

## Case Study – pediatric patient with sudden onset devastation

6 y.o. AA male lives on Eastern Shore of Maryland with mother, 9 y.o. old sister, 3 y.o. brother. The mother does not work outside of the home, the older children attend the local public school and the family is dependent on public transportation. All 3 children are insured through the state's medical assistance program. This child has a history of ADHD managed on focalin, moderate asthma controlled on BID flovent and sickle cell disease with four hospitalizations in the past two years for acute chest pain crises.

He was attending a local summer day camp and experienced an acute stroke due to dehydration. As a result of the insult, he has required a tracheostomy, and a gastrostomy tube. At discharge from the hospital he continues to experience significant deficits including depressed respiratory drive at sleep, difficulty chewing and swallowing as well as focal arm and leg deficits. He is requiring positive pressure ventilation while sleeping, continuous feeds at night and occupational therapy for fine motor skills with his left arm, physical therapy for walking and speech therapy. He will have routine follow-up appointments with his hematologist and a neurologist at UMMC.

He is being discharged directly from the pediatric in-patient floor to home because of the transportation concerns for his family. His mother has received some teaching regarding his tube feedings and he began his rehabilitation process with in-house therapists. He will require home nursing visits for several weeks, rehab services three times a week and is currently scheduled to see the hematologist and neurologist within 2 weeks of discharge.

### Issues:

- home ventilator
- transportation
- pharmacy
- home feeding needs
  - \* equipment/supplies
  - \* formula
- rehab services (at home vs at an office; provided by specialists vs nursing)
- specialist follow-up visits in Baltimore
- primary pediatrician follow-up
- home schooling
- Support for mother as primary caregiver
- support for siblings (lack of attention, unable to participate in usual activities)