

Lost to Follow-Up

Kelly Welton, BA, RRT-NPS

“Complex, complicated surgeries. Custom shunts and conduits. This was the stuff of my RT world in the ‘80s and ‘90s. I worked in a cardiac surgery unit that admitted adults, kids, and neonates. Before robotics or catheter surgeries, we still had children’s most complicated complex cardiac defects to repair or palliate.”

Complex, complicated surgeries. Custom shunts and conduits. This was the stuff of my RT world in the ‘80s and ‘90s. I worked in a cardiac surgery unit that admitted adults, kids, and neonates. Before robotics or catheter surgeries, we still had children’s most complicated complex cardiac defects to repair or palliate. These children often returned yearly for a revision as they outgrew their shunts and patches or needed more pulmonary blood flow as they got older. We often remembered these kids when they came back. The families remembered us. And then – they would disappear. “Lost to follow-up” was the term that went in their chart to anticipate their return for a check-up and to schedule surgery. Some families would move, requesting surgical and pediatric cardiology records as they went.

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Moreover, some would just never be seen again. How would the parents ever explain the type of surgery performed, how many times, and the expected outcomes if the kid is still growing? In an upcoming symposium, one of the talk titles is *Primary Care Physicians – what to look for in a former preemie*. In the same way as

these cardiac kids, many families move around a lot and when presenting to the new clinic or doctor, simply stating, ‘my kid was born at 28 weeks’ does not cover all of the possible future issues the child may have. Here are some things to definitely be on the lookout for if a former preemie comes to you for care, either in your MD office or in your ED if you are an RT or RN:

- When did your child reach any milestones, such as walking and talking?
- What percentile on the growth chart is the child?
- Have any vision or hearing problems been diagnosed?
- How is the child’s appetite/how are feeds going?
- Is the child active when at a playground or park?
- Does the child have recurrent respiratory issues?
- How is the child doing overall in school?

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Many former preterm infants are not diagnosed correctly with cerebral palsy, autism, or ADHD until much later in life. If the parents can state how long the child was on a ventilator and how long they were in the NICU, that information can help you determine a course of care over several systems. The difference between a standard ‘Well Baby Check’ and spending time taking a thorough NICU history can mean the difference between success and failure on many levels, from school to chosen profession to general health.

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