EGID PARTNERS

Welcome!

We are EGID Partners, an **online registry for people with eosinophilic gastrointestinal diseases, also called EGIDs**. Patient advocacy groups and researchers created EGID Partners together. Our goal is to help improve what we know about EGIDs. We also want to support people living with these conditions.

www.egidpartners.org

Please scan here to learn about EGID Partners and how to get involved.

We have created this packet to provide you with basic information about EGIDs, helping you stay informed and educated about this condition. **This packet will help you learn**:

- ✓ What EGIDs are
- ✓ How EGIDs are diagnosed
- ✓ Treatment options
- ✓ Helpful resources

This packet does not replace medical advice. Please talk with your doctor about your own health questions or concerns.

Wake Forest University School of Medicine

UNC SCHOOL OF MEDICINE

SECTION 1:

What are EGIDs and how common are they?

Eosinophilic gastrointestinal diseases (EGIDs) are chronic conditions that affect the digestive system. EGIDs occur when too many eosinophils, allergic cells and inflammatory cells build up in the digestive system. Eosinophils are a type of white blood cell that is also involved in allergies. There are many symptoms you might experience depending on the location in the gastrointestinal tract that is affected. Details about symptoms are in the next section.

EGIDs are named based on the part of the digestive tract they affect:

- Eosinophilic Esophagitis (EoE): Affects only the esophagus. The esophagus is the tube that carries food from the mouth to the stomach.
- Eosinophilic Gastritis (EoG): Affects the stomach. The stomach connects the esophagus to the small intestine and helps break down food.
- Eosinophilic Enteritis (EoN): Affects the small intestine. The small intestine connects the stomach to the large intestine and helps absorb nutrients. The small intestine has three parts:
  - Duodenum (EoD) – The first part of the small intestine, closest to the stomach.
  - Jejunum (EoJ) – The middle part of the small intestine.
  - Ileum (EoI) – The last part of the small intestine, closest to the large intestine or the colon.
- Eosinophilic Colitis (EoC): Affects the colon or large intestine, which helps the body get rid of waste.
- Multi-Segment Disease: Affects more than one part of the digestive tract.
  - Examples: EoG + EoN; EoE + EoG

EGIDs are often grouped into two types: EoE and non-EoE EGIDs.

EoE is better understood than non-EoE EGIDs. There are more educational resources, diagnostic and treatment guidelines, and FDA-approved treatments for EoE. EoE was once considered rare, but it now affects about 1 in 700 people in the United States.

Non-EoE EGIDs is a rare disease and is still being studied. Together, non-EoE EGIDs affect about 3 to 7 out of every 100,000 people.

Interested in learning more?

Below is a link to published research in *Gastroenterology* that describes in more detail what we know about EoE and non-EoE EGIDs, as well as general overviews from APFED and the CURED Foundation:

gastrojournal.org/article/S0016-5085(25)06042-1/fulltext#fig1
apfed.org/about-ead/egids/
curedfoundation.org/egids/

Eosinophil

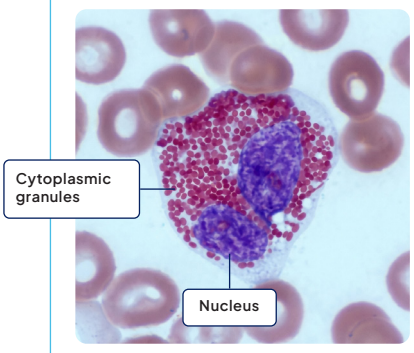


Figure from American Partnership for Eosinophilic Disorders (APFED).

Figure 1. A view of a normal eosinophil, seen in the blood and surrounded by much smaller red blood cells.

Digestive Tract

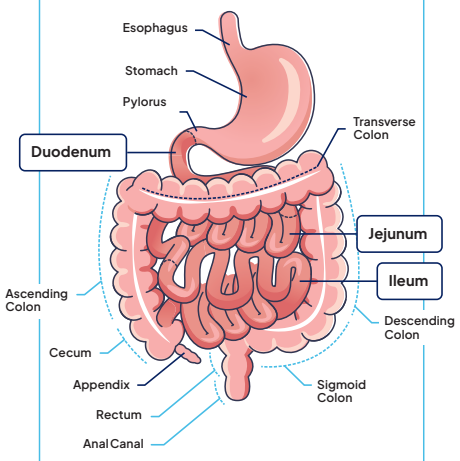


Figure from American Partnership for Eosinophilic Disorders (APFED).

Figure 2. This figure shows a labeled anatomical diagram of the digestive tract.

SECTION 2:

What are the causes and symptoms of EGIDs?

The exact cause of EGIDs is not known. These conditions may be linked to how the immune system reacts to certain foods or other allergens. Allergens are things that can cause an allergic reaction.

EGIDs can start in childhood, adolescence, or adulthood. Some studies suggest that factors related to where a person lives, such as climate, air quality, or water quality, may play a role in EoE. However, more research is needed to better understand these connections.

The symptoms of EGIDs can be different for each person. They depend on which part of the digestive tract is affected. Common symptoms may include: trouble swallowing, feeding problems, nausea, vomiting, abdominal or stomach pain, cramping, bloating, diarrhea, constipation, weight loss.

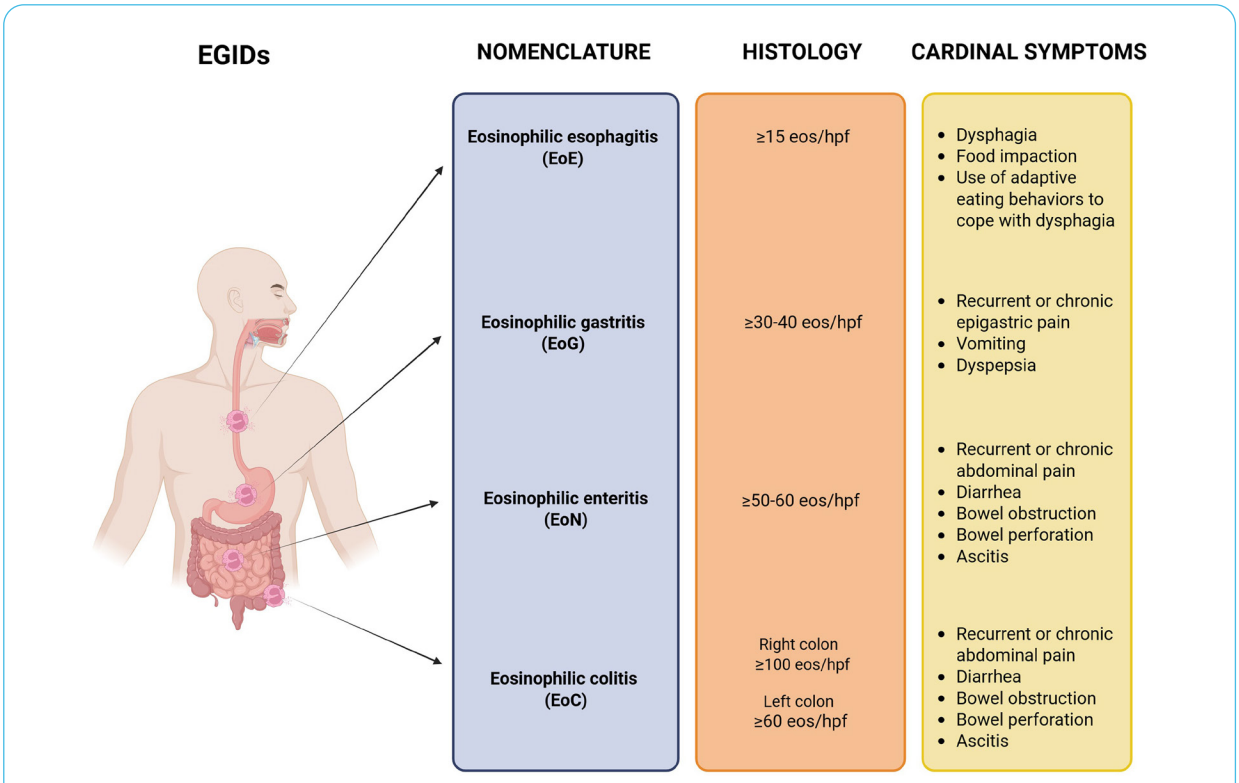


Figure 3. The figure above outlines the corresponding locations in the digestive tract, diagnostic histology criteria based on eosinophil counts, and the most common symptoms associated with each condition.

Interested in learning more?

Below are links to more details on what we know about the causes and symptoms of EoE and non-EoE EGIDs from the EOS Network – Eosinophilic Diseases Charity:

EoE Symptoms and Causes: eosnetwork.org/eoe-symptoms-and-causes
Non-EoE Symptoms and Causes: eosnetwork.org/eog-eon-eoc-eosinophilic-diseases-lower-gut

SECTION 3:

How are EGIDs diagnosed?

Getting a diagnosis of EoE or non-EoE EGIDs can take time. **Diagnosis may be delayed because**:

- Symptoms may be different from person to person
- Symptoms may change over time
- EGID symptoms can look like other common GI conditions or stomach problems
- Doctors may not suspect EoE or non-EoE EGIDs right away
- Doctors may check for other conditions first
- Tissue samples obtained during an endoscopy may have been taken from less-affected areas and show fewer eosinophils

Doctors have accepted diagnostic guidelines for EoE. Approaches for non-EoE EGIDs are still evolving and may vary among clinicians and institutions. Before making a diagnosis, doctors must ensure that a patient's symptoms and biopsy findings are not caused by another condition. **To diagnose an EGID, doctors look at**:

- Your symptoms
- Findings from your endoscopy
- Biopsy results showing higher-than-normal numbers of eosinophils

What to Know About an Endoscopy:

- An endoscopy is an important test used to help diagnose EGIDs and is performed by a gastroenterologist (GI doctor)
- It is not surgery
- It is an outpatient procedure, which means you can go home the same day
- You will be given medicine to help you sleep during the procedure
- You may have an endoscopy once a year so your doctor can check for changes related to EoE or non-EoE EGIDs

During an endoscopy, a doctor uses a thin, flexible tube with a camera and light, called an endoscope, to look inside the digestive tract. The doctor will take small samples of tissue from the digestive tract (called biopsies). These samples are checked to see if there are too many eosinophils. The biopsies are also examined under a microscope for other signs of disease that could be causing symptoms. In some cases, doctors may also use a scoring system to describe what they see, such as the Eosinophilic Esophagitis or Eosinophilic Gastritis Endoscopic Reference Score (EREFS and EG-REFS, respectively). The table below shows the eosinophil count criteria that GI doctors use when diagnosing EGIDs.

Criteria Numbers for Each EGID:	Nomenclature	Histology
	Eosinophilic esophagitis (EoE)	≥15 eos/hpf
	Eosinophilic gastritis (EoG)	≥30–40 eos/hpf
	Eosinophilic enteritis (EoN)	≥50–60 eos/hpf
	Eosinophilic colitis (EoC)	Right colon: ≥100 eos/hpf Left colon: ≥60 eos/hpf

Interested in learning more?

Below is a link to more details describing what we currently know about diagnosing EoE and non-EoE EGIDs from the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR):

cegir.rarediseasesnetwork.org/resources/researchers-clinicians/endoscopy-guidelines

SECTION 4:

How are EGIDs treated?

There is currently no cure for EGIDs. However, there are treatment options that can help. Treatment is not the same for everyone. Your treatment will depend on the type of EGID you have and your symptoms. Your doctor will recommend additional endoscopies to check if the treatment is working. This includes looking for signs of healing in the GI tract and improvement in biopsy results.

Treatments Sometimes Used for EoE:

- Food Elimination Diets
  - These types of diets focus on removing foods that may trigger EoE symptoms.
- Medicines:
  - Proton Pump Inhibitors (PPIs)
    - Examples: Esomeprazole, lansoprazole, omeprazole, pantoprazole, rabeprazole
  - Swallowed Topical Steroids
    - Examples: Budesonide oral suspension, fluticasone
  - Biologics
    - Example: Dupilumab
- Esophageal dilation
  - This procedure stretches the esophagus.
  - This may be done when the esophagus becomes narrow, making it hard to swallow or causing food to get stuck.

Treatments Sometimes Used for EoG, EoN, and EoC:

- Food Elimination Diets
- Medicines:
  - Topical steroids
    - These are made to coat the GI tract.
    - Example: Budesonide enteral release
  - Systemic corticosteroids
    - Example: Prednisone
  - Anti-inflammatory or immunomodulators
    - These medicines help reduce swelling and calm an overactive immune system.
  - Biologics
    - These medicines are still being studied.

Right now, there are no FDA-approved medicines in the United States specifically for EoG, EoN, or EoC. Medicines may be prescribed for these conditions "off label." This means they are FDA-approved for other conditions but a doctor may choose to use it for an EGID based on their medical judgment and the best available evidence.

Interested in learning more?

Below are links to more details describing what we currently know about treating EoE and non-EoE EGIDS from Apfed:

EoE: apfed.org/about-ead/egids/eoe/
EoC: apfed.org/about-ead/egids/ec/
EoG and EoN: apfed.org/about-ead/egids/eg/

SECTION 5:

Where to go for support?

Patient Advocacy Groups (PAGs) support people living with EGIDs and their families. These groups bring together patients, caregivers, doctors, and researchers. They help improve care, raise awareness, and build community. **PAGs may offer**:

- Support: Connect with others who understand EGIDs
- Education: Learn about your diagnosis, treatments, and daily life with EGIDs
- Advocacy: Support better access to care, insurance coverage, and research funding
- Funding for Research: Help partner with experts and support studies that can lead to better understanding of EGIDs
- Community: Offer events, conferences, and online groups to keep you connected

EGID PAGs:

U.S.-Based Patient Advocacy Groups

American Partnership for Eosinophilic Disorders (APFED)

APFED supports people living with eosinophil-associated diseases. This group offers patient education, research funding, advocacy, and community support programs. APFED also offers educational webinars, a podcast series, and virtual support group meetings. The organization hosts an annual patient education conference featuring medical experts, research updates, and opportunities to connect with others navigating EGIDs.

Website: apfed.org

Facebook Page: facebook.com/APFED

Campaign Urging Research for Eosinophilic Disease (CURED)

CURED was founded by a family affected by EGIDs. This group supports research, raises awareness, and funds scientific studies. They also host national conferences and events for patients, families, and clinicians. CURED's annual EGID research conference and patient education program includes a teen program for ages 13 and older.

Website: curedfoundation.org

Facebook Page: facebook.com/curedfoundation

Support Group: facebook.com/groups/5735651 2284/

Eosinophilic Family Coalition (EFC)

EFC supports families affected by EGIDs. This group offers events, education, and resources. They partner with CEGIR and offer teen and family focused programs such as Camp Courageous ("EOS"). EFC also organizes Mom's Night Out and the CAPES program. The CAPES program supports youth with EGIDs and engages teens in awareness and community building activities.

Website:
eoscoalition.org

Facebook Page:
facebook.com/Eosfamilyco

Other Support Groups

Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR)

CEGIR is a research group supported by the National Institutes of Health (NIH) to improve the understanding and treatment of EGIDs. Their work includes major clinical trials and close partnerships with advocacy groups.

Website:
cegir.rarediseasesnetwork.org

There are also **international patient advocacy groups** that support patients with EGIDs, such as **EOS Network** in the United Kingdom, **ausEE Inc.** in Australia, **AEDESEO** in Spain, **ESEO Italia** in Italy, and others.

References

American Partnership for Eosinophilic Disorders (APFED) – EGIDs Overview
https://apfed.org/about-ead/egids/ec/
https://apfed.org/about-ead/egids/eg/
https://apfed.org/about-ead/egids/eoe/

Cleveland Clinic – Endoscopy Overview
https://my.clevelandclinic.org/health/diagnostics/25126-endoscopy

Common and Disparate Clinical Presentations and Mechanisms in Different Eosinophilic Gastrointestinal Diseases
https://pmc.ncbi.nlm.nih.gov/articles/PMC11162323/

Current and Novel Therapies for Eosinophilic Gastrointestinal Diseases
https://pmc.ncbi.nlm.nih.gov/articles/PMC10607071/

Eosinophilic Gastrointestinal Diseases Endoscopic features of EGIDs
https://pmc.ncbi.nlm.nih.gov/articles/PMC12167602/

Eosinophilic Gastrointestinal Diseases Beyond the Esophagus: An Evolving Field and Nomenclature
https://pmc.ncbi.nlm.nih.gov/articles/PMC9666791/

Epidemiology, Natural History, and Treatment of Eosinophilic Gastrointestinal Diseases
https://www.gastrojournal.org/article/S0016-5085(25)06042-1/fulltext

Extraintestinal Symptoms of Pain Are Common in Patients with Eosinophilic Gastrointestinal Diseases
https://www.sciencedirect.com/science/article/pii/S2772572325001190

How I Approach It: Eosinophilic GI Diseases Beyond EoE
https://pmc.ncbi.nlm.nih.gov/articles/PMC9064904/

Prevalence and Costs of Non-esophageal Eosinophilic Gastrointestinal Diseases in the United States
https://pubmed.ncbi.nlm.nih.gov/41843038/

Figure 3 is reprinted from Reviews in Basic and Clinical Gastroenterology and Hepatology, Volume 170, Issue 3, Pierfrancesco Visaggi & Evan S. Dellon, Epidemiology, Natural History, and Treatment of Eosinophilic Gastrointestinal Diseases, P476–494., Copyright (2026), with permission from Elsevier.

EGID PARTNERS

EGID Partners is an online research community. It was created by patient advocacy groups and researchers. Our goal is to learn more about EGIDs, including EoE, EoG, EoN, and EoC.

Patients can join by completing private surveys to share their experiences. This information helps guide future research. People without EGIDs can also join. Their information gives researchers helpful comparison data.

You can join if you are 18 or older and:

- You have been diagnosed with an EGID
- You do not have an EGID but want to support research
- You are a parent/caregiver of a child under 18 with or without an EGID

The first survey takes about 30 minutes. There are follow-up surveys sent twice a year. Joining is voluntary and secure. EGID Partners focuses on research, not fundraising. Your data will never be sold.

Recent Research Highlights

- **Early Life Exposures and EGID Risk**: One study found that some early life factors may be linked to a higher risk of EGIDs. These included C-section birth, NICU stays, and antibiotic use during infancy.
- **Impact of Disease**: People with non-EoE EGIDs reported many healthcare visits each year. They also reported high out-of-pocket costs. This shows that EGIDs can affect health, time, and finances.

EGID Partners
Website:
egidpartners.org

EGID Partners
Facebook Page:
facebook.com/profile.php?id=100093458885789

This packet was created with support from an educational grant awarded by Sanofi US to Wake Forest University School of Medicine. It was developed in collaboration with the EGID Partners Scientific Advisory Group. This group includes members from APFED and the CURED Foundation. The funding source did not develop or approve the content of this packet.