
Disease	Lyme-IACCI (Chronic Lyme Disease or PTLDS)
Drug(s)	Atovaquone 150 Mg/ML Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Case Characteristics



Age Group: 41 – 50 years

Sex assigned at birth: Female

Country Treated: United States

Race(s): White

Ethnicity: Not Hispanic/Latino

Other Conditions



Underlying Conditions prior to infection: Smoker (current or past), Autoimmune disorder (Sjogren's, Lupus, Celiac, Raynaud's, etc.)

Underlying Conditions after infection: Autoimmune disorder (Sjogren's, Lupus, Celiac, Raynaud's, etc.), Dysautonomia, Gastroparesis, Irritable Bowel Syndrome (IBS), Sleep apnea

Pre-IACC medications: Levothyroxine (Synthroid, Levoxyl, Euthyrox, etc.)

Presentation



How diagnosis was made: Serology detected antibodies

Level of care for acute infection: The patient had symptoms, but did not require admission to the hospital

Symptom duration: >48 months

Symptom: A worsening of symptoms that occurs after even minimum physical or cognitive exertion (Post-Exertional Malaise or PEM)

Impact on quality of life: Very severe

Symptom: Alternating bowel habits (e.g., constipation and diarrhea)

Impact on quality of life: Severe

Symptom: Burning sensation on the patient's skin (Paresthesia)

Impact on quality of life: Severe

Symptom: Changes to your mood or increased emotional volatility (Mood disturbance/affective disorder)

Impact on quality of life: Mild

Symptom: Chemical or medication sensitivities

Impact on quality of life: Moderate

Symptom: Chronic nerve pain (burning and/or tingling and/or numbness in the face/legs/hands) (Neuropathic pain)

Impact on quality of life: Severe

Symptom: Cognitive impairment / Brain fog (difficulty processing information or concentrating) (Cognitive dysfunction)

Impact on quality of life: Very severe

Symptom: Digestive issues

Impact on quality of life: Moderate

Symptom: Feeling lightheaded or like they might faint when the patient stands up (Orthostatic syncope or presyncope)

Impact on quality of life: Moderate

Symptom: Food intolerances (e.g., lactose, gluten, etc.)

Impact on quality of life: Severe

Symptom: Frequent and/or debilitating headaches (Migraine or chronic daily headache)

Impact on quality of life: Severe

Symptom: Gastroparesis or gastroparesis-like symptoms

Impact on quality of life: Moderate

Symptom: General fatigue

Impact on quality of life: Severe

Symptom: Heat intolerance

Impact on quality of life: Severe

Symptom: Joint pain (Arthralgia)

Impact on quality of life: Severe

Symptom: Joint swelling (Arthritis)

Impact on quality of life: Moderate

Symptom: Low blood pressure (Hypotension) regardless of lying or standing position

Impact on quality of life: Moderate

Symptom: Mast Cell Activation Syndrome (MCAS) or mast-cell type symptoms

Impact on quality of life: Moderate

Symptom: Muscle pain (Myalgia)

Impact on quality of life: Severe

Symptom: Nausea

Impact on quality of life: Severe

Symptom: Neuropathic pain, tingling, or numbness

Impact on quality of life: Very severe

Symptom: New or worsening sleep apnea (Obstructive sleep apnea or OSA)

Impact on quality of life: Moderate

Symptom: Pain with breathing (Pleurisy)

Impact on quality of life: Severe

Symptom: Poor circulation (cold or discolored extremities) (Raynaud's phenomenon)

Impact on quality of life: Moderate

Symptom: Prolonged loss of sensation or pain in the patient's extremities (Neuropathy or neuralgia)

Impact on quality of life: Severe

Symptom: Recurrent urinary tract infections (UTIs)

Impact on quality of life: Severe

Symptom: Ringing in ears (Tinnitus)

Impact on quality of life: Severe

Symptom: Sensitivity towards stimulation of the senses (light/sounds/temperature/touch, etc.)

Impact on quality of life: Moderate

Symptom: Shaking or feeling jittery (Tremors)

Impact on quality of life: Moderate

Symptom: Short-term memory loss

Impact on quality of life: Moderate

Symptom: Shortness of breath when exercising or being active (Exertional dyspnea)

Impact on quality of life: Severe

Symptom: Stomach pains (Abdominal pains)

Impact on quality of life: Moderate

Symptom: Swollen lymph nodes

Impact on quality of life: Moderate

Symptom: Unsteady gait, balance, or coordination issues

Impact on quality of life: Moderate

Symptom: Vomiting

Impact on quality of life: Severe

Treatment Details



Ceftriaxone 2000 Mg Injection:**Dose:** 0**Route:** Intravenous (IV)**Duration:** 3 Month(s)**Adverse event:** Yes**Adverse event(s) details:** Allergic Reaction**Adverse event outcome:** Desensitization protocol in ICU was required for the ceftriaxone treatment to be started.**Rifampin:****Route:** Oral (PO)**Duration:** 6 Month(s)**Adverse event:** Unknown**Atovaquone 150 Mg/ML Oral Suspension [Mepron]:****Route:** Oral (PO)**Duration:** 3 Month(s)**Treatment on-going:** No**Adverse event:** Unknown**Azithromycin:****Route:** Oral (PO)**Duration:** 6 Month(s)**Adverse event:** Unknown**Additional medication details:** I was initially treated with oral doxycycline but after a brief improvement my symptoms returned and continued to get worse. Despite repeated attempts at retreatment and a long course of doxycycline my symptoms did not resolve until I was able to receive IV ceftriaxone.**Helpful alternative therapies:** Physical therapy

Outcome

Symptom: Short-term memory loss

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Significant symptom improvement

Time to outcome: 6 Month(s)

Symptom: Frequent and/or debilitating headaches (Migraine or chronic daily headache)

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Significant symptom improvement

Time to outcome: 3 Month(s)

Symptom: General fatigue

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Mild symptom improvement

Time to outcome: 3 Month(s)

Symptom: Changes to your mood or increased emotional volatility (Mood disturbance/affective disorder)

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Significant symptom improvement

Time to outcome: 6 Month(s)

Symptom: Cognitive impairment / Brain fog (difficulty processing information or concentrating) (Cognitive dysfunction)

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Significant symptom improvement

Time to outcome: 1 Year(s)

Symptom: Joint pain (Arthralgia)

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Moderate symptom improvement

Time to outcome: 6 Month(s)

Symptom: Shaking or feeling jittery (Tremors)

Treatment: Atovaquone 150 Mg/MI Oral Suspension [Mepron], Azithromycin, Ceftriaxone 2000 Mg Injection, Rifampin

Outcome: Complete symptom resolution

Time to outcome: 3 Month(s)

Pregnancy

Pregnant during acute infection: Yes

Pregnant while experiencing the IACC: No

Additional Details

Research priorities: Antibiotic therapies need to be used more broadly and new antibiotics tested in the clinical setting. Non-acute cases with clear neurological involvement have a hard time accessing IV ceftriaxone under current medical guidelines. There have also been promising studies in recent years for more effective antibiotics against the Lyme bacteria in vitro that still need to reach clinical trials. While other repurposed compounds might have potential as well, Lyme is still a bacteria and an antibiotic therapy is most likely to be the best solution we can find.

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