Disease	Lyme-IACCI (Chronic Lyme Disease or PTLDS)
Drug(s)	IV Antibiotics, IV Antifungals, IVIG, Plasmapheresis, Rituximab

Case Characteristics

Age Group: 31 - 40 years

Sex assigned at birth: Male

Country Treated: United States

Race(s): White

Ethnicity: Not Hispanic/Latino

Other Conditions

Underlying Conditions prior to infection: Autoimmune disorder (Sjogren's, Lupus, Celiac, Raynaud's, etc.), CIRS

Underlying Conditions after infection: Mast Cell Activation Syndrome (MCAS)

Presentation

Start of first acute infection symptoms: April 2015

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

Acute infection complications: Pulmonary embolism

Symptom duration: >48 months

Symptom: Memory Loss

Impact on quality of life: Very severe

Symptom: Seizures

Impact on quality of life: Very severe

Symptom: Paralysis

Impact on quality of life: Very severe

Symptom: Aseptic Meningitis

Impact on quality of life: Very severe

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

Impact on quality of life: Very severe

Symptom: Personality or behavior changes

Impact on quality of life: Very severe

Treatment Details

IVIG:

IV Antifungals:

IV Antibiotics:

Plasmapheresis:

Rituximab:

Additional medication details: Hyperbaric oxygen therapy helped IVIG IV Glutathione

Outcome

Symptom: Personality or behavior changes

Treatment: Rituximab

Outcome: Significant symptom worsening

Time to outcome: 1 Month(s)

Symptom: Memory Loss

Treatment: Rituximab

Outcome: Moderate symptom improvement

Time to outcome: 1 Month(s)

Symptom: Personality or behavior changes

Treatment: IVIG

Outcome: Significant symptom improvement

Time to outcome: 9 Month(s)

Additional Details

Research priorities: Story Title: Look Beyond the Psychosis, There's Something There Story Description: After a tick bite led to 13 years of debilitating illness, misdiagnoses, and severe neurological symptoms, a mother's relentless advocacy helped her son, Jeremy, uncover late-stage neurological Lyme disease and find a path toward healing, hope, and systemic medical change. Story Overview: I am Amy Hirschland, a dedicated mother and primary caregiver for my son, Jeremy. Our family spent 13 years navigating the complex, heartbreaking realities of late-stage neurological Lyme disease, mold, co-infections, alpha-gal syndrome, and autoimmune encephalitis. After visiting over 100 doctors and enduring years of severe psychiatric misdiagnoses, we fought to identify the underlying infectious triggers driving his condition. Through targeted immunological and antimicrobial treatments, Jeremy is in pursuit of recovery. Our lived experience equips us to advocate fiercely for families navigating complex tickborne illnesses. Target Audience: We aim to reach primary care physicians, neurologists, and mental health clinicians who evaluate patients presenting with sudden-onset psychiatric or cognitive symptoms. By highlighting our journey, we hope to compel medical professionals to look beyond surface symptoms, investigate underlying tickborne infections, and implement timely, comprehensive diagnostic protocols. Priority: The single most urgent priority is establishing clinical protocols to screen for tickborne and infectious drivers in patients presenting with new-onset neurological, cognitive, or psychiatric symptoms. Too often, patients with neurological Lyme or autoimmune encephalitis are mislabeled with purely psychiatric conditions and subjected to ineffective, invasive interventions while infection spreads unchecked. Standardizing comprehensive diagnostic testing—including advanced tickborne panels and immunological evaluations—at the onset of psychiatric symptoms will prevent years of misdiagnoses, avoid unnecessary suffering, save millions in healthcare costs, and ensure patients receive timely, targeted treatments that enable true recovery. Story: It's a hot, humid, Georgia June morning. I catch my breath, close the cartop carrier, and head inside to try to talk my 27-year-old son, Jeremy, into "going to get Dunkin Donuts". Dunkin donuts is one of the only reasons he will leave the house, and thankfully, through the veil of psychosis, he agrees. We use the drive-through to pick up his favorite drink, a medium Iced Coffee–one of his few pleasures. Instead of heading home, we start driving 1,814 miles to Phoenix. We're desperate and in search of hope. We cross the Mississippi-Alabama state line before Jeremy asks "Are we almost home?". I brace for the explosion. I haven't told him where we're going (or that we're going) not only for fear that he won't agree, but also because it might set off his Lyme rage. I calmly explain that we're heading to Phoenix, to a specialty clinic that can help him, can help us. I see him tensing as he shouts: "I am not seeing any more doctors!". Jeremy originally started to become sick as a senior in college in 2013 while living in a mold infested apartment, where two of four of his roommates developed serious medical conditions: recurring brain cancer & kidney failure. But that was only the start. In April of 2015, Jeremy went turkey hunting with his primary care Doc and was bit by a tick. Even though the bite was present for a year and a half, it was disregarded and not taken seriously that it could have made him sicker. And he was getting much, much sicker. He had repeated sinus surgeries at the recommendation of his ENT–5 in total over 2 years. An Infectious Disease Doctor evaluated him and found evidence of mold colonizing his sinuses and Lyme disease. Finally, IV antifungals and antibiotics via a pic line fixed the repeated need for sinus surgery; he hasn't had one since. At the time, he was also experiencing "spells" --staring, non-responsiveness, eye fluttering, finger movement–we learned were likely seizures deep in the brain. He had lost both his short and long-term memory. While being evaluated for seizures in a prominent Florida hospital, they removed his pic-line since they believed the spells were psychogenic. In absence of the antibiotics, Jeremy developed aseptic meningitis, which we later learned was the beginning of

late-stage neurological Lyme (published by Columbia). At this point, Jeremy had seen too many doctors to keep track of (over 100). Eventually, additional more detailed testing revealed that Jeremy was positive not only for Lyme, but also for Bartonella and Babesia. I drove him to a specialist in Maryland every three months; when he restarted antibiotic treatment, he repeatedly had bullseye and bartonella rashes. He experienced frequent Herxheimer reactions, and they often resulted in rage spells that were incredibly difficult to manage. But we started to make progress, to calm his system down and bring our son back. In 2017, after recovering enough to walk at a park near our home, Jeremy was bit by a second tick. His inflammation soared, and it truly felt like he had a "brain on fire". In a moment where he lost it, he attacked me. There was no place that would treat him based on his clear, abnormal test results, while also helping us manage his psychiatric symptoms. We had no choice but a psychiatric center. From the second tick bite, he contracted Ehrlichiosis and Alpha Gal Syndrome–unbeknownst to us–and was vomiting into garbage cans at the hospital. After he was somewhat stabilized, we took him home. Unfortunately, this was only the start of a horrific cycle of 911 calls and emergency room visits in response to seizures, violent psychotic episodes, below the neck paralysis, and uncontrollable vomiting causing dehydration. Eventually, an infectious disease doctor helped get IVIG approved for Jeremy as a result of immunodeficiency test results and his Autoimmune Encephalitis diagnosis. And slowly, he started to improve. He became healthy enough to draw, watch television, and hold somewhat of a conversation. After seven months of IVIG his hippocampal atrophy improved from the 11th normative percentile to the 22nd. But, as has been his story, his trajectory had another setback. We enrolled Jeremy in a research study at Houston Methodist, and I drove him cross-country from Georgia to participate. Unfortunately, Jeremy had a bad reaction inside the hospital; his face turned red, and he couldn't keep food down. We think looking back that he was reacting to being in a moldy environment. Upon returning to Georgia, he lost 10 lbs. in the first week, and it didn't stop there. In and out of the Emory hospital system, we were desperate. With his neurologist, we agreed to have Jeremy try Rituxin, a second-line therapy for autoimmune encephalitis. He wouldn't go to the hospital so I had to go to court to get

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