

Susannah's Story

Susannah is a 2-month-old (adjusted age) born with congenital cytomegalovirus (CMV) infection. She was born four weeks early (she is chronologically 3 months old, but her age is adjusted for her prematurity, for developmental assessments*). Susannah is the daughter of Christine and Matt, who live in a small town in northern Wisconsin.

Susannah is their second child. Their first child, Aiden, is 22 months old and typically developing. He goes to an in-home day care where several of Christine's teacher colleagues have their toddlers during the school year. Aiden's daycare provider has indicated that she will take Susannah when Christine returns to work. Christine is on leave from her job as a kindergarten teacher but is going to have to return to work in about two weeks. Matt is a self-employed commercial fisherman on Lake Superior.

Susannah was born in the local hospital but then transferred to a hospital in Duluth, MN, where she spent three weeks in the neonatal intensive care unit (NICU). Her CMV was diagnosed while she was in the NICU. There was some initial concern about Susannah's organ function, specifically her liver and spleen, but these issues appeared to resolve during her NICU stay. She did not pass the newborn hearing screening in one ear (right) but passed in the left ear. Her head circumference is a little small in relation to her height and weight. The neonatologist explained to Christine and Matt that this is not unusual for a child with congenital CMV infection. He did indicate that while Susannah had not had any seizures while in the NICU, they should watch her carefully as seizures can develop in children born with CMV. In addition to monitoring her organ function after she leaves the hospital, they need to be on the lookout for problems with her muscles, her vision, and possibly her cognitive development. Lastly, the doctor indicated that Susannah would continue to "slough" the disease, and they had to be careful about exposure to other friends and family members who might be pregnant. Infection can be prevented with hand-washing and good hygiene. The doctor painted a potentially bleak picture for Christine and Matt but told them to have hope. They left the hospital with their baby girl totally confused and deeply frightened.

Susannah had a hearing test two weeks after she got home and was found to have hearing loss in both ears. She was diagnosed with a severe-profound hearing loss in the right ear and a moderate hearing loss in the left. The audiologist told Christine and Matt that Susannah's hearing may worsen and that she would benefit from hearing aids right now. In the future, they might consider a cochlear implant in one or both ears. Christine feels like Susannah can hear her sing when she holds her and sings to her because Susannah seems to look at her face. Christine is concerned, however, that Susannah does not follow her visually when she moves her head. She has tried moving a toy from side to side, and Susannah does not follow it with her eyes. Susannah is feeding well. She uses her voice, and both Christine and Matt can tell that she is hungry, tired, or bored by the sound of her voice. Matt believes that Susannah can hear his voice. He says she brightens up when he talks to her.

Both Christine and Matt are very concerned about Susannah's hearing and are worried about how she is going to learn to talk, especially if she loses more hearing. They wonder if they should be learning sign language. They had used some baby signs with their son, Aiden, when he was little, so they know some signs like "more," "want," "milk," "eat," and "play." Susannah is doing many things that Aiden did when he was a baby. She is cooing a little, and they think they have seen a smile. She sleeps well through the

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night and is eating well. They are worried about her vision, but are afraid to hear that something else might be wrong and what that might mean for Susannah's future and their family life.

*For the sake of the Functional Screen, a child's chronological, not adjusted, age is used. Therefore, Susannah's development should be compared to that of a 3-month-old. Pediatricians typically use the adjusted age when assessing development. Adjusted age is determined by subtracting the number of weeks between the gestational age at which the baby was born (36 weeks in this case) from the typical gestational age of 40 weeks. This is why Susannah is initially introduced as being 2 months old even though she is actually 3 months old. Age is only adjusted until prematurely born children are 2 years old, because those who are able to catch up developmentally are expected to do so by age 2.

Summary

Susannah's parents are worried about Susannah's hearing and communication development but are also deeply concerned about what other medical and developmental issues are on the horizon related to congenital CMV infection. They are worried that they are not going to be able to find the therapies she might need in their small town and what that might mean for their future. Christine is worried about going back to work, whether her day care provider will be able to care for a child with a hearing loss, and how well her provider could manage if Susannah develops seizures. Would the day care provider know what to do? Both Christine and Matt are worried that they may have to move in order to be closer to therapies that Susannah may need and what that might mean for Matt's business.

Susannah has a diagnosed condition, congenital CMV infection, which has affected her hearing and possibly her vision. Her current hearing loss is significant and will likely have a negative impact on her capacity to acquire oral language skills. Susannah is at risk for additional developmental problems in the areas of motor, communication and cognitive development. She is also at risk for medical problems, including seizure disorder and liver and spleen function.

Follow-Up Questions

1. *How are Susannah's motor skills developing? How is her head control, and is she trying to turn onto her side at all?*
2. *Her parents believe that she can hear them as she seems to look at them when they talk to her. Does she respond to loud noises by startling or blinking if they are not holding her?*