

HUS Surveillance Notes— Sarah's Story

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Hemolytic uremic syndrome (HUS) is a rare disorder characterized by microangiopathic hemolytic anemia, microthrombi, and multiorgan injury. Although infection with Shiga toxin-producing *Escherichia coli* is the most frequently identified cause, *Streptococcus pneumoniae* is increasingly recognized as a cause of HUS, and increasing illness and death have been documented for this rare precipitant (1).

Cases of pediatric HUS are ascertained prospectively from an active, ongoing national surveillance program (2). Clinicians approach parents to seek consent for study enrollment when they deem the child is clinically stable. Parents of children affected by HUS are given a patient information sheet, a consent form, and a questionnaire if consent is given. As part of the surveillance, parents are asked to answer several open-ended questions at year 0, and 1 and 5 years after enrollment. Questions pertain to the status of the child's health and whether visits to doctors and ongoing hospital treatments are still needed. The questionnaire also asks parents to assess their child's illness since the initial visit to the hospital and the effects of this illness on the family.

In 2006, a 1-year-old girl was admitted to a pediatric hospital in Glasgow, Scotland, because of microbiologically confirmed pneumococcal infection and superimposed HUS. Such cases are typically characterized by empyema, meningitis, and bacteremia in children, and also by major renal and neurologic injury requiring extensive dialysis (3). Unfortunately, this was true for Sarah.

The following account is the child's story as told by her mother.

Year 1

The pneumococcal infection that caused Sarah's HUS left her severely brain damaged. She has virtually no voluntary movement, cannot walk, talk, speak, or sit unaided, and she cannot feed orally. Sarah attends physiotherapy and speech and language therapy at a hospital for rehabilitation after her brain injury. It is hard to know how much of Sarah's disability was caused by

HUS and how much by the pneumococcal meningitis we also believe she had. Obviously, having a severely disabled child has affected the family. I have given up work to be Sarah's full-time caregiver. We also lead a different sort of family life from what we had hoped to have, although our second child is due to be born at the end of the month. We are so proud of Sarah for making it through to celebrate her second birthday last week.

Year 5

Sarah is thriving: she was 6 years old on her birthday and is big sister to Peter, now 4 years old. I am still full-time at home but have started an Open University degree and have several voluntary jobs with organizations in our local community. This enables me to maintain my skills but also be available for Sarah. As you know, with complex needs, her health can change dramatically. However, we are lucky that she keeps generally in good health.

Sarah attends a full-time specialist school and is making small improvements in the consistency of her responses and communication, although she is still nonverbal. We have had her sight and hearing tested and, although she has 100% normal hearing, Sarah is registered as blind (seeing only light and dark). She also goes to a residential respite center twice a month, so between that and school she has an active independent social life away from us, which we believe is essential for her. Sarah adores her brother Peter and has infinite patience with his play and noise and physical contact.

Peter also adores his sister and is protective of her and matter of fact about explaining to friends that Sarah cannot talk because her brain is broken (how we have explained things to him). Five years later, many of the emotions are the same, but many have changed, as have the difficulties.

The effect of pneumococcal HUS on the parents of children with this disease has never been documented. These brief notes convey the remarkable fortitude shown by Sarah's family and the difficulties experienced by parents coping with the needs of a child affected by the disease. Early administration of antimicrobial drugs and dialysis considerably improve prognosis in this severe and rare infectious complication, but the long-term effects on young children and their families remain.

Acknowledgments

The names of the children have been changed. I thank the parents of Sarah for their consent in allowing their experiences to be shared.

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References

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