

## United Cerebral Palsy (UCP) of Central PA

E. was born right on time, but with some cardiac conditions that required multiple surgeries and procedures. He needed a ventilator to help him breathe and a pacemaker to correct his heart rhythm. After 6 long weeks in the intensive care unit, E. was able to go home with his family, who were eager to have Early Intervention services started. At the age of 3 months, occupational therapy, physical therapy, and Special Instruction-Nutrition (SI-Nutrition) therapy kicked off to help this little guy overcome some developmental delays and feeding challenges. E. required a nasogastric (NG) tube to assist with feeding, as he did not have enough strength to eat a full day's worth of breastmilk and formula by mouth. OT and SI-Nutrition worked with the family to ensure that E. has a safe swallow function, an appropriate suck-swallow-breathe rhythm system while feeding, a good latch on his bottle, and the best tools for bottle feeding with his medical conditions. SI-Nutrition worked closely with E.'s medical team locally and at Children's Hospital of Philadelphia, to monitor his oral intake by bottle, his tube feeding intake via NG tube, an appropriate concentration of breastmilk and formula, and his weight. In young babies, especially those who are underweight, it is crucially important for the family and medical team to have support from SI-Nutrition to evaluate a child's caloric intake and growth on a frequent basis, and to help to monitor for any additional medical concerns or symptoms in between doctors' visits.

E. continued to have some feeding challenges over the next several months including 3 separate rounds of oral thrush and ongoing reflux that made bottle feeding very difficult at times and required additional medications to treat.

At the age of 6 months, E. had a second cardiac catheterization to help dilate an arch in his heart in order to allow for improved cardiac function. His overall stable weight and caloric intake allowed for a much quicker recovery, being able to discharge after a short hospital stay. E. is no longer requiring the NG tube to supplement his oral formula feedings. His weight has increased from <2% to 7% on the growth chart. While E. is still young and his weight is still lower than optimal, his EI service for SI-Nutrition has already provided support to the family allowing for improvement in his current feeding regimen. His medical team is pleased with his continued growth. He is now permitted to start working on introducing baby foods by spoon, a significant feeding milestone!