

James Ciannello's Story



James Ciannello is 14 years old and has been living with many medical issues since birth where he presented with feeding difficulties, reflux, and allergies.

James was diagnosed with Eosinophilic Esophagitis (EoE) at 11 months old. Eosinophilic Esophagitis is a Gastroenterology/ allergic inflammatory disorder where his esophagus becomes inflamed as a result of too many eosinophils. His body interprets food as a foreign invader and attacks it with eosinophils which cause scar tissue and damage to the GI tract as well as many unpleasant daily side effects. Eosinophils are a type of white blood cells. This disorder causes James to have a limited diet, currently he can safely eat 6 foods. When we introduce a new food to James, one food is usually eaten for about 2 weeks to watch for a reaction both allergic and from an EE standpoint. We usually do about 2 or 3 foods and then James will have an Endoscopy with biopsies. He has had 23 endoscopies to date. Unfortunately, eosinophils are only able to be seen under a microscope and at present time, the only true test for diagnosis/management is an Endoscopy. Due to the limited diet, James had a feeding tube surgically put in when he was 4 years old and has been supplementing elemental based formula since then.

James also has Common Variable Immune Deficiency (CVID) His body makes very few of his own antibodies. Antibodies fight off infection. This makes James susceptible to getting sick easily. He receives IVIG every 3 weeks, which is

human plasma that infuses antibodies to help keep him stay infection free. This is about a 3-hour infusion he receives through his port every 3 weeks.

James lungs are very complex and remain a daily source of struggle for him. He has severe asthma, exercise induced asthma, bronchiectasis, arytenoid prolapse, laryngomalacia, vocal cord dysfunction, and small volume lung aspiration which he had surgically corrected in March 2015 but was left with some unpleasant side effects causing some new issues. James sometimes requires the use of oxygen at home, frequent breathing treatments, averaging 7 to 10 times in 24 hours and still struggles to breath daily. He is currently involved in a trial medication for his lungs.

James has had about 40 hospital admissions over the years between Children's Hospital of Philadelphia, Robert Wood Johnson, National Institute of Health, and National Jewish Health. He's undergone general anesthesia about 30 times for medical procedures and 4 surgeries. He currently remains allergic to more than 60 foods/medications.

We continue to seek the best care, research, and trials out there for James in hope of improving his quality of life. Our family never takes a day for granted.

