

Re: IV ABX Study for Psychosis

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- *From:* itsybitsyone@xxxxxxxxxx
 - *Date:* Fri, 22 Feb 2008 08:37:40 -0800 (PST)
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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.

Yes. Sad that jerry died.

Very sad.

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

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?

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

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

People in general want to say, "That's not fair!"...you hear it a lot on Lymentut 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 your cool and maintain respect at all times.

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

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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.

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

A rhumatologist 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.

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".

Took me a few months to get into an LLMD, who was recommended to me by

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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.

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

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 do about that. 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.

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... 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 thyroid 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.

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

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something like that? 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?

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.

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 Lyment 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.

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.

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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 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. 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.

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

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

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