

## **“It’s a parent’s worst nightmare” – mothers share experiences on serious child illness to highlight new report**

Two mothers whose children were seriously ill in hospital welcomed a new academic report designed to stop their experience from happening to others.

Kerry Fisher, whose daughter, Rubie, died from meningitis at 6 weeks old, and Rose Edmonson, whose son Charlie, now 9, contracted sepsis aged 4, helped to inform the Before Arrival at Hospital (BeArH) report.

Infection is a major cause of childhood deaths in the UK and globally, particularly in the under 5 year age group. The Universities of Northampton and Plymouth led the BeArH report to understand when and how children with serious infectious illness (SII) went to hospital, and what happened prior to their arrival.

The study found that: improving information for parents and health professionals on symptoms of serious childhood illness; simplifying health services; ensuring that parents with children suspected of having SII are nearer to the centre of decision-making; and ensuring children see the same health professionals could help accelerate treatment and reduce deaths.

The hope is that the study, funded by the National Institute for Health Research (NIHR), will provide a foundation to combat the problems identified, and enable parents to seek more consistent, positive help.

Providing personal accounts and vital evidence that fed into the report, Kerry and Rose share their stories below.

### **Kerry, from Staffordshire, talks about her last hours with Rubie – from refusing her feed at 10.30pm, to passing away less than 12 hours later.**

“It happened in May 2015, and it’s a parent’s worst nightmare. Rubie wasn’t taking on as much milk as she had been previously and seemed a little under the weather. Assuming it was a cold, I gave it a couple of days and took her to the GP in her pram. It was quite an informal consultation as I knew him well – I think he trusted my assumption, and I trusted his view. He didn’t take her out of the pram and examine her, but suggested we kept her upright in the car seat to help with her breathing.

“I gave her lots of cuddles and TLC, then at 10.30pm that night, I put her to bed in the car seat, planning to keep an eye on her. I knew something was wrong when she hadn’t woken for her bottle by 4am and she was almost grunting with her breathing. I called 999, the first responder gave her some oxygen, then at 5am we were at A&E.

“I was just outside the room where Rubie was being treated and, as they’d offered us a family room on another ward to stay in, I remember thinking ‘she must be ok as they’re giving us somewhere to stay’. There was talk of low blood sugar and potentially diabetes, and the only person who stayed in the room consistently was the nurse. She then called the rest of the team back in as Rubie had a fit and needed CPR, then she had another fit. At 9am we’d lost her. I can’t believe how quickly it all happened.

“The consultant stayed with us and told us it was Meningitis, and six weeks later, we found out that it was bacterial Meningitis caused by late onset group B strep. I remember the consultant telling us that, as very young children can’t talk, trying to identify a problem is like having knots in a long piece of string and having to untie each one individually to rule it out.

“Sharing our story and informing the BeArH report is not about blaming anyone. I know how hard health professionals train, and I feel that I myself did everything I could to help my little girl. It’s about sharing the situation to stop it happening to anyone else, and, for us, keeping Rubie’s memory alive in the process.”

**Rose, from North Manchester, explains how her son Charlie, now 9, was put into an induced coma following a diagnosis of sepsis in December 2015 – but had it not been for her monitoring him, she might not have intervened in time.**

“Charlie had been at the childminder during the day and came home a little quieter and more tired than normal. The following morning, he had a temperature, his skin was mottled and he looked really ill. He hadn’t really had a sickness bug before, so I assumed it was just how he presented. He perked up after some medicine and food, and I phoned the GP but no one was available to talk straight away.

“As much as I thought sleep would help him, I was watching TV so decided to keep Charlie up with me and monitor how he was doing. I then noticed a bruise like mark on his neck, but I was on my own with him, so had no one to check or discuss my fear that it might be Meningitis. I was starting to put clues together though and did an online search for reassurance – then when Charlie collapsed on the toilet later that day, I phoned the ambulance. The first responder gave him a shot of antibiotics, and upon arrival in hospital he was put into an induced coma for 8 days. They discharged him on Christmas Day, although he couldn’t walk or feed himself, and he then went back in to hospital for a few days over New Year.

“The first hospital visit was confirmed sepsis, brought on by Meningitis B. Sepsis is so difficult to diagnose in kids but I’d always say to someone, you know your child – keep monitoring them and if there’s something that isn’t characteristic, get help as soon as you can. You’re not a hypochondriac, you’re looking after your child’s best

interests. Ordinarily, I would have put Charlie to bed without seeing him get worse – and if I'd done that, I don't honestly know if he'd still be here."

**Professor Sarah Neill** from the University of Plymouth is chief investigator of the BeArH project. She said: "During our research, we heard heart-breaking accounts from parents like Kerry and Rose. I'd firstly like to express my thanks to them for their time and courage in sharing their stories, and to the health professionals who contributed to the report for lending us their valuable insights.

"The findings from the BeArH research provide important insights into the complex interplay of factors that influence the timing of treatment for these serious infectious illnesses.

"Parents, already distressed when their child is unwell, feel disempowered in the face of the established knowledge of health professionals in an overstretched service. For both, that system can be a complicated terrain to navigate.

"This can lead to a 'perfect storm' with tragic outcomes, ironically in a system designed to stop this. We hope that the BeArH findings and follow-up investigations will help to reduce child deaths."

The BeArH project is independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0416-20011). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Read more about the findings [here](#).

## **ENDS**

\*The BeArH research was funded by the National Institute for Health Research. The full list of partner organisations is:

- Edge Hill University
- Kettering General Hospital NHS Foundation Trust
- Meningitis Now
- Mother's Instinct Support Group
- Northamptonshire Healthcare NHS Foundation Trust (NHFT)
- University of Leicester
- University of Leicester Hospitals NHS Trust
- University of Liverpool
- University of Northampton
- University of Plymouth
- Meningitis Research Foundation
- UK Sepsis Trust
- Encephalitis UK

\*\*Ferrerias-Antolín, Oligbu et al. 2020.

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- Attracting, training and supporting the best researchers to tackle complex health and social care challenges;
- Collaborating with other public funders, charities and industry to help shape a cohesive and globally competitive research system;
- Funding applied global health research and training to meet the needs of the poorest people in low and middle income countries.

NIHR is funded by the Department of Health and Social Care. Its work in low and middle income countries is principally funded through UK Aid from the UK government.

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