

Bella's Story

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Learning from the Tragedy of Disseminated Neonatal Herpes Simplex Virus

BACKGROUND

The process of child death review is not new, however ensuring the process involves families and provides useful learning for all health care professionals has still not been perfected. We have worked closely with Bella's family to ensure that lessons are learnt from her death. Their bravery has allowed us to use both her name and pictures to ensure that the learning is about a precious baby, rather than 'Patient X', and to share this both locally and worldwide via social media. We hope that her story shows the positives that can come from the child death review process for both staff and families.

BELLA'S STORY

Bella is her parent's first baby, born following an uncomplicated pregnancy, with no risk factors for infection and discharged home within a few hours. She was reviewed on day 5 by the midwife. She had lost 12% of her birthweight and was referred into hospital for review. Bella had been bottle fed from birth. She was managing 30-60mls but it took a long time. Parents commented she was sleeping 90% of the time and she slept through her examination. There was no fever, no rash and (apart from breathing quickly) her examination was normal. She had some bloods taken, a chest x-ray and was admitted for observation. Her CRP was raised and the x-ray showed some changes so she was started on antibiotics for sepsis. Bella remained very sleepy and started to have pauses in her breathing, she was admitted to the PICU.

On PICU she was ventilated for a short while. Blood markers of infection were improving and HSV PCR from her lumbar puncture was negative. Because she was so sleepy she had metabolic tests sent. Her ALT was high, doctors assumed this was due to her resolving sepsis. Bella was extubated and was breathing on her own. She was getting ready to go to the ward when staff noticed she was oozing excessively from a heel prick site. She had repeat bloods taken to check her clotting and liver function.

These came back very abnormal - showing liver failure and coagulopathy. She was immediately discussed with the regional liver unit and started on antiviral medication. A review of the notes at this time found a comment, from shortly after admission, that Bella's mum was worried she had cold sores.

Bella died from disseminated HSV infection at 11 days of life. Review of her care showed opportunities for learning and where treatment for HSV could have been considered. We met with Bella's family to discuss their concerns and talk through what had happened. Their hope is that her legacy will be that ALL healthcare professionals (HCP's) seeing neonates will [#ThinkHSV](#) and investigate and treat appropriately.

THE LEARNING

NEONATAL HERPES SIMPLEX VIRUS (HSV) INFECTION

Infants <60 days of age with a positive HSV PCR from skin, mucous membranes, blood or CSF

INCIDENCE

6.9 per 100,000 live births in the UK
This is roughly one baby born every two years in UHL

HSV TRANSMISSION

Intrauterine (5%)
Perinatal (85%)
Postnatal (10%)

DID YOU KNOW?

50% of pregnant mothers with genital herpes never experience symptoms
40% of cases with disseminated HSV do not have skin lesions

TREATMENT

Please scan QR codes for local guidance

THINK HSV!

1. In any sick neonate presenting with nonspecific signs (poor feeding, sleepiness)
2. Regardless of maternal history (often asymptomatic, check if any close contacts have orofacial lesions)
3. Transaminitis can be an early sign
4. If clinical suspicion-obtain skin swabs (eye, mouth, NPA & vesicles), blood, CSF for HSV PCR and
5. Treat with Aciclovir IV

LABORATORY ABNORMALITIES

CSF: ↑ lymphocytes
Blood: FBC: ↓ neutrophils, ↑ Plts
Coag: Coagulopathy
UFT: ↑ ALT, ↑ AST, ↑ Bilirubin
CRP often normal



The trust learning bulletin was personalised and reissued to all relevant staff across the trust and community services.

LEARNING BULLETIN

Baby Bella's Story

Baby Bella was born in autumn 2021, first baby to Chloe and Joshua. The pregnancy was uncomplicated and Bella was born in good condition, at a healthy birthweight and with no concerns. Mum and baby were both discharged home appropriately within a few hours.

Following her routine midwife visit on day 5, Bella was found to have lost more than 12% of her birthweight and was referred into the Children's Emergency Department (CED) for review. Bella was reported by mum to be very sleepy and needing to be woken for feeds. She was taking 30-60mls of formula feed but it was taking long periods for her to manage this.

Following investigations, that showed a raised CRP (infection marker) and an abnormal chest x-ray, Bella was started on treatment for potential sepsis and admitted to the Children's Hospital. Bella continued to be very sleepy and started to have pauses in her breathing. She was admitted to the Children's Intensive Care Unit and was briefly ventilated but seemed to be improving with her CRP lowering.

Bella had some other abnormal blood tests and these were thought to be due to her presumed sepsis. Her LP had been sent for HSV PCR (Herpes Simplex Virus) and this came back as negative. She was getting ready to move to the ward when she became more unwell and nursing staff noticed her heel prick sites were oozing blood. Repeat blood tests showed Bella had extremely abnormal liver function tests and clotting and she was urgently transferred to Birmingham Children's Hospital for treatment of liver failure.

Review of the notes at this time noticed the mention of a possible cold sore on Mum's mouth from day 2 of her stay. Bella sadly died in Birmingham, at only 11 days of age, from disseminated Neonatal Herpes Simplex Infection.

Her care has been reviewed at the Paediatric M&M meeting and it was felt that there were some significant learning points for sharing across the services. This is to aid both recognition and suspicion of Neonatal HSV and to aid early management plans where we feel this could be the diagnosis. Having met with UHL, Bella's family hope that her story and the lessons learnt may prevent other families going through what they have.



VS

Learning Bulletin - Learning from Deaths

NEONATAL HERPES SIMPLEX VIRUS

Recently the Trust provided care to a woman and baby during pregnancy, birth and the early days of the baby's life. Her pregnancy was uncomplicated and her baby was born in good condition, at a healthy birthweight, with no concerns. Mum and baby were both discharged home appropriately. At 6 days of age, the baby was referred into the Paediatric Emergency Department due to excessive weight loss. The baby was reported by mum to be very sleepy and needing to be woken for feeds. Following investigations and commencement of various treatments for potential sepsis the baby was admitted to the Children's Hospital. Sadly, the baby's condition deteriorated and after a period of time in Children's Intensive Care the baby was transferred to Birmingham Children's Hospital due to very abnormal ALT blood results and a presumption of a liver problem. Sadly the baby died and this was found to have been due to Neonatal Herpes Simplex Virus.

The case has been reviewed at the Paediatric Mortality & Morbidity meeting and it was felt that there were some significant learning points for sharing across the services. It was noted that Maternity, Neonatology, Paediatric ED and the Children's Hospital staff would all benefit from the findings being shared. This is to aid both recognition/suspicion of Neonatal HSV, and aid early management plans for neonates who demonstrate symptoms.

HSV in neonates is rare and is seen in less than five per 100,000 births and usually presents within two weeks of birth. HSV can be transferred to a baby during pregnancy, birth and the postnatal period. Whilst people are often alerted to the possibility of HSV where a mother has reported a history of either genital herpes or cold sores, **most neonates with HSV disease are born to mothers without a history of HSV infection or other identifiable risk factor.**

The mortality rate for neonatal HSV if untreated is 85-100%. This can be massively reduced to approx. 30% if early treatment with acyclovir is initiated. In order to commence treatment, people first need to be suspicious of potential HSV as a possible cause for the presenting symptoms or concerns.

- A poster was produced to inform HCP's about Neonatal HSV - highlighting our trust guidelines and to [#ThinkHSV](#)
- Bella's story was shared on [#EM3FOAMed](#) social media platforms and has had over half a million views to date.
- Information from the Kit Tarka Foundation is now given to all new parents warning of the dangers of Neonatal HSV.

FURTHER INFORMATION

- Visit www.tinyurl.com/ThinkHSV for Bella's full story
- Visit www.kittarkafoundation.org for free resources for parents on preventing Neonatal HSV
- Scan the QR code for a copy of Bella's poster with space to add your local guidelines

A huge thank you to Chloe and Joshua, Bella's mum and dad, who allowed us to share her story ❤️



SCAN FOR OUR POSTER

TAKE HOME MESSAGES

Please check that you are...

- ✓ Giving new parents information on the dangers of HSV infection.
- ✓ Ensuring that if HSV is in your differential ALL swabs (blood, CSF, skin & throat) are negative before stopping treatment.
- ✓ Listening to families - numbers need context and they are the ones who can provide this.
- ✓ Keep an open mind - sometimes we treat the wrong thing for all the right reasons. If the clinical picture doesn't add up, think again.

@EM3FOAMed

[#ThinkHSV](#)

University Hospitals of Leicester NHS Trust