



# Complex Child E-Magazine

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## Life Without Food: Living with an Eosinophilic Disorder

by Barbara Cullens Crosby

Imagine the smell of mom's homemade chocolate chip cookies when you came home from school. Imagine the sweet, cool treat of homemade ice cream on a hot summer day. Now imagine never being able to eat food again! This is the reality of many children and adults living with Eosinophilic Disorders.



Imagine not eating birthday cake at your own birthday party because to do so would make you so sick, but instead watching your friends enjoy it because so much of our society's culture revolves around food. Think about the worst case of food poisoning or stomach flu you've had, and imagine that is the way you would feel every time you eat! Imagine living like this, isolated from so many everyday activities that the rest of us take for granted...no class parties, no holiday dinners, no dinner dates, no popcorn and movie nights...no food!

Can you imagine a life without food? This is the reality we face. Our son was diagnosed with a type of rare Eosinophilic Gastrointestinal Disease (EGID) at the age of thirteen months. He will turn two later this month. Although there will be a big party to celebrate

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the occasion, my son will get to have his special medical formula and some ice chips for his treat.



Eosinophilic Disorders occur when there is a malfunction within the immune system that causes the body to mistake foods for parasites, causing eosinophils, a type of defensive white blood cell, to attack different parts of the body. These disorders can have effects on every part of the digestive tract, and can lead to symptoms including the following:

- Severe abdominal and chest pain
- Vomiting
- Diarrhea
- Chronic debilitating pain
- Choking
- Inability to swallow
- Organ damage within the digestive tract
- Anemia
- Malabsorption
- Developmental delay
- Bleeding
- Seizures (rarely)

Many people also experience nutritional deficiencies and/or side effects from medications, such as neuropathy (nerve damage) or osteoporosis (decrease in bone mass).

There is no cure for EGIDs and very little treatment available. Most treatment is in the form of elimination diets, removing certain foods from the diet that trigger an immune

response. For some, like our son, any and all foods trigger a response, and these children cannot have any food. Our son survives on a medically prescribed, amino acid based formula. We are fortunate that he tolerates this and is currently able to get enough formula by mouth, but many patients on formula must have a feeding tube surgically implanted in order to get enough formula to survive.

EGIDs are relatively rare, although their incidence rates are rising. Because of the rarity of these disorders, finding adequate medical care is difficult. There is also currently no federal funding for research into these devastating diseases.

One of the most difficult aspects of dealing with a rare disease is that it makes it harder on the families because the people around them have never heard of the disease. They do not understand the debilitating sickness and pain that goes along with a diagnosis of EGID. They don't understand why you can't eat certain foods or cannot have any food at all. They don't understand how someone who looks just like you and me and appears healthy could really be so sick.

Our ultimate goal is to find a cure for these devastating diseases, but for now I am focused on raising awareness in our community so that my son doesn't have to feel alone, isolated or different because he can't eat. As we garner enough awareness, eventually the National Institute of Health will fund research and we WILL find a CURE. But until then, I'll love my precious son with all my heart and fight with all my strength to ease his pain, helping him thrive physically and emotionally in a world that revolves around food.

If you would like to find out more about Eosinophilic disorders and what you can do to help, please visit [www.apfed.org](http://www.apfed.org) or [www.curedfoundation.org](http://www.curedfoundation.org)