

A Closer Look: Coping with Food Allergies

By Mary Levis, N.C.S.P., CdLS Foundation Clinical Advisory Board Member and mother of Josh

Josh was diagnosed with CdLS when he was four years old. Once he was diagnosed, we contacted the CdLS Foundation, and one of the first newsletters we received highlighted silent reflux. So many of the symptoms described were similar to what Josh was experiencing, so we met with a pediatric gastroenterologist at Johns Hopkins Hospital. Josh was diagnosed with reflux, treated with medication, and had regular follow-ups. However, he continued to have changes and irritation in his esophagus and stomach, so he underwent a Nissen Fundoplication when he was six.



Josh with family members

Despite this procedure, Josh continued to suffer many symptoms of gastritis and did not progress nutritionally as hoped. He was found to be lactose intolerant. He followed a lactose-free diet, but he was still nutritionally at great risk.

By the time he was 10 years old, Josh was seriously undernourished and had very poor energy. At this point, his doctors recommended that a feeding tube be placed. Since he had so many eosinophiles (white blood corpuscles) in his esophagus, food allergies were suspected. We began a course of an amino acid-based formula (Vivonex T.E.N.) through the feeding tube.

The plan was to reintroduce foods gradually to discover what he was allergic to. The feeding tube was supposed to be temporary until the allergens could be identified. We discovered Josh is allergic to casein (milk protein) as well as lactose (milk sugar). Additionally, he is highly allergic to certain shellfish, in particular mussels, oysters and scallops.

Today, Josh is 26 years old and still using the Vivonex T.E.N. for supplemental nutrition. Each time we have tried to wean him off these feedings, his weight and health has declined dramatically. Josh carries a list of the foods he needs to avoid so that when he goes grocery shopping or is at a friend's house, he can inspect the labels of the food before he eats it. He manages this quite well independently and continues to progress and be healthy.