

Babies at Risk

Neonatal Herpes Awareness

Findings from a survey of expectant and new parents examining awareness and behaviours regarding potentially dangerous infections in young babies

January 2022



Preventing newborn baby deaths
through research & education

About Kit Tarka Foundation

Kit Tarka Foundation is a small UK charity working to prevent newborn baby deaths primarily through raising awareness of neonatal herpes, funding research, and providing advice for healthcare professionals and the general public. The charity was founded in 2018 following the death of baby Kit to a neonatal herpes infection.

Introduction

Some infections which are common and usually mild in adults and older children can be very dangerous for babies. These include group B streptococcus (GBS), varicella (chicken pox) and herpes simplex virus (HSV).

Neonatal herpes simplex virus disease (also called 'neonatal herpes', or 'neonatal HSV') occurs when a newborn baby is infected with HSV. These infections are very common in adults and older children, typically causing mild symptoms such as cold sores and genital sores. Symptoms may be so mild that they go unnoticed, and most people have no symptoms at all¹. HSV is much rarer in very young babies but can be extremely dangerous, leading to significant disability or even death. Prompt recognition and treatment with antiviral medication have been shown to significantly improve the outcomes of babies with this infection.

HSV can be transmitted to babies in three ways:

1. during delivery, through an infected birth canal;
2. after delivery, following direct contact with someone with an active herpes infection e.g. cold sore or herpetic whitlow (HSV infection on the finger);
3. before birth, via the placenta (although this is very rare).

Studies have shown that the incidence rate of neonatal HSV in the UK has been rising in recent years^{2,3,4}

Some HSV infections in newborn babies could be prevented by avoiding exposure to active herpes infections; this may be achieved through improved hygiene measures (such as handwashing) and not kissing babies who are not your own.

Kit Tarka Foundation carried out a survey of expectant and new parents between September and November 2021, during the Covid-19 pandemic. The survey examined parental awareness of potentially dangerous infections in babies and looked at current behaviours related to this.

About the survey

The survey was designed by Kit Tarka Foundation and created using the SurveyMonkey portal. It was shared by the National Childbirth Trust (NCT), Bounty and National Maternity Voices on social media channels and with recipients of their email newsletters. Expectant parents and those with a baby under 1 year of age were invited to participate in the survey. Responses were anonymous with no identifiable data collected. Those who completed the survey were offered the opportunity to be entered into a prize draw to win a £100 voucher.

1,529 completed questionnaires were returned. Of these, 18 (1.2%) were completed by non-birthing parents. This report analyses the responses of the 1,511 questionnaires completed by pregnant people and birthing parents only.

At the time of the survey, 562 of these respondents (37%) were pregnant and 949 (63%) were the mother or birthing parent of a baby under 1 year old. 82% of parents described their ethnic group as White and 18% were parents from Black, Asian, mixed or minority ethnic backgrounds. <1% chose not to answer this question.

1,501 (99%) of respondents identified as female (including transgender women), 2 identified as male (including transgender men), 2 as non-binary and 6 preferred not to say. Note, for simplicity of language in the remainder of the report, we will use the terms 'mothers', 'mums' and 'pregnant women' but this should be taken to include all birthing parents and pregnant people.

Respondents were invited to participate through pregnancy and parenting platforms, suggesting a certain level of engagement with pregnancy and parenting issues and possibly better knowledge of these issues. 1,195 (79%) of respondents said they had completed a college or university education or higher compared to 42% of the general UK population⁵.

Key findings

Sources of knowledge - where participants usually get information about pregnancy and/or newborn health

Participants were asked to indicate from a list where they usually obtained information about pregnancy and/or newborn health. The most common responses were: midwife (78%); friends and family (66%); and websites (60%). The most common websites cited were the NHS website and Bounty.

Hygiene and behaviour around young babies

Participants were asked how they would respond to others coming into close contact with their newborn or very young baby (less than 3 months of age).

People they don't know well touching their baby

When asked whether they would allow people they don't know well to touch their baby, 17% of respondents said they would allow it without asking them to wash their hands first. 87% of these said they would do so 'reluctantly'. 16% of mothers of babies between 3 and 12 months told us they had not experienced anyone they didn't know well touching or requesting to touch their baby and 59% of these specifically mentioned Covid or lockdown in their comments. Conversely, we also had some comments from mothers who had experienced people touching their babies against their will.



Some people (strangers out in public) would come up and touch my daughter before I even had the chance to say no!

Mother of a baby aged between 3 and 6 months, Wales, 2021



People they do know well holding their baby

14% of pregnant women said they would allow people they know well to hold their baby without asking them to wash their hands. This rose to 46% for mothers of babies who had been born, perhaps indicating a difference between intention and lived experience. 38% of respondents said they would allow it after asking them to wash their hands. 2% of respondents commented on the impact of Covid e.g. asking for a negative lateral flow test before visiting.

People they do know well kissing their baby

45% of respondents said they would allow people they know well or members of their family not living with them to kiss their baby. 52% of these said it would be or was allowed 'reluctantly'. 39% said they would not allow it all. Several people said they would allow kissing from grandparents or close family, but nobody else. We received some comments from people who had experienced friends and family kissing their baby but weren't comfortable with it.



"They do it without asking which I wish they wouldn't! I would say no."

Mother of a baby aged between 0 and 3 months, UK, 2021



Some mothers with babies born at the peak of the pandemic mentioned that lockdown restrictions had meant that the issue never arose. Others said they would allow kisses on the head or cheek only, not on the lips. This may reduce the risk of transmission of HSV but not eliminate it entirely.

Behaviour if experiencing cold sores or blisters

The risk of postnatal transmission of HSV is highest following contact with an active herpes infection, such as a cold sore or herpetic whitlow. Infection can be passed on directly (for example, by a kiss) or indirectly (for example, by touching an area with an active infection and then immediately touching the baby). It can also be spread during breastfeeding if the mother has HSV lesions on the breast or nipple.

What parents would do if they had a cold sore when their baby is under three months old

We were pleased to see that 82% of expectant or new mums knew to stop kissing their baby if they had a cold sore. However only 32% said they would cover up the cold sore, which could make transmission much less likely. Only 28% said they would take all three steps we advise which are to cover up the cold sore, stop kissing their baby and treat the cold sore with antiviral cream.

What breastfeeding mothers would do if they noticed a blister or lesion on their nipple

Of the mothers who breastfed, 18% said they would continue breastfeeding from both breasts if they noticed a blister. 76% of pregnant women said they would 'definitely' contact a health professional, but this dropped to 66% for mothers whose babies had been born. Only 41% said they would stop breastfeeding from one or both breasts *and* seek advice from a health professional.

Knowledge of infections which could be dangerous for an unborn or newborn baby

59% of respondents were not aware that herpes could be 'extremely dangerous' for young babies. Awareness of other dangerous infections, including Group B Streptococcus, rubella and toxoplasmosis was slightly better.

Knowledge of herpes

Respondents were asked what proportion of the UK population they thought carried the herpes virus, selecting from a list of possible answers. Just over one third gave the correct answer of 70%⁶. 59% of respondents thought that only half, or less than half, of the UK population carried HSV.

A large proportion (92%) of respondents were aware that cold sores are a symptom of herpes infection. Awareness of asymptomatic carriage (infection without any symptoms, such as cold sores or blisters) was 93%. 21% of respondents did not know that the herpes virus lasts for life after the initial infection, with 11% thinking it goes after a month or less.

Although most respondents knew that the herpes virus can be spread through sexual intercourse (91%) or oral sex (92%) not as many (67%) knew it could also be spread indirectly through touch. Although transmission of HSV is most likely when symptoms such as cold sores or ulcers are present, the virus can 'shed' at any time, even in the absence of symptoms. 36% of respondents were not aware of this. **As 70% of the UK population carry HSV, most of whom will have very mild or no symptoms, it is essential that everyone exercises caution around young babies by practicing appropriate hygiene measures.**

Information given in pregnancy

The survey found that only 15% of respondents knew they had been asked about their history of herpes infections by any health professionals during their pregnancy, and 43% did not recall being asked about sexually transmitted infections at all. Of the 88 respondents who knew they had a genital herpes infection, 48% said it was not discussed with a health professional during their pregnancy, and 41% said they had to raise the issue with a healthcare professional (rather than being asked about it). This is relevant as not all individuals may be forthcoming with this type of information due to the perceived social stigma around STIs. 6% of respondents reported having a history of genital herpes infection, compared to the UK rate of 23%⁷ for HSV-2 in adults.

The risk of HSV transmission during delivery of the baby increases if genital herpes infections occur during the third trimester. The risk is particularly high if the mother has never had genital herpes before (this is called a 'primary infection'). In these circumstances, a caesarean section may be offered to minimise the risk of transmission to the baby. Recurrent infections may be treated with oral antiviral medications⁸. 40% of respondents did not know that catching genital herpes during pregnancy could be dangerous for their baby and 48% said they did not know or weren't sure that they should avoid sexual activity in the third trimester if their partner develops signs of genital herpes.

Conclusions and recommendations

Key points

- 1 Young babies are particularly susceptible to infections, yet more than 1 in 6 mothers and birthing parents surveyed would allow a person that they did not know well to touch their baby without first washing their hands. A third of parents said they would *not* ask family and friends to wash their hands before holding their very young baby.
- 2 Despite increased public awareness of infection control practices during the COVID-19 pandemic, almost half of the mothers and birthing parents surveyed stated that they would allow friends and family to kiss their very young baby. This figure may have been even higher prior to the pandemic. As part of the open responses in the survey, numerous parents reported that their babies had been kissed by friends or family members without consent being given. Responses suggested that some parents were aware of the potential risks of spreading infection but did not feel comfortable or able to ask others to change their behaviour.
- 3 Most parents were aware that they should avoid kissing their baby should they develop a cold sore, but fewer knew that covering the cold sore and treating it with antiviral cream could further reduce the risk of HSV transmission.
- 4 Blisters on a breast or nipple can indicate an HSV infection, yet most breastfeeding mothers and birthing parents were not aware they should stop breastfeeding from the infected breast and seek professional advice should they experience this.
- 5 **Almost 6 in 10 parents did not know that herpes infections in young babies can be extremely dangerous.** This is concerning as herpes infections are extremely common amongst the general public (70%).
- 6 Advice from health professionals on herpes infections during pregnancy was lacking; almost half of women and birthing parents with a known genital herpes infection received no information on this from their midwife or doctor. Only 15% of respondents were asked about previous genital herpes infections.

Recommendations

- 1 Public health campaigns are needed to raise awareness of the dangers of cold sores to newborn babies, and the importance of good hygiene when visiting very young babies.
- 2 Expectant and new parents reported that midwives were their most commonly used source of information. Professionals working in maternity services should receive specific training on:
 - herpes infections in pregnancy and, in particular, the risks associated with primary genital herpes infections in late pregnancy;
 - how to reduce the risk of postnatal transmission of herpes infections.
- 3 All pregnant women and birthing people should be specifically asked about their history of genital herpes infection at their first midwife appointment (booking appointment). They should be advised at booking to contact their midwife or GP should they develop any symptoms of herpes during their pregnancy.
- 4 All health professionals (including GPs, pharmacists and dentists) seeing patients with new or recurrent cold sores or blisters should receive training about the risks of HSV to newborn babies, so that they are able to provide accurate advice on reducing transmission.

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Further info

For further information about neonatal herpes please visit the Kit Tarka Foundation website at kittarkafoundation.org.

Full results of the survey are available on request by email to info@kittarkafoundation.org.

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