

# Experiences of Children with Facial Nerve Paralysis caused by Lyme Disease: Diagnosis, Treatment and Ongoing Support

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## Introduction

Lyme disease is the most common cause of facial nerve paralysis in children and is caused by the tick-borne spirochete of the *Borrelia species*. It can be misdiagnosed as **Bell's Palsy**, which risks not identifying the infectious cause of the condition and **antibiotic treatment** being delayed possibly resulting in a worse outcome for the child. Infected ticks have now been found throughout the U.K. and considering this, **should Lyme disease be considered the working diagnosis when a child presents with facial palsy until proven otherwise?**



## Objective

The charity **Lyme Disease UK** conducted a small study of children's experiences of facial palsy caused by Lyme disease after receiving **anecdotal reports of difficulty of diagnosis** from parents who were seeking support. The objective was to see if the child and families reported similar or differing experiences.



## Methodology

The method used for the study consisted of an anonymous survey consisting of ten open ended questions that enabled the respondents to **describe their child's care in their own words** and to express themselves freely. The survey was shared in a variety of places including **LDUK's public social media channels** and various online support forums in the UK to try to capture as many responses as possible. All children included in the study had a **confirmed diagnosis of Lyme disease**, either by **serology, lumbar puncture** or by identification of **Erythema Migrans rash**.

## Results

Although a small study, it was evident that the **families' experiences had recurring themes**. All but one respondent stated that **Lyme disease was not considered initially as the differential diagnosis**.

Two respondents reported that when Lyme disease was subsequently diagnosed, their child was not prescribed an adequate dosage of antibiotic as recommended by the **NICE guideline (2018)**.

One parent reported she was only aware about the inadequate dosage when she sought support from LDUK. All reported that **no follow up support was offered**, and in one case this led to a 6-year-old boy being ostracised and bullied by his peers. The family had to self-refer to **CAMHS (Child & Adolescent Mental Health Services)** such was the distress of their child.

*Q. Did the medical team treating your child consider a diagnosis of Lyme disease as soon as the facial paralysis developed?*

*A. "No, the registrar googled it, said probably viral and sent us home refusing to do any testing"*

*A "Because of the initial test being negative they were dismissive of my concern".*

*"A. "I was told it was nothing to worry about on the phone".*

Survey respondents



Image: By kind permission of LDUK member, Katy Howard

## Conclusion

The findings of this study seem to indicate that **Lyme disease as the cause of facial palsy in children can be overlooked** in the first instance when presenting to urgent care. However, **limitations of this study are the small sample of case studies** collected up to date, although as previously stated, **the study is ongoing**.

The researcher's inability to share the survey to wider health care settings has limited the number of responses received but it is hoped the research can be updated later. **It would be interesting to see if these results would be replicated by a much larger study of children with Lyme disease associated facial palsy in the UK** and add to the knowledge base of treating these children so that **children with this condition always receive quick diagnosis and optimum care**.

## Find out more about this study

Please visit [www.lymediseaseuk.com/facial-palsy-resources](http://www.lymediseaseuk.com/facial-palsy-resources)



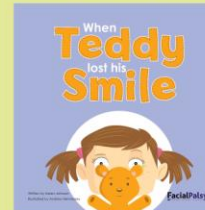
*"Facial palsy in children is debilitating not only physically but socially.*

*Treatable causes need to be identified quickly and managed to reduce the risk of long-term sequelae in children."*

Adel Fattah,  
Facial Palsy UK Medical Advisory Board

## Resource for families

Facial Palsy UK launched their first children's book, **'When Teddy Lost His Smile'** by Karen Johnson & Andrew Hennessey (Illustrator).



The book aims to improve self-esteem in children with facial palsy by **normalising the condition, reduce feelings of isolation** in children so they don't feel they are 'the only one' and **increase awareness of facial palsy** in schools and the wider community.

Thanks to **Facial Palsy UK** for allowing permission to share this resource.

**FacialPalsy** INFORM • SUPPORT • RESEARCH [www.facialpalsy.org.uk](http://www.facialpalsy.org.uk)

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