CASE STUDY

**Description**

Conner was born at 36 weeks of gestational age. Delivery was via C-section because of fetal distress. Prenatally Conner had known diagnoses that included megacystis and hydronephrosis. A vesico-amniotic shunt was placed in utero at 18 weeks of gestation.

At the time of birth Conner’s birth weight was 2610 grams; and APGARS were five and eight. He was intubated shortly after birth for respiratory support and a gastrostomy tube was placed to ensure adequate feeding. Conner spent eight weeks in the Neonatal Intensive Care Unit (NICU). He made the transition between intubation and Continuous Airway Positive Support (CPAP) but subsequently had to be re-intubated.

**Diagnoses and medical-surgical history:**

* VATER syndrome ( Vertebral, Anal, Tracheal, Esophageal, and Renal abnormalities- also see chapter 9)
* Tracheo-esophageal fistula, requiring repair shortly after birth
* Bladder exstrophy
* Prune belly syndrome with omphalocele repair
* Imperforate anus with colostomy
* Cervical and lumbar hemivertebrae
* Left club foot
* Chronic kidney disease

*Learning Questions*

* What PT needs may Conner and his family experience, based upon his diagnoses?
* How would the home nurse help address the PT needs of Conner after discharge?
* What systems may play a role in financing the cost of PT for Conner and his family?

Conner is the first child for his parents. They live in a small community about an hour away from a major metropolitan center and a large children’s hospital. After his eight weeks in the NICU, Conner was stable enough to go home for the holidays with his parents. However, he still needed ventilatory support because of the tracheo-malacia and his difficulties with cough and airway clearance (see Chapter 7), and was sent home on home mechanical ventilation via tracheostomy with 24-hour nursing care in the home. In addition, Conner needed clean intermittent catheterization every four hours- (see Chapter 6) and drip kangaroo feedings at night through his gastrostomy tube (see Chapter 9).

Conner enjoyed being at home with his family for ten or eleven weeks before returning to the hospital because of respiratory distress. He was admitted to the Pediatric Intensive Care Unit (PICU), where he remained for 78 days. Because of Conner’s medical needs, his parents made the difficult decision to have his mother move to the city to be closer to the hospital. Conner was discharged to that city- home with his mother. He still required 24-hour nursing care. After six months, at mother’s request, nursing care was decreased to twelve hours at night and four to five hours during the day.

Conner had his tracheotomy removed at about two-and-a-half years of age. At that time, Conner and his mother were able to move back home and rejoin his father. Conner continued to be eligible for albeit reduced in-home nursing care. However, his family found it difficult to arrange for consistent in-home nursing care in their rural community.

*Learning Questions*

* What might the rural home nurse do to assist Conner and his family with his motor needs?
* How would the nurse help the family access PT services?
* What information would the nurse report in a referral for PT services?

Conner has been involved with therapy services since birth, both privately and in Early Intervention- ( see Table 7) . From a PT perspective, initial intervention focused on positioning to prevent contractures, and management of his club foot with bracing. Conner developed torticollis. His PT provided education to his mother and nursing staff regarding positioning and stretching to correct the neck deformity. The PT then began to shift focus to his gross motor development, muscle strengthening, and promotion of better balancing skills. The PT developed caregiver education materials as well as a comprehensive home exercise program (HEP).

*Learning Questions*

* What is the role of the home nurse in the HEP?
* What needs can the nurse anticipate for Conner and his family as they participate in the HEP?
* What observations of the HEP would be important to share with members of the PT team?

Conner is now a three-and-a-half year old boy who loves trucks and wrestling with his dog. Despite his diagnoses, long hospital ordeals, and significant medical and surgical history, Conner continues to make gains in all of the developmental domains. He attends preschool with peers, speaks in full sentences and recently learned to ski! His family works intensively with a feeding therapist with the goal of eliminating the G-tube in favor of more normal oral eating. When he gets sick, Conner occasionally requires suctioning because he has difficulty clearing his secretions.

Conner will likely require more surgeries in the future. However, he enjoys his childhood thanks to the diligence and dedication of his parents and the quality of service and training they received from Conner’s numerous health care providers. His PT feels fortunate to have participated in Conner’s care and for having the opportunity to know this devoted family and their delightful and resilient boy.

*Learning Questions*

* From a developmental standpoint, what PT related needs might Conner have in the future?
* When might the home nurse anticipate additional support from the PT team?