



HOW COVERAGE OF MEDICAL FOODS CAN SAVE LIVES & COSTS

SHORT BOWEL SYNDROME

Short Bowel Syndrome (SBS) can result in the loss of a significant amount of the intestine. The intestine allows for the absorption of necessary nutrients, fluids and electrolytes. In the case of SBS, life-saving nutrition called total parenteral nutrition (TPN) is needed. Patients require catheters into which this crucial nutrition is provided through large blood vessels in the body. Unfortunately, the use of TPN and the necessary catheters may result in life-threatening infections, requiring hospitalizations, replacement of the catheters and liver disease - that may result in eventual liver failure and death. We know that by providing nutrition through in the intestine, patients can eventually be tapered from TPN. By receiving all of their nutrition via the intestine, there is no longer the need for permanent intravenous catheters, which significantly reduces the risk of infection and ongoing liver disease. There are an estimated 200,000 children with intestinal failure in the country.

Although life-saving, some insurance companies will not cover the use of the specialized formulas that allow children to be tapered from TPN. The formulas are considered “foods,” which may limit the ability of the family to obtain these formulas due to their costs. If these children are unable to obtain the specialized formulas, it may limit their ability to be tapered from TPN or remain off of TPN.

There are multiple complications associated with TPN.

- Patients may require frequent hospitalizations for infections. The cost of a 7-day hospitalization for an infection can be \$20,000 dollars or more.
- The cost of TPN has been estimated to be \$150,000/year or more. These costs do not include the hospitalizations, home nursing support or the intravenous antibiotics that are sometimes needed.
- Long-term TPN usage can result in the need for children to undergo organ transplantation, of which some children will die on the waiting list.
- If a child is tapered from TPN, some companies will no longer pay for the formula unless it is going through a feeding tube. These feedings tubes can be a sense of embarrassment for children, especially if they are “different” from their classmates or relatives.

Growth in childhood is crucial for growing into productive adults. Poor weight gain or failure to thrive may result in decreasing the child’s ability to obtain his/her full potential with regard to height and cognitive ability.

	TPN	FORMULA	
		Standard	Pre-digested
Average cost per month for 1st year	\$10,000-15,000	\$300	\$1,500

Unfortunately, many commercial insurance carriers will not cover the cost of enteral therapy because the commercial pediatric formula is considered a “medical food,” effectively limiting the patient’s treatment options to the more expensive and more toxic pharmacologic option. The Patient & Providers for Medical Nutrition Equity Coalition calls on Congress to address this issue by passing the bi-partisan Medical Nutrition Equity Act.

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CASE STUDY

Diego is a happy and thriving 9-year-old boy from Chicago, IL with a history of intestinal atresia. This means that part of his intestine did not develop before he was born. He was on total parenteral nutrition (TPN), nutrition through his vein, for a few years. He was then transitioned to just nutrition through a feeding tube in his stomach when he was 3 years old. Once he started receiving all of his nutrition through a feeding tube, his central line was removed, thus eliminating the risks of life threatening blood infections. When he was receiving state medical insurance, his formula was covered. However, his father got a new job and was then able to place the family on his private insurance through his employer, but the new insurance carrier will not cover his medical food. The cost of the food is approximately \$1,000 dollars each month. This has a significant impact on his family. Diego was tried on a home-made blenderized diet, but he was unable to gain weight for more than one year. Now his mother has been paying for some of the formula to help with his growth. His mother was recently able to receive a \$4,000 grant to help pay for his medical food. This is a temporary solution that will soon run out.

Unlike adults, children are constantly growing and developing, especially their brains. If children are unable to receive the right amount of nutrients, their growth can be delayed and they may not be able to learn as well as their other counterparts.

Diego depends on medical nutrition to keep him healthy and growing. He, and children like him across the country, are depending on YOU to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of the bill sponsors (find them at nutritionequity.org/leads) to co-sponsor.