

I am pleased to announce the following:

Since April 1999, 150 ALS patients have been tested for Lyme disease with a panoply of tests - incl Western Blot, LUAT, PCR. Not one patient has been found to be negative across all tests. Many have been shown to be PCR positive.

The prognosis and disease development of these patients is entirely consistent with ALS.

Treatment with oral antibiotic therapy has shown mixed results. In particular the use of conventional antibiotics (esp. doxycycline) has been associated with deterioration of ALS patients. In one case the patient rapidly succumbed. In earlier stage ALS patients there is some evidence for improvement, with restoration of speech in two patients and some reported easier swallowing, when treated with oral metronidazole or tinidazole.

The reactivity of ALS patients to Lyme tests has been previously reported .

In the course of the past 9 weeks a patient (body weight 125lbs, 66 years of age) with advanced ALS symptoms has been treated aggressively with IV metronidazole + conventional antibiotics (Biaxin initially) at doses of 500mg tid metronidazole IV and 500mg Biaxin bid orally. The diagnosis of ALS was made at the Mayo clinic. The patient was admitted in respiratory failure with tongue fasciculations, weakness in the right arm. The immediate prognosis was poor and the attending physician expected the patient to expire within 24 hours. The patient was ventilated. In the course of 7 weeks of the above therapy the patient has improved and is now ambulatory and off of ventilation using only occasional nasal oxygen. On the IV therapy the tongue fasciculations disappeared.

After 7 weeks the patient was taken off of the IV meds and treated with only oral tetracycline (500mg qid). On this treatment the tongue fasciculations returned. The IV therapy was reinstated with IV Rocephin replacing the oral Biaxin and the tongue fasciculations ceased. The patient continues to improve on a daily basis.

Tentative conclusions:

The etiologic agent of ALS is *Borrelia burgdorferi*.

Effective treatment of late stage ALS is possible with aggressive antibiotic therapy that must include metronidazole. Other researchers have recently reported success in treating early stage ALS with antibiotic therapy.

ALS patients should not be treated with simple "textbook" antibiotic therapy which does not include a nitroimidazole.

This therapy should be considered experimental at this stage.

Regards

Martin Atkinson-Barr PhD

(physician e-mails only please, I cannot reply to every patient e-mail - it would be too many - but physicians who want to ask me detailed questions will be able to contact me and help multiple patients)

From: Martin Atkinson-Barr (mcmab@peoplepc.com)

Subject: Re: Successful treatment of late-stage ALS

Newsgroups: sci.med.diseases.lyme

Date: 2001-05-21 21:16:29 PST

Let us be clear how I come up with the figure of 150.

When I published my work on metronidazole in Lyme around 20 patients contacted me and said

Let us be clear how I come up with the figure of 150.

When I published my work on metronidazole in Lyme around 20 patients contacted me and said they had Lyme AND ALS.

Once I had decided there may be a connection between the diseases I encouraged every ALS patient I came across, and a few physicians to test for Lyme. All told that is about 30. This is the most important group for they were unselected. There were NO negatives in this group and for the most part they were either IgG or IgM Western Blot positive, mostly to CDC criteria (which is over strict and ignores the 39kDa line)

Dr Nick Harris has been sending on to me all of the ALS patients that have contacted him who were positive. These patients I questioned closely to determine if they had a clinical picture of ALS. All did. There have been around 20.

When my website was up (thanks to the ISP it was lost) around another 80 ALS patients contacted me with their results, all positive. No ALS patient has ever been in contact with me who is negative. There must be some.

If we were to take 150 Lyme patients we would be VERY surprised to have 150 positives, more like 100. However many of the above were pre-selected (why would you contact me if you were diagnosed ALS but Lyme negative, I would be snake oil.).

BUT, if the diseases were independent, we would expect a MAXIMUM of 100 cases in the whole of the US, so 150 becomes a significant number.

Now, those patients who were diagnosed ALS and tested Lyme positive carried on to develop the sequelae of ALS. Last Thursday we lost Dean Chioles who has a web page at <http://www.shoptown.com/dean/> . Note that he was diagnosed with Lyme in 1998, before I published anything on Lyme.

We should also remember: Brian Pierson and Katherine Crowe who we also lost, both Lyme positive. Brian was 43 years old or so.

Now there have been 5 papers that describe clinically diagnosed ALS patients with Lyme reactive serologies (including the Halperin paper which finds a statistically significant number of Bb positive patients with ALS) and one letter by Mandell, Steere et. al. NEJM 1989;320:255-6 which found NO Bb antibodies in any ALS patients.

The responsibility is now with Mandell, Steere et. al. to come forward and explain how they can find NO Lyme positive ALS patients when I can find them so easily and even ALS patients themselves can see the connection.

How about it Dr Steere, this is an open venue? Perhaps one of the Yale workers will read this and we can enter into a debate that will explain why this connection has been stalled for 12 years.

With best regards to all.

Dr Martin Atkinson-Barr