

Medical Disagreement over Lyme borreliosis Treatment is Misused to Charge Parents of Child abuse and/or Munchausen by Proxy

I. Introduction

Lyme is a bacterial infection. Both Lyme Borreliosis and relapsing fever borreliosis have stages of dissemination and multiple varieties of symptoms afflicting multiple bodily systems in relapsing remitting fashion —similar to syphilis, another spirochetal infection. Lyme is transmitted by the bite of infected ticks, by congenital transmission (from mother to children) and may be transmitted by other means.¹

If left untreated the infection can spread to joints, the heart, and the nervous system and all organs; this may cause life-threatening complications. Early signs of infection include fever, headache, fatigue, and a characteristic skin rash called erythema migrans.

Early or acute Lyme disease can be successfully treated with a short course of antibiotics. Successful treatment is more challenging once the bacteria disseminates throughout the body

There is strong evidence that Lyme compromises the immune system and evades the immune system by hiding in areas of the body where it is difficult for antimicrobials to penetrate. For these reasons, on-going treatment, including antimicrobials, may be required to manage the illness.

There is no consensus regarding the treatment of Lyme. There are two international treatment guidelines for Lyme borreliosis, one is the 2006 guidelines written by the Infectious Diseases Society of America (IDSA) and the second is the 2016 Guidelines written by International Lyme and Associated Disease Society (ILADS).

These two guidelines differ in their approach to treating Lyme. IDSA recommends a restricted duration of treatment, whereas ILADS recommends treating according to patient response. IDSA does not recognize that Lyme infection can persist after a restricted duration of treatment, whereas ILADS recognizes the scientific evidence that finds the bacteria may persist after a short course of antibiotics.

In most countries, it is the law to report suspected child abuse or neglect. Everyone, including members of the public and professionals who work closely with children, is required by law to report suspected cases to a child protective service agency.

In many countries, child protective services do not have the capacity to resolve cases where there are medical disagreements. Additionally, resolution of medical disagreements typically falls outside their area of responsibility. Under such circumstances, it is inappropriate to ask

¹ There are indications Lyme may be transmitted by other means as well.

child protective services to determine whether children should receive treatments according to one or the other of two international Lyme Guidelines.

It is not uncommon for parents to seek treatment that follows ILADS International Lyme guidelines after a short course of antibiotics fails to improve their children health. Parents have the right to protect their children's health and choose the medical treatment that follows ILADS International Lyme guidelines when treatment failure occurs after a short course of antibiotics.

Confusion, misinformation, disagreement and ignorance regarding Lyme borreliosis and Lyme treatment has resulted in parents who have children with Lyme being wrongly accused of child abuse and/or Munchausen by Proxy in Europe, the US, Canada, and Australia.

Munchausen by Proxy is a very rare mental health illness whereby a caregiver abuses a vulnerable person. The caregiver does this by fabricating an illness or injury in a person under his or her care, such as a child, person with disability or an elderly adult.

Unfortunately, the medical disagreement over how to treat Lyme borreliosis has been wrongly used to make charges of child abuse and/or Munchausen by Proxy.

Fortunately, parents have successfully overturned these wrongful accusations. Parents have also reported those persons who made the wrongful charges, and this has resulted in formal reprimands and other punishments.

In addition, parents have organized collaborative efforts with hospitals and other institutions to improve the understanding of Lyme and ensure the medical care of their children is not interrupted by wrongful accusations of child abuse and/or Munchausen by Proxy.

This report presents cases that may inform appropriate responses to correct wrongful child abuse and/or Munchausen by Proxy accusations and protect the human rights of children living with Lyme borreliosis.

II. Medical Disagreement over treatment for child with chronic Lyme disease is overturned in Canada

The following example is not a Munchausen by Proxy case. The Canadian case is illustrative of how medical disagreement over Lyme treatment can lead to wrongful allegations of child abuse.

The Wheeler family has a son who suffers from a complex case of Lyme. His debilitating symptoms interfere with his quality of life. Despite his need for on-going medical care, the Wheelers have been unable to access care from their local medical system.

In Nicholas' case, his parents have ensured he has access to the best of care by those who understand that Lyme infection can persist. This included taking him to the US for treatment.

By receiving this additional care, they were able to significantly improve Nicholas' quality of life, and his health.

Nicholas' medical care for Lyme follows the ILADS International treatment guidelines posted the Public Health Agency of Canada website. The government of Canada recognizes two international treatment guidelines for Lyme borreliosis, one is the 2006 IDSA guidelines and the second is the 2016 ILADS Guidelines. Links to both these guidelines are posted on the website of the Public Health Agency of Canada.²

A short course of antibiotics failed to sufficiently improve the health of the Wheeler's son. Their son's health has improved with medical treatment that follows ILADS International Lyme guidelines. The Wheelers have the right to choose medical treatment that follows ILADS International Lyme guidelines without discrimination or interference.

The Wheeler family also uses services provided by the Children's Hospital of Eastern Ontario (CHEO). CHEO is a major children's hospital and university.

A CHEO doctor wrongly reported the Wheeler parents to the Children's Aid Society (CAS) because of concern for the child's well-being and a disagreement over appropriate treatment. The doctor had made the report because he believed under treatment according to a recognized international Lyme Guidelines, Nicholas was at risk of harm despite Nicholas improving and showing no signs of decline.

The doctor should not have reported a case of medical disagreement as child abuse to CAS. CAS does not have the capacity to resolve cases where there are medical disagreements and the resolution of medical disagreements typically falls outside their mandate. It is, therefore, inappropriate to ask CAS to determine whether children should receive treatments according to one or the other of two international Lyme Guidelines.

Each individual case should be considered individually and recognize a patient's and/or caregiver's rights to choose among treatment options from guidelines that meet international standards, as well as care from different medical professionals. *This is an ethical obligation to be upheld by fellow physicians of their colleagues and the families involved.*

Ignorance or confusion over the two Lyme Guidelines is not an adequate excuse for reporting families to children's services. Therefore, the Wheelers went through a complaints process with the hospital to address the wrongful allegations of their family to child protective services and to assert their rights to health for their child.

Nicholas' parents successfully fought these allegations. The mother, Jennifer Wheeler, also organized a successful policy meeting with CHEO to work with the hospital to address issues that families of children with Lyme face, and to aid in ultimately attaining a better quality of care, patient experience, and to minimize the stigmatization associated with Lyme Disease within the medical community in Canada.

² IDSA and ILADS Lyme Guidelines are posted on the website of the Public Health Agency of Canada.
<https://www.canada.ca/en/public-health/services/diseases/lyme-disease/health-professionals-lyme-disease.html>

The attendees and presenters included hospital staff, medical doctors from both Canada and the US, a Former UN Senior Advisor, nurses, advocates and member of Parliament.

The meeting had a number of educational objectives and the goal to ensure no other families suffer the Wheeler experience.

The meeting ended with the set of general recommendations that follow:

1. Elect an Ombudsman to will facilitate quarterly Lyme and tick-borne disease meetings with the hospital, be available to patients who face challenges in obtaining care, is informed of proceedings and actions that involve cases of suspected and verified Lyme and tick borne illness.
2. Require Case Studies of Lyme patients be integrated at meetings with the goal of improving care (The Ombudsman should attend these meetings)
3. Suggest a pilot period for the implementation of new policies. These include policies on parental rights, and the right to choose among guidelines and treatment options.
4. Undertake a three-year-study that compares the frequency of hospital visits among patients with clinical versus serological diagnosis and who have received short term versus a long course of generic antibiotics/other antimicrobials

It was the Wheeler's objective to bring awareness to the ways in which families can be better supported by the hospital and the medical profession to ensure better outcomes for children with Lyme Disease.

The Wheelers also hope their efforts will help other families avoid the unnecessary stress of wrongful investigation by CAS.

The Wheelers are hopeful that together with CHEO, they can improve the circumstances for families and children living with complex cases of Lyme in Canada.

III. Wrongful charge of Munchausen by Proxy becomes a national scandal in the Netherlands

In the Netherlands, so many wrongful Munchausen by Proxy cases were made that it became a national scandal. The accused parents of over 150 families took corrective action. Of these 150+ cases, more than one third had children suffering from Lyme borreliosis.

It is now estimated that as many as 500 Dutch families have been wrongfully accused of Munchausen by Proxy, many of them have children suffering from Lyme borreliosis.

The video, [Dutch State accuses parents of ill children of Munchausen by Proxy](#) shows national news coverage of the Munchausen by Proxy scandal³.

³ Dutch State accuses parents of ill children of Munchausen by Proxy
https://www.youtube.com/watch?v=hCJguJZiqaQ&fbclid=IwAR2Qn_8edgF4jY8BI1wrgO9IAqMAVSKI7__VkDY5JBU6H4NFJMGtjK2CeGE

IV. United Nations Human Rights Council's Special Rapporteurs hear cases of false Child abuse and/or Munchausen by Proxy charges

Misinformed doctors, teachers and other persons wrongfully report the parents of children suffering from persistent Lyme with child abuse and/or Munchausen by Proxy.

Jenna Luché-Thayer, an international human rights experts and former Senor Advisor to the UN and US Government, analyzed how the wrongful charges generate human right violations. Luché-Thayer documented the human right violations found in the Dutch cases for UN record. They are found in two published reports, The Situation of Human Rights Defenders of Lyme and Relapsing Fever Borreliosis Patients⁴ and Updating ICD11 Borreliosis Diagnostic Codes⁵.

The following is an excerpt from Updating ICD11 Borreliosis Diagnostic Codes (page 6):

“In a number of countries, there are many documented cases of government authorities taking children who are sick with Lyme borreliosis away from their parents.

For example, in the Netherlands, an independent organization known as BVIKZ or Interest Group for Intensive Child Care, has undertaken an investigation into false claims of child neglect and abuse by the Dutch Child Protection Services.

To date, BVIKZ has compiled and researched 168 individual cases. *Over thirty percent of these cases are about children with Lyme disease.*

Many of these children have the complicated and persistent forms of Lyme borreliosis, or Lyme borreliosis with other coinfections. The degree and duration of the illness often results in children missing school for extended periods of time.

BVIZK chairman Hooglugt observes that “Apparently national Lyme policies dictate that after a few weeks of treatment, the cause of the disease is suddenly a 'mental issue' regardless of the fact that these children are still as ill as before.

Again and again we hear stories of parents who tried everything to get medical help in the Netherlands, but who had to go abroad to find better help.”

⁴ The Situation of Human Rights Defenders of Lyme and Relapsing Fever Borreliosis Patients, Edition One, March 6, 2018. Copyright Global Network on Institutional Discrimination and the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes. All Rights reserved © 2018. ISBN-10: 1722988061, ISBN-13: 978-1722988067

⁵ Updating ICD11 Borreliosis Diagnostic Codes (Edition One (March 29, 2017) Global Network on Institutional Discrimination and the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes. All Rights reserved © 2017. ISBN-10: 1978091796, ISBN-13: 978-1978091795

One lawyer has taken up and won three cases on behalf of the parents.

BVIZK chairman Hooglugt thinks that they are only just seeing ‘the tip of a much larger iceberg’ and wants to encourage other parents to be brave and come with their complaints in case of false allegations.”

Luché-Thayer found numerous human rights violations related to wrongful child abuse and/or Munchausen by Proxy charges. For example:

The wrongful and forcible seizure of these children often leads to their placement in government sponsored institutions where the children are forced to consume unnecessary psychiatric medicine and are denied their Lyme treatments.

This is incarceration and the denial of medical care of incarceration children. In this situation, the children’s right to freedom from torture and cruel, inhuman and degrading treatment has been violated.

Other human rights violations commonly found in these cases are:

1. Right to highest attainable standard of health
2. Right to life
3. Right to liberty and security of person
4. Right to nondiscrimination and equality

Luché-Thayer and members of the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes⁶ presented these cases to two United Nations Human Rights Council’s Special Rapporteurs. They are Dainius Pūras, Special Rapporteur for the right of everyone to enjoy the highest attainable standard of physical and mental health and Michel Forst, Special Rapporteur for the situation of human rights defenders.

⁶ Jenna Luché-Thayer is the founder and director of the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes or Ad Hoc Committee. The Ad Hoc Committee is an international voluntary group of professionals that formed to update the International Classification of Diseases or ICD11 codes for Lyme borreliosis. The Ad Hoc Committee also documents and reports the human rights violations against this vulnerable patient population in order to end practices of discrimination and medical marginalization and improve their access to diagnosis and treatment.

V. Summary

The Lyme epidemic has been surrounded by confusion, ignorance, misinformation and medical disagreement. This has led to denial of medical care for children and other human rights violations.

The violations included parents who have children with Lyme being wrongly accused of child abuse and/or Munchausen by Proxy in Europe, the US, Canada, and Australia:

- are on record at the UN
- have been presented to UN special Rapporteurs and other officials
- have also been presented to members of parliament in many nations

Fortunately, more and more parents in many countries are publicly sharing their experience of how they succeeded in winning these cases. These parents are demanding the involved institutions change their practices so that wrongful charges and other discriminatory practices against Lyme patients, their caregivers and their human rights defenders cease, and their concerns are properly addressed by these institutions.