ABOUT APFED
Founded in 2001, the American Partnership for Eosinophilic Disorders (APFED) is a 501(c) 3 nonprofit organization dedicated to supporting patients and families affected by eosinophil-associated diseases. Our work is funded by donations, grants, and membership dues.

EDUCATION AND AWARENESS
APFED is the number one source of patient education for eosinophil-associated diseases. Apfed.org offers fact sheets, toolkits, downloads, and recorded webinars. Our patient conferences bring together patients and families to learn from leading clinicians and scientists about disease management, promising research, and to interact with one another. We raise disease awareness through a variety of platforms, and successfully led efforts to have the third week of May officially recognized as National Eosinophil Awareness Week.

SUPPORT
We are here for patients who have questions or need to talk to someone who “gets it.” Our online community on the Inspire Network (apfed.inspire.com) connects thousands of patients and caregivers around the globe for peer-to-peer support. Our patient conferences offer families the opportunity to connect in person.

RESEARCH
APFED’s Hope on the Horizon Research Grant Program provides grants to investigators to pursue unique research ideas and collect preliminary data that may be used to apply for larger grants. We work with federal agencies to ensure the research needs of patients with eosinophil-associated diseases are met, we serve as collaborating partners of the Consortium of Eosinophil Gastrointestinal Disease Researchers (CEGIR), and we work with research teams and industry to advise on research protocols and trial recruitment.

ADVOCACY
We advocate for improved and affordable access to medical care and treatment, including state and federal legislation for the insurance coverage of medical foods, such as amino-acid based formulas to treat eosinophil gastrointestinal diseases (EGIDs). We also successfully advocated for the establishment of EGID diagnostic codes and continue to advocate to have them established for subsets of eosinophil-associated diseases that do not have a code.

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HELP US TO HELP OTHERS
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HOW YOU CAN HELP
Join the Eosinophil.Connect Patient Registry

Patient registries connect patients who need a cure with the researchers who are working on one. These registries are vital to research because they help speed up the discovery process. Your participation in the Eosinophil.Connect patient registry will give investigators a better understanding of disease characteristics to pinpoint areas that need more study, and it will help pharmaceutical companies to develop improved treatments.

To learn more and to register, visit: https://connect.patientcrossroads.org/?org=apfed

EOSINOPHILIC ESOPHAGITIS (EoE)

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Eosinophilic esophagitis (EoE) is a chronic, allergic inflammatory disease that occurs when there is an increased number of eosinophils in the esophagus (the tube connecting the mouth to the stomach). Eosinophils are a type of white blood cell that help fight parasite infections and are involved in allergic reactions. They are not normally found in the esophagus, although they may be found in small numbers in other areas of the gastrointestinal tract. Gastroesophageal reflux disease (GERD), drug reaction, and inflammatory bowel disease (Crohn’s disease) can also cause elevated numbers of eosinophils. The eosinophils cause injury to the surrounding tissues.

People with EoE often have other allergic conditions such as nasal and eye/ocular allergies, asthma, anaphylactic food allergies, and/or eczema. EoE can be associated with conditions such as nasal and eye/ocular allergies, asthma, drug reaction, and inflammatory bowel disease. Gastroesophageal reflux disease (GERD) may be found in small numbers in other areas of the gastrointestinal tract. Gastroesophageal reflux disease (GERD) is a condition where the LES (sphincter muscle that separates stomach and esophagus) is not functioning properly. Gastroesophageal reflux disease (GERD) can lead to serious complications if not treated, such as severe heartburn, esophageal strictures, and Barrett's esophagus.

WHAT ARE THE SYMPTOMS OF EoE?

Common symptoms of EoE include:

- Reflux
- Difficulty swallowing
- Food impactions (food gets stuck in the esophagus)
- Nausea and vomiting
- Failure to thrive (poor growth, malnutrition, or weight loss)
- Abdominal or chest pain
- Feeding refusal/intolerance or poor appetite

HOW IS EoE DIAGNOSED?

To diagnose EoE, a gastroenterologist will perform an upper endoscopy. This procedure is typically not uncomfortable and can be done on an outpatient basis. During this procedure, the patient is sedated or put under anesthesia, and a small tube called an endoscope is inserted through the mouth. The esophagus, stomach, and the first part of the small intestine are examined for tissue injury and inflammation, and the esophageal wall is examined for thickening. A patient may have EoE even if the esophagus looks normal during endoscopy. Small tissue samples are taken (biopsies) for a pathologist to analyze under a high-powered microscope. If eosinophils are present in the samples, the pathologist will count how many are visible. Increased numbers of eosinophils (usually >15 eosinophils per high-powered microscopic field) is highly suggestive of EoE.

An endoscopy with the biopsies is the only reliable method of diagnosing EoE at this time, although less invasive diagnostic and monitoring methods are currently under investigation.

HOW IS EoE TREATED?

Currently, there are no FDA-approved drugs indicated for the treatment of EoE. The two main treatments recommended are diet management and medications that were approved to treat other conditions, such as swallowed topical corticosteroids (fluticasone or a budesonide mixture/slurry), and proton pump inhibitors (acid suppressors). A combination of these therapies may be recommended. Repeat endoscopies with biopsies are needed to monitor the effectiveness of the treatment plan.

Diet management may include:

- **Common allergen elimination diet** – Common allergy-causing foods (milk, egg, soy, wheat and, at times, other foods such as shellfish, fish, peanuts/tree nuts based on current studies) are removed from the diet, rather than using food allergy test results to determine which food(s) to remove.
- **Elemental diet** – All sources of protein are removed from the diet and the patient drinks only an amino acid formula. Sometimes, a feeding tube may be required.
- **Food trial** – Specific foods are removed from the diet, and then added back, one at a time, to determine which food(s) cause a reaction.
- **Directed elimination diet** – Food allergy testing is used to direct which foods to remove from the diet. While this may help guide food trials and/or evaluate for IgE reactions, empiric allergen elimination diets are more often used for EoE.

Medications may include:

- **Topical steroids** – Swallowed from an asthma inhaler or mixture, to control inflammation and suppress the eosinophils.
- **Proton pump inhibitors (PPIs)** – May help reduce inflammation and control acid production.

DO ADULTS GET EoE?

EoE affects the entire age spectrum, from infants to adults. Some adults have had symptoms since childhood and are diagnosed later in life, and others first develop symptoms later in life. Adults are more likely to have problems with food “sticking” in the throat (food impactions). Medications are more commonly used to treat adult patients.

LIVING WITH EoE

The initial diagnosis of EoE can be overwhelming. It is almost always a chronic and lifelong disease, but with proper ongoing care and treatment, individuals with EoE can lead a normal life. EoE does not appear to limit life expectancy and data does not suggest EoE causes cancer of the esophagus.

The challenges of living with EoE vary, depending on the severity of illness and other factors. The following tips will help:

- **Become knowledgeable**
- **Find a supportive community; connect with others, ask for help, and learn from one another**
- **Take along safe foods when you leave home**
- **Communicate your needs to restaurant staff and caregivers**
- **Organize parties, gatherings, and activities that don’t involve food**

Continue your therapy and follow up with your doctor, even when you feel well since untreated EoE can cause strictures (scar tissue that forms as the result of chronic inflammation). Be sure you know how to use prescribed medications in terms of dosing, mixing, timing, and administration.