

American Partnership for Eosinophilic Disorders (APFED)

What is APFED?

Imagine the aroma of fresh baked chocolate chip cookies, the texture of fresh-baked bread and the refreshing feel of ice cold lemonade on a hot summer day – now **imagine** you can no longer enjoy these foods – ever. Many children and adults with eosinophilic disorders live without food in a food-focused society, fed by a surgically implanted feeding tube. **Imagine** living like this, not knowing anyone who shares the difficulties of day to day life with the foods we all take for granted... Now **imagine** this scenario is a reality for your family. **What would you do?**

Beth Mays, Founder of APFED does understand. Her son Charlie receives medical nutrition therapy, in the form of a special formula, through a feeding tube: All day, every day since he was 2 years old. The treatment followed years of misdiagnosis and misguided therapy for a rare and poorly understood disease: **Eosinophilic gastroenteritis**.

APFED was created in 2001 to become a place where families of patients (adults and kids) could come together to share knowledge, educate themselves, are themselves with credible information, meet and support one another, raise public awareness and generate research dollars. APFED would be that glimmer of hope, a definite resource for eosinophilic disorders.

All of the volunteers who manage and staff APFED are parents and patients themselves. We all have a deep desire to enhance the lives of those suffering and waiting for help. There is a founding principle with APFED – “**We Get It.**”. And we do. And we strive to make sure all new patients do, too.

Mission Statement

American Partnership for Eosinophilic Disorders (APFED) is a volunteer based 501(c)3 non-profit organization dedicated to patients and their families coping with eosinophilic disorders. APFED strives to expand **education**, create **awareness** and support **research** while promoting **advocacy** amount its members.

We at APFED Strive to:

- Create** a credible source of information for physicians and patients.
- Reach** out, find and support those who feel alone in their pain (patients and families).
- Unite** the physician and patient communities in an effort to empower both sides with a better understanding of one another.
- Teach** the general public to understand what “eosinophilic” means to affected families.
- Promote** and support research into the cause and cure of eosinophilic disorders.

How We Do It:

- **Patient Education Conferences**
- **Educational Materials**
- **Local Support Groups and on-line support**
- **Peer reviewed Research Grant Program**
- **Physician Education**

Eosinophil Associated Disorders

FACT SHEET

A group of uncommon chronic illnesses, **eosinophil** (E-o-'si-n-o-'fil) **associated disorders**, are rapidly emerging as a healthcare problem worldwide. Yet, many patients suffering from these disorders go undiagnosed for years due to a lack of information or awareness of these diseases.

What is an Eosinophil?

- A type of white blood cell associated with allergies, parasites, and cancers

What are Eosinophil Associated Disorders?

- High numbers of eosinophils accumulate in body tissues causing inflammation and damage
- Classified by body tissue where eosinophils accumulate
- Diagnosed and monitored by tissue biopsies
- Chronic diseases requiring long term treatment, with no known cure
- Debilitating diseases leading to missed work, school, social outings
- Delays in diagnosis are common

Eosinophilic Esophagitis

- Causes inflammation and damage to the esophagus, affecting the ability to eat
- Estimated prevalence of more than 1 per 2000
- Increase in new cases (2 – 10 fold) over the past 10 years
- Patients may depend on steroids or medical nutrition therapy through a feeding tube

Eosinophilic Gastroenteritis (EGE), and Eosinophilic Gastritis (EG)

- Causes inflammation and damage to the stomach and/or small intestine, often misdiagnosed
- Estimated prevalence of EGE and EC combined is 1 per 3500
- Causes severe abdominal pain, forceful vomiting and/or diarrhea
- Treatment may involve a limited diet, feeding tube and/ or steroids

Eosinophilic Colitis (EC)

- Causes inflammation and damage to the large intestine (colon)
- Often misdiagnosed as Irritable Bowel Syndrome (IBD) or Crohn's disease
- Patients may require restricted diet therapy, elemental formula or chronic steroids

Hypereosinophilic Syndrome (HES)

- Diagnosed by very high numbers of eosinophils in the blood and tissue
- Causes potentially fatal damage to one or more organs in the body (heart, lungs, gut, skin)

Churg-Strauss Syndrome (CSS)

- Eosinophils cause damage to small to medium blood vessels (vasculitis)
- Patient may initially be diagnosed with severe asthma
- Causes potentially fatal lung, heart, brain or gastrointestinal damage
- Estimated to be 60-80 CSS cases/million asthmatics/year

What is the Role of APFED?

- 501(c)3 non-profit lay advocacy organization for those living with eosinophilic disorders
- Mission: Awareness, Education, Support and Research
- Raise funds for research through a peer-reviewed grant program

The following is a list of physicians who serve on APFED's Medical Advisory Board, who specialize in areas of Eosinophilic Disorders and are available for comment.

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