

## Eosinophil-Associated Gastrointestinal Disorders (EGIDs)

Apfed

American Partnership for Eosinophilic Disorders

*Connecting the Eosinophilic Community*

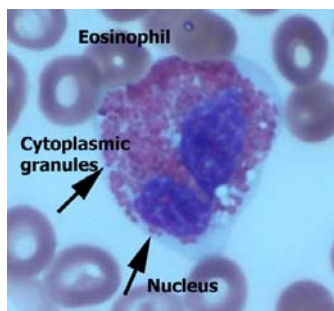
### Origin of APFED

The diagnosis of Eosinophilic Disorders, once considered rare, has risen dramatically. However, many families still experience a delay in obtaining a correct diagnosis, appropriate treatment, or even up to date information on these disorders. This prompted mothers of children with eosinophil-associated gastrointestinal disorders to take action, and in 2001 APFED was created in an effort to connect and assist other families affected by eosinophilic disorders. Since then, APFED's membership has grown to include both children and adults affected by eosinophilic esophagitis, eosinophil-associated gastrointestinal disorders, hypereosinophilic syndrome, and Churg-Strauss Syndrome. APFED is a 501(c) 3 nonprofit organization dedicated to patients and their families coping with eosinophilic disorders. Our mission is to provide **Education, Awareness, Support and Research to patients with these diseases and to physicians who care for them.**

Our education and awareness efforts are made possible by educational grants from the American Academy of Allergy, Asthma and Immunology and the American College of Allergy, Asthma & Immunology. We are also indebted to our Medical Advisory Board for their continued support.

### What is an Eosinophil?

**Eosinophils**, a type of white blood cell, are an important part of the immune system, helping us fight off certain types of infections, such as parasites. Many different problems can cause high numbers of eosinophils in the blood including allergies, parasitic infection, eosinophil associated gastrointestinal disorders, leukemia, and other problems. When eosinophils occur in higher than normal numbers in the body, without a known cause, an eosinophilic disorder may be present. Eosinophil disorders are further defined by the area affected. For example, eosinophilic esophagitis means elevated numbers of eosinophils and inflammation in the esophagus.



*Eosinophil, Courtesy of Dr. Margaret Collins*

### What are Eosinophilic Gastrointestinal Disorders (EGIDs)?

EGIDs are a relatively newly recognized group of diseases that over the past decade have been increasingly diagnosed in children and adults. This increase is thought to reflect an increase in diagnosis as well as a true increase in EGID cases, particularly an increase in EGID affecting the esophagus. Fortunately, the medical community is responding and new scientific information is

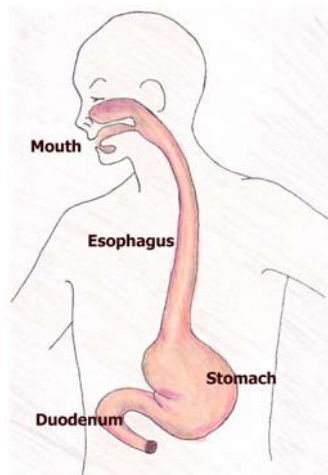
emerging to guide management of this disorder, which often persists with ongoing or recurrent symptoms. A recent publication of diagnostic criteria was supported by APFED.

EGIDs affect people of all ages and ethnic backgrounds. Males are more commonly affected than females. In certain families, there may be an inherited (genetic) tendency. A variety of stimuli may trigger this abnormal production and accumulation of eosinophils, including certain foods.

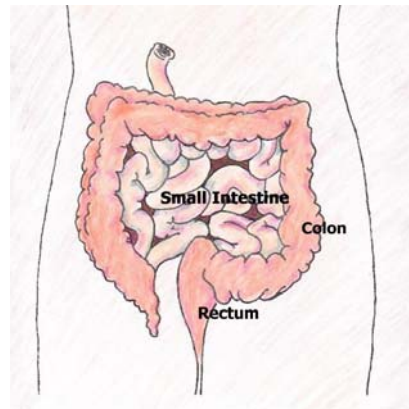
Eosinophil disorders are further defined by the area affected. For example, eosinophilic esophagitis (-itis means inflammation) means elevated numbers of eosinophils and inflammation in the esophagus.

- **Eosinophilic Esophagitis (EE)** involves only the esophagus. EE is the most frequently diagnosed EGID. Recently, there has been a large increase in published research on EE.
- **Eosinophilic Gastritis (EG)** means eosinophils infiltrating the stomach.
- **Eosinophilic Gastroenteritis and Eosinophilic Enteritis** affecting the stomach and/or the small intestine.
- **Eosinophilic Colitis (EC)** describes the occurrence of high levels of eosinophils in the large intestine.

Eosinophils are not normally present in the esophagus, although they may be found in small numbers in other areas of the digestive tract. While diagnostic criteria exist for EE, the exact criteria for other EGIDs have not been well characterized. Diseases other than EGID can cause eosinophils in the digestive tract including gastroesophageal reflux diseases (GERD), drug allergy (hypersensitivity) response, and inflammatory bowel disease (Crohn's). The diagnosis of EGID is further described below.



*Upper gastrointestinal tract*



*Lower gastrointestinal tract*

### **What are the symptoms of EGIDs?**

Symptoms vary between individuals and also vary with the affected area of the digestive tract. Common symptoms include:

- Nausea and Vomiting
- Diarrhea
- Failure to thrive (poor growth or weight loss)

- Abdominal or chest pain
- Reflux that does not respond to medicines which block acid production
- Dysphagia (difficulty swallowing)
- Food impactions (food gets stuck in the esophagus)
- Gastroparesis (delayed emptying of the stomach)
- Poor appetite
- Bloating
- Anemia
- Blood in the stool
- Malnutrition
- Difficulty sleeping

#### How are EGIDs **diagnosed**?

At present, the only way to definitively diagnose EGID is through endoscopy with biopsies (upper endoscopy and/or colonoscopy, depending on symptoms). The endoscopy may be performed after treatment with reflux medications (acid suppressors) have failed to relieve the symptoms. During an endoscopy, the gastroenterologist looks at the lining of the gastrointestinal tract through an endoscope (small tube) and takes multiple biopsies (small tissue samples) which a pathologist reviews under the microscope. The gastroenterologist may be able to see a problem through the endoscope, but an EGID may be present even if the digestive tract looks normal to the doctor. That is why the biopsy samples are important to making the diagnosis of EGID. GERD also causes eosinophils in the esophagus, but typically far fewer and only in the part of the esophagus closest to the stomach. The pathologist will also look for injury, inflammation, and thickening of the tissue in the digestive tract.

Once the diagnosis of EGID is confirmed, food allergy testing may be recommended to guide treatment. Skin prick testing to different foods is the most common type of allergy testing.

**Treatments will vary according to which part of the digestive system is affected.**

#### **Treatment**

At present, the two main treatments recommended are dietary management and medications. Dietary therapy typically is guided by a comprehensive allergic evaluation to foods and aeroallergens.

#### Dietary Therapy

Treatments vary with different individuals and with different areas of the digestive tract. Many children and adults with EGID (especially EE) respond favorably to dietary treatments. Dietary treatment may include:

- **Elimination** diets, in which all 'positive' foods on allergy testing are removed from the diet, may be the only treatment needed for some individuals with EGID.
- **Six-food elimination diet** is another type of elimination diet that has shown success in some EGID patients. Instead of basing dietary elimination on skin testing, patients eliminate the top 6 most allergenic foods (dairy, eggs, wheat, soy, peanuts/other nuts, fish/shellfish).
- **Elemental diets**, in which all sources of protein are removed from the diet, are another dietary therapy. An elemental diet includes only an amino acid formula (building blocks of protein), no whole or partial proteins. Simple sugars, salt and oils are permitted on an elemental diet. Because these formulas are not palatable, the use of a strict elemental diet may require a feeding tube. Amino-acid based formulas are very expensive and are only



sometimes covered by health insurance. Elemental diets are effective in treating many individuals with EGID.

- **Food trials** involve adding back one ingredient at a time to one's diet to determine specific foods causing a reaction. Food trials begin after symptoms resolve and eosinophils have cleared. Food trials are handled differently by different professionals, but may involve repeat endoscopies with biopsies as foods are introduced to determine which foods are 'safe' for an individual.

### Medications

Medications for EGID most commonly include steroids to control inflammation and suppress the eosinophils. Steroids can be taken orally, intravenously, or topically (swallowed asthma medicine). Other medications, especially anti-inflammatory drugs, also are used to treat certain types of EGID. Acid suppressors may also help symptoms in some patients who also have gastroesophageal reflux disease.

### **EGID requires ongoing care**

Patients with EGID may require additional endoscopies to assess how the digestive tract is responding to specific treatment. Physicians and scientists are working to discover other methods of monitoring and diagnosis. Novel medicines are also being tested that may help with future management of EGID.

### **Prognosis**

EGID does not appear to limit life expectancy. Untreated EGID may lead to malnutrition, poor growth and anemia. In some patients, EE is complicated by the development of esophageal narrowing (strictures) which may cause food to lodge in the esophagus (impaction). It is not clear how long EE has to exist before strictures form. However, since knowledge about the natural history of EGID is only emerging, careful monitoring and long-term follow-up is advised. The initial diagnosis of EGID can be overwhelming and often affects the entire family. A positive attitude and a focus on non-food activities go a long way in learning to live with EGID. With proper treatment, individuals with EGID can lead a normal life.

### **About APFED**

American Partnership for Eosinophilic Disorders (APFED) is a non-profit organization dedicated to patients and their families coping with eosinophilic disorders. Our mission is to provide **Education, Awareness, Support** and **Research** to patients with these diseases and to the physicians who care for them.

All medical information is reviewed for accuracy by our medical advisory board. For more information on eosinophilic disorders, or to find out information about our annual education conference for patients, visit [www.apfed.org](http://www.apfed.org). Our educational efforts would not be possible without an educational grant from the American Academy of Allergy, Asthma and Immunology and the American College of Allergy, Asthma & Immunology and the support of our Medical Advisory Board.



Membership Application  
American Partnership for Eosinophilic Disorders  
Connecting the Eosinophilic Community

Please print clearly

Name: \_\_\_\_\_ Phone number (\_\_\_\_) \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ Zip: \_\_\_\_\_

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\_\_\_\_ I would like to become a member \_\_\_\_ \$30 US \_\_\_\_ \$45 Canada \_\_\_\_ \$55 International

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\_\_\_\_ I would like to make a tax-deductible donation \_\_\_\_ \$50 \_\_\_\_ \$100 \_\_\_\_ \$250 \_\_\_\_ \$500 \_\_\_\_ \$1000  
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Please send the completed application, with check or money order to: **APFED 3419 Whispering Way Drive Richmond, TX 77469** or enroll online at [www.apfed.org](http://www.apfed.org) "Join APFED"