

James DeLano is a 12-year-old boy who has lived his life with rare, chronic disease. As a young child, James was diagnosed with an eosinophilic gastrointestinal disease and inborn error of metabolism. Due to the many issues that his conditions caused to his digestive tract, James was prescribed medical foods (formula) at the age of 4 to ensure proper nutrition and help him to gain weight. Over the course of the next few years, James was to the point that he relied 100% on elemental formula. He eventually had a feeding tube inserted. James's formula was covered by private insurance through his father Jim's employer for a few years until the employer changed to insurance providers that did not provide coverage for the formula that James needed.

The DeLano family soon found themselves in the position of having to navigate the system by themselves to facilitate a plan exception from Jim's employer to get the formula coverage. Even after the exception was made, the family's claims for coverage continued to be denied. "I was spending at least 12 hours each week filing claims, addressing denials, researching, and providing information to the insurance company and the employer," shares James's mother, Victoria. "It was time away from a sick child who desperately needed that quality time with us, and we needed to devote that time to him. But we simply couldn't afford to pay an estimated \$1,500 a month on formula." "Due to the volume of formula needed to keep James alive, we could not buy it off the shelf from a store. We had to go through a medical supply company, and you cannot self-pay there. It was frustrating."

It was then that Jim made a drastic decision – to leave the job he had for more than 20 years so that he could find an employer with health benefits that covered the special formula his son needed. "We worked to have a special plan exception made for formula coverage through Jim's new employer," Victoria said. "We were excited that coverage seemed to be falling into place, but our heart sank when our first claim was denied through the new insurance company. It was back to the drawing board, fighting the denials and providing the same documentation over and over again. Although it has settled now, we live each day with uncertainty and fear about formula coverage in the future. James depends on it for survival." "What would it mean to our family to have federal legislation that provided consistent coverage of medical foods like elemental formula prescribed for eosinophilic gastrointestinal diseases? It would mean health stability for our son. It would mean financial stability for my family. It would mean that my husband would be free to pursue whatever professional opportunities he wishes, without having to factor in whether or not the employer's insurance plan would cover the therapy prescribed to our son."