guy is indian and trained there and later here. But they treat conventionally too. years of experience. Nurse had lyme too. Really really nice people too. Hermitage is north of pittsburgh about an hour.

Psychiatric manifestations might indicate a primarily physical problem (brain tumor for example).

Agreed. However, I have a friend who almost died from a benign brain tumor because they were happy to give her migraine meds and antidepressants at the PCP's office. Emergency brain surgery made her way more nuts than she was before. WAY more. Not a whole lot you can

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do about that.

A shame.

I think in a perfect world, those things may be true.
But the reality in practice is often different. Medicine, in my opinion, is too reactive and not proactive enough. This drives people to try to dx themselves, which, if you read the thyroid boards, is dangerous.

The lyme boards are more than enough insanity for me.

There are people who flock to thyroid boards with all sorts of maladies, wanting to be dx'ed hypo just as badly as some of the people who find lymenut want lyme. Problem is, the thyroid boards really DO give medical advice, they are NOT always just saying, here, eat this root, but they tell people how to get steroids online for their imaginary adrenal insufficiency (even though, like me, they might have an infection that steroids can HURT), and how much to dose themselves with prednisone or whatever in conjunction with their thyroid meds...

I'm wondering did they (doctors) dose you with pred when you had the sjogren's dx?

And how did you react?

then these people wonder why they are getting worse and why they are gaining huge amounts of weight... so the 'specialists' tell them to take more of both the thyroid meds AND the pred, because they just must not be taking enough. Oh, and thryroid tests aren't reliable so IF you don't test hypo you could still be BUT if you do test hypo then you definitely ARE...it's a lot like lymenut. But worse. Meanwhile, they were never hypo to begin with (even though to read there you would think everyone is) they are just taking lots of T4 and prednisone. Dangerous.

Can't imagine worse than lymenut. Are they as hostile to reason?

I'm just saying that IVIG generally is used to treat non
psychiatric

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symptoms that are primarily neurologic so a neurologist is more likely to try it in a trial for peripheral neuropathy from lyme than fallon.

Are there any good neurologist researchers out there who might do something like that?

Probably not ones you'd like. Fallon is about the only lyme friendly guy to get NIH funding. And he is not by any means a Lyme radical.

From his perspective I think he hasn't had to be so involved with the lyme wars on the front lines because he is usually NOT the guy rxing abx, he is usually a consultant on a case, dealing with the psychiatric issues and rxs psych meds. Good guy but because of being a shrink his involvement with the lyme wars has been more as an advocate to other shrinks saying "hey your crazy patient might have lyme" and writing about psych manifestations.

I'd love to figure out what I could do for my MS-like symptoms. These bother me more than other things because of the uncertainty. Arthritis is one thing, but neuropathy and weakness is a whole other thing. I have to wonder what will happen if it continues to progress. I wonder what I would have to have a dx for, in order to try it and have it not be experimental?

I don't know how expensive collustrum is but why not research it and talk to your doc about trying it if it is affordable as an alternative to IVIG?

lol. Indeed. Can we have wheelchair races and cane jousts, too? Or, is that moving too fast?

I'm not in a wheelchair and don't use a cane. And certainly not on the first date.

I'm not either. BUT I'm always a step ahead of myself. Maybe meeting for bloodwork and snacking on the free milk and cookies (if provided) would be more suitable? Oh wait...lactose intolerant. Bad idea.

Blood work and drinks in the hospital caf sounds like such a great

date!

> My point is that the tests of "long term treatment" have not ever

evaluated long term treatment a la llmds,

Well, true. The Fallon or Kempler studies did not go as long as some of these people go on IV. There is a girl from Lymanut who now goes to LE's and sometimes LNE that did IV followed by oral omnicef who is doing really really well and not on abx anymore at all. That's sure an inspiration to me...and one of the reasons why I keep taking these pills even though I don't enjoy it.

I think long term abx and the passage of time do wonders for many.
Keep hope alive!

Hey if you vote for obama he is all about hope. And change. He will end the war in iraq and ALL WAR! All americans will be rich! He will make sure all americans are insured but it won't matter HE WILL END ALL DISEASE! We will have peace and prosperity and

(I think he's a great orator but give me a break, I just can't stand all the bs anymore).

Wondering who your doctor is? Doesn't sound like that nut from colmar pa.

NONE of my current doctors are PA docs. I've had my fill. When I said I had been to some losers, I meant ones I have seen in PA. Never saw an LLMD in PA, but have seen enough doctors there to know I don't want to do that again. I live in SW PA on the Maryland border. My GP is in Maryland, near my job, and my LLMD is in West Virginia. About an hour's drive.

What do you do? If not specifically, generally?

Again reveal only as much as you feel comfortable.

Is your doc on the llmd lists? Or someone who is open minded but doesn't treat a lot of lyme?

GP isn't an LLMD. He will treat for Lyme if you do it his way. He's

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the one who will treat to a titer. A close friend of his had Lyme and ended up in a wheelchair before they could get a diagnosis. The said friend spent 2 years on doxy before he started getting better, but did get better. So, in GP's mind, this is how you treat it, you treat it will long term, low dose doxy until ELISA titer and symptoms are gone.

Actually sam donta wrote about long term tetra although IF I remember he advocated higher dose?

Here's a link to a repost, don't know if you've ever seen this? By the way not everyone swears by donta:

http://groups.google.com/group/sci.med.diseases.lyme/browse_thread/thread/144b51d6da72aaef/ca8cd3e80c1403df?hl

He will dx Lyme, test for it, believe in the severity of the symptoms... though he is kind fuzzy on what those symptoms are...but he is very unique in his views (based on no current protocol or scientific research as far as I can tell) and treatment. I'm not comfortable with it. And he doesn't clinically dx. You have to be CDC positive via labcorp. It has to be an acceptable enough case to be reported to the health department. Like me.

Sounds like he's half in and half out. Of course so many of the "llmds" are bad news unfortunately. Not much different than lymenut, dx everyone w lyme and treat them with anything and everything half of which they sell out of their offices.

My LLMD is on at least one list, I think the LDA's.

Not an LDA fan.

She is associated with WV University. She is an ILADS member. She got involved because she had Lyme and had to go to an ILADS doctor to get help. However, she does other things too.

Interesting. Many of the good ones got involved because they or a family member had a tough case and they realized that what the mainstream is saying and teaching is wrong at least for a substantial percentage of cases (might be fine for many who get lyme though).

One thing I can say is that at least my GP, though sometimes stubborn and not too happy with me that I went elsewhere for Lyme treatment,

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doesn't get all out of whack or fire me for being on long term minocycline.

If he does just tell him it is for acne or gum problems. Then it is fine.

Right now, I am in a pickle because LLMD wants me to go to physical Therapy to get back into shape and start to exercise again. I know she is right, and I want to do this to see if it will help my weakness and my arthritis. However, getting time off from work for repeat visits to PT when I already have to do the taking the kid to the orthodontist and LLMD visits is not reality. I'm not overweight, I'm finally about just right (I used to be too thin), but getting some tone back and some energy is really important. I think I could feel better than I do. I also think I would like to see a pain management specialist to see what my options are.

Go for the opiates! Just kidding I actually think the less pain meds you can get by on the better. I don't know about how effective biofeedback is or accupuncture but narcotics long term aren't good. Sometimes pt can be really helpful for people, stretching and stuff sometimes helps a lot.

Of course too much pt too soon can be really bad and set you back.

My neuropathic and arthritis and headaches (tho better than the headaches used to be) are a little more cumbersome than I would like to have to deal with. It makes me grouchy and I get in trouble at work for my 'attitude' problem. Lyrica and neurontin were useless, the side effect trade off for the minimal relief didn't equal out for me. So were antidepressants...yuck. I get great results from opiates unlike people with fibromyalgia complain they don't get relief from pain pills. However, they don't like to hand those out to people with chronic pain because of the possibility of abuse. I don't like taking pills enough to abuse them. So, I am thinking its time to see about finding ways to just make myself more comfortable.

I hope you find something that works. Pain is awful and chronic pain is worse. Stresses the entire body and mind.

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