

Congenital Lyme Disease: Rare or Rarely Diagnosed?

Scientific Literature Congenital Lyme Disease	UN Convention of the Rights of the Child	Lyme Monitor The Netherlands 2019	Case Mother / Child	Recommendations Improving the Position of Children with CLD and their Mothers
<p>1977</p> <ul style="list-style-type: none"> Steere AC, Malawista SE, Snyderman DR, Shope RE, Andiman WA, Ross MR, et al. Lyme arthritis: an epidemic of oligoarticular arthritis in children and adults (First description of Lyme Disease) 	<p>Article 3</p> <p>In all actions concerning children (.....) the best interest of the child shall be a primary consideration</p>	<p>The Dutch Lyme Disease Association conducted a population survey among Dutch Lyme Disease Patients</p>	<p>Mother</p> <p>1980</p> <p>Tick bite + erythema upper left leg during 9 years Lyme Disease (LD) not considered / no treatment</p>	<p>Recognition in the ICD-11 of the fact that Lyme can be transmitted during pregnancy is urgent and necessary</p>
<p>1985</p> <ul style="list-style-type: none"> Schlesinger PA, Duray PH, Burke BA, Steere AC, Stillman MT Maternal-fetal transmission of the Lyme disease spirochete, <i>Borrelia burgdorferi</i> 	<p>Article 6</p> <p>State Parties recognize that every child has the inherent right to life.</p>	<p>In the Netherlands (NL) > 25,000 people contract Lyme each year, 1000-2500 of whom suffer persistent symptoms</p>	<p>Severely ill; stops study and work</p> <p>1987</p> <p>Severe arthritis left knee during 24 months; hospitalization; wheelchair</p>	<p>Reinstatement of 1C1G.2 Congenital Lyme borreliosis</p>
<p>1986</p> <ul style="list-style-type: none"> Markowitz LE, Steere AC, Benach JL, Slade JD, Broome CV. Lyme disease during pregnancy 	<p>State Parties shall ensure to the maximum extent possible the survival and development of the child</p>	<p>There is no information on the prevalence and incidence of Congenital Lyme Disease (CLD) in the Netherlands</p>	<p>No diagnosis / no LD treatment</p> <p>1991</p> <p>LD-IFA pos 1:1024; clinical diagnosis LD</p>	<p>(1)Development of preventive measures to avoid <i>Borrelia</i> infections of newborns</p>
<p>1987</p> <ul style="list-style-type: none"> MacDonald AB, Benach JL, Burgdorfer W. Stillbirth following maternal Lyme disease 	<p>Article 24 – 1 & 2</p> <p>State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health</p>	<p>The Dutch Lyme Disease Association is keen to gain insight into the number of women and children living with CLD</p>	<p>Hospital: LD is a self limiting disease -> no LD treatment</p> <p>1992</p> <p>Search for advice,</p>	<p>(2)Development of diagnostic procedures and treatment of mothers at risk during pregnancy and newborns / children with Congenital Lyme Disease (CLD)</p>
<p>1988</p> <ul style="list-style-type: none"> Weber K, Bratzke HJ, Neubert U, Wilske B, Duray PH <i>Borrelia burgdorferi</i> in a newborn despite oral penicillin for Lyme borreliosis during pregnancy 	<p>State Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p>For the first time worldwide a question about CLD is included in a population survey amongst LD patients</p>	<p>Hospital: <i>"transmission of Borrelia Burgdorferi is only a theoretical possibility, and has never been diagnosed in NL"</i></p> <p>No LD treatment</p>	<p>(3)Identification and treatment of children and adolescents with undiagnosed and un(der)treated CLD</p>
<p>1996</p> <ul style="list-style-type: none"> Figueroa R, Bracero LA, Aguero-Rosenfeld M, Beneck D, Coleman J, Schwartz I Confirmation of <i>Borrelia burgdorferi</i> spirochetes by polymerase chain reaction in placentas of women with reactive serology for Lyme antibodies 	<p>State Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:</p>	<p>Congenital Lyme Disease is mentioned by 58 people (n = 1858; 3,2% of cases)</p>	<p>Difficulties during pregnancy, hospital not concerned about consequences of untreated LD</p> <p>1996</p> <p>Problems during childbirth</p>	<p>(4)Inclusion of casestudies in decision procedures (CLD = rare condition)</p>
<p>1997</p> <ul style="list-style-type: none"> Trevisan G, Stinco G, Cinco M. Neonatal skin lesions due to a spirochetal infection: a case of congenital Lyme borreliosis? 	<p>to diminish infant and child mortality;</p>	<p>10 respondents report a CLD child (n=260; 3,7% of cases)</p>	<p>Hospital: <i>"transmission of Borrelia Burgdorferi is only a theoretical possibility, and has never been diagnosed in NL"</i></p> <p>No LD treatment</p>	<p>(5)Research which addresses the different clinical pictures related to different <i>Borrelia</i> species and to direct onset and late onset CLD, including psychiatric / psychological disorders, immune system related problems, skin disorders, neurological problems etc. (+ retrospective research in documented cases)</p>
<p>2020</p> <ul style="list-style-type: none"> Lambert J.S. An Overview of Tickborne Infections in Pregnancy and Outcomes in the Newborn: The Need for Prospective Studies 	<p>to ensure the provision of necessary assistance and health care to all children with emphasis on the development of primary health care;</p>	<p>44 adult respondents report CLD as cause of their chronic LD (n=1325; 3,2% of cases)</p>	<p>Postnatal sepsis and ileus</p> <p>Child</p> <p>1997</p> <p>No diagnostic protocol Congenital Lyme Disease (CLD) pre/post natal, no CLD treatment</p>	<p>Research that addresses the potential impact of CLD and the <i>'knowledge gap'</i> (Waddel, E.A., Greig, J; 2018)</p>
<p>2020</p> <ul style="list-style-type: none"> Lambert, J.S., Peronne, C. Time to recognise Congenital Lyme: an open letter to the WHO 	<p>to combat disease(...) through the application of readily available technology (...)</p>	<p>Rating of healthcare in NL for CLD on scale 1-10: Adult respondents n=44: 1,4 Parents n=10: 1,8</p>	<p>Continuously health, behavioural, psychiatric, sleep, educational problems</p> <p>Experienced stigma from medical / psychiatric profession: LD can't be discussed as a causal factor of health and psychological issues</p> <p>2017</p> <p>MSIDS Questionnaire (HMQ): high probability of a tick-borne disorder</p>	<p>(6)Monitoring and guidance of the (mental) health and educational situation of children with CLD</p>
	<p>to ensure appropriate pre-natal and post-natal health care for mothers</p>		<p>Clinical diagnosis LD: IgM-pos; IgG-pos; Western Blot-pos; 6 weeks AB; relapse after 3 months</p> <p>2020</p> <p>GSQ30 (Fallon, 2019): score 71 -> severe impairment of study, social and family functioning -> treatment AB+</p>	