



# HOW COVERAGE OF MEDICAL FOODS CAN SAVE LIVES & COSTS

## LIVER DISEASE IN CHILDREN

A number of liver diseases affect children. While some conditions are treatable and potentially reversible, many result in chronic liver disease and require transplantation.

The incidence of chronic liver disease in children is unknown but relatively rare. For example, biliary atresia (the most common reason for liver transplantation in children) occurs in roughly one in 10,000 to 20,000 live births.

The liver performs a number of important roles in the body, including filtering or detoxifying the blood; producing or digesting nutrients (like fats, proteins, and sugars); and storing those nutrients to release in the body as needed. The liver primarily eliminates toxins and other materials through the production and subsequent release of bile into the intestines. Bile also plays an important role in absorbing certain fats and vitamins (A, D, E and K) from food.

Therefore, when bile production is altered or if bile cannot be excreted (like with chronic liver disease), children develop fat and vitamin deficiencies. Possible symptoms or complications of these deficiencies include diarrhea, poor growth, rashes, poor wound healing, a weakened immune system, excessive bleeding, broken bones, and neurologic deficits, among others.

These complications can be prevented, however, with vitamin replacement therapy and specialized nutrition. Specific formulas (such as Pregestimil) contain a high percentage of medium chain triglycerides (MCT), a fat that can be absorbed in the intestine without bile. In fact, MCT is the only fat that can be absorbed this way; it is for this reason specialized formulas with high MCT concentrations are used in children with chronic liver disease.

These medical foods are critically important in preventing nutritional deficiencies and ensuring adequate growth. For children who need a liver transplant, in particular, nutrition is especially critical: better nutrition prior to transplantation results in fewer complications, a shorter hospital stay, and better outcomes.

**Unfortunately, many commercial insurance carriers will not cover the cost of Pregestimil and similar pediatric formulas because they are considered “medical foods.” This effectively forces the family to buy these expensive products out of pocket. The Patient & Providers for Medical Nutrition Equity Coalition calls on Congress to address this issue by co-sponsoring the bi-partisan Medical Nutrition Equity Act (S. 1194/H.R. 2587).**

## CASE STUDY

Josiah is an adorable baby boy who lives with his parents and older sister Middletown, New York.

His story starts like that of most babies, with a relatively uneventful birth. Though Josiah was jaundiced (a yellowing of the eyes and skin) in the nursery, his family was told it would go away – after all, nearly all babies experience some degree of jaundice – and he was discharged home with his family. But after about a month of waiting, Josiah’s jaundice remained and his worried parents sought additional medical help.

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Within days, Josiah was admitted to the Children’s Hospital at Montefiore (Bronx, New York) and had met enough doctors to last a lifetime. But after a liver biopsy and whirlwind of testing, his doctors eventually gave the family a diagnosis: biliary atresia.

Biliary atresia is a condition in which the bile ducts (the “tubes” which carry bile from the liver to the intestine) are underdeveloped or absent. The exact cause of biliary atresia is unknown. But because bile cannot be excreted through the ducts, it accumulates in liver cells, causing progressive inflammation and scarring.

Children with biliary atresia typically have surgery (called a hepatoportoenterostomy, or Kasai procedure) in an effort to save the liver from this irreversible damage. Unfortunately, Kasai procedures are often unsuccessful and Josiah’s procedure, like most, didn’t work. Now, at 8 months of age, he is waiting for a liver transplant.

Despite all of their hardships, one of the greatest challenges Josiah’s parents face is something most of us take for granted: feeding their baby. Because of his chronic liver disease, Josiah requires specialized formula in order to absorb a sufficient amount of fat. The first formula the doctors prescribed, Pregestimil, tasted horribly and Josiah routinely refused bottles. His weight suffered and, for a brief period of time, he needed a nasogastric tube (a tube going from the nose to the stomach) to gain weight. He improved somewhat on a slightly more palatable formula, Alimentum, but was not able to tolerate the extra fat (called MCT oil) his doctors prescribed.

Nutrition in children with chronic liver disease is critical. It is well documented, for example, that infants who are larger and have a better nutritional status at the time of their transplantation have better the outcomes (a higher likelihood of a successful surgery and lower likelihood of complications).

Josiah’s special formula costs approximately \$450 a month – this is in addition to several hundred dollars of co-payments for prescription medications. Despite having good commercial insurance through his father’s work, it took the family months of appeals, several letters of medical necessity from the doctors, and even several phone calls from the hospital for the insurance company to pay any of the formula costs. In this sense, Josiah is lucky; the overwhelming majority of specialized formulas are considered “medical foods” and therefore not covered at all by insurance.

Josiah depends on medical nutrition to keep him healthy and growing prior to his liver transplant. He, and children like him across the country, are depending on YOU to co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587). Please contact the offices of Senator Grassley, Senator Casey, Representative Herrera Beutler or Representative Delaney today.