

# Multidisciplinary Approach Coupled with Advocacy Achieves Positive Outcome for Congenital Short Bowel Patient

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## Introduction

Successful management of pediatric short bowel syndrome (SBS) requires skilled orchestration of an array of medical, surgical and paramedical services. This case study highlights the complex interactions necessary between a Pediatric Nutrition Support Team (NST) at a major pediatric teaching hospital, and a Home NST (HNST) from a leading national home infusion provider culminating in a positive pediatric outcome.



## Methods

C.B. was born at 37 weeks estimated gestational age with Apgars of 6/9. Diagnosed prenatally with intestinal obstruction, surgery on day 1 of life corrected types I and IIIB jejunal atresia, and ileal necrosis with perforation. End-to-end jejunal-colic anastomosis left 80 cm of residual small bowel and no ileocecal (IC) valve. C.B. was discharged home at 10 weeks of age to continue on home PN. He also nipped expressed breast milk (EBM); however, advancement of feeds was limited by excessive stooling in spite of bowel decontamination with a weekly rotation of oral antibiotics.

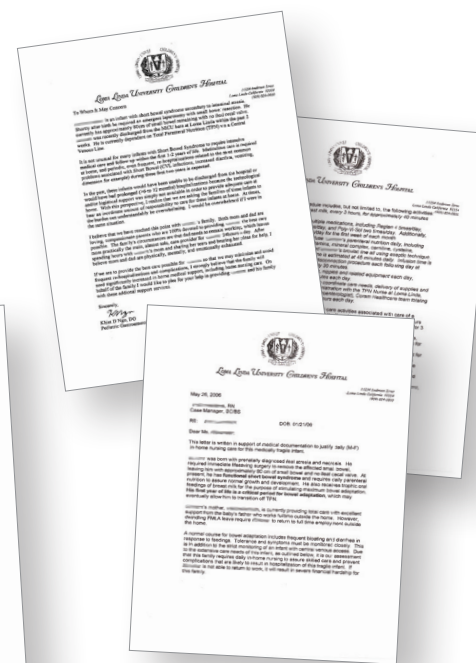
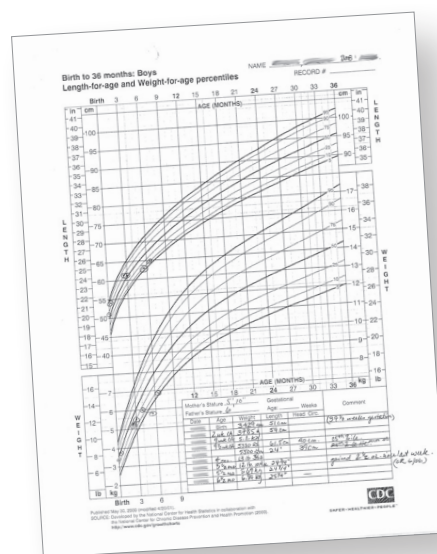
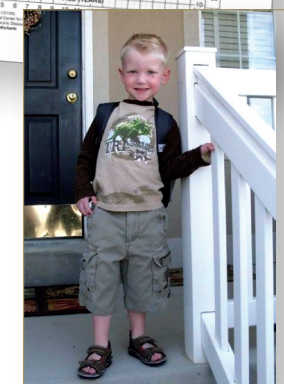
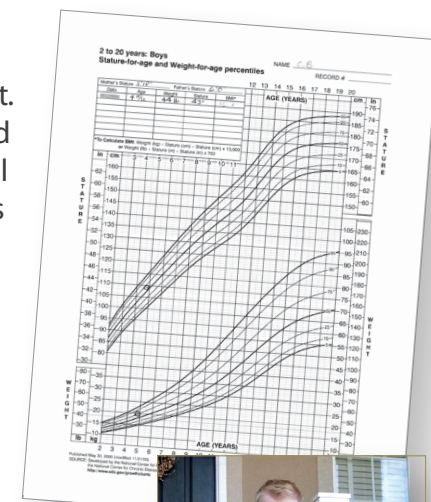
## Results

It was recognized early on by both the NST and HNST of the need for intensive team management to optimize outcome for this child. The HNST RD attended all TPN clinic visits and acted as a liaison between the NST and HNST to coordinate all necessary care. Relatively poor prognosis associated with Type IIIB jejunal atresia is due to typically significant mesenteric defect resulting in distal bowel necrosis and subsequent SBS. The use of EBM is critical to promoting maximal bowel adaptation; fortunately C.B.'s mother was highly motivated to provide this while maintaining scrupulous cleanliness. By five weeks post discharge the challenge of routine infant care complicated by daily PN infusion, administering multiple medications, expressing breast milk and maintaining a clean infant with frequent, explosive diarrhea was taking its toll. Since C.B.'s birth, the mother had lost 40 pounds and expressed that she was completely overwhelmed and exhausted. During this time, the HNST's Patient Advocate provided emotional support and introduced methods to cope with this highly stressful situation.

The mother's Family and Medical Leave Act (FMLA) benefits were approaching expiration, and her EBM supply was dwindling due to stress and sleep deprivation.

Shift nursing was not a covered insurance benefit. Intensive collaboration between the NST and HNST included submission of several medical appeals to C.B.'s insurance payors. The requests identified the critical need for intense monitoring of a medically fragile infant with central venous access, prevention of central line infection and associated hospitalization, and the estimated 10 hours/day necessary to provide his daily medical care. Multiple telephone requests were made, and written documentation was submitted to the Medical Group, and two insurance providers. After six weeks of follow up on this request, daily shift nursing (eight hours/day; five days/week) was approved for three months. This permitted C.B.'s mother to return to work and avoid financial hardship while C.B. continued to receive appropriate care in the home.

*"C.B. is very outgoing and he's always inventing things. He's better than average in his academics and grasps concepts quickly." --C.B.'s mother*



## Conclusion

A tapering enteroplasty was performed at five months to correct on-going excessive stooling; tolerance of oral foods gradually improved as evidenced by reduced stool output. At age 9 months, the family moved out of state and C.B.'s HNST care was transferred to the local infusion branch. He was eventually transitioned off HPN at age 15 months. At 5 years old, his physical, mental and emotional development are appropriate for his age. And subsequently, C.B.'s mother is now poised to enter nursing school, inspired by the positive team support resulting in such a normal outcome for her child.