



# Apfed

American Partnership  
for Eosinophilic Disorders

Expanding  
**Education**  
Creating  
**Awareness**  
Funding  
**Research**  
of  
**Eosinophilic  
Disorders**



## Press Kit

APFED  
PO Box 29545  
Atlanta, GA 30359



713-493-7749  
mail@apfed.org  
www.apfed.org

APFED welcomes inquires from the media.

We can provide you with accurate, up-to-date information about eosinophil associated diseases and assist you in contacting medical experts in the field and families living with these diseases.

**Media Contacts**

Wendy Book, APFED President [wendy@apfed.org](mailto:wendy@apfed.org)

Mary Jo Strobel, Executive Director, 571-435-3826, [mjstrobel@apfed.org](mailto:mjstrobel@apfed.org)

**General Inquires: [mail@apfed.org](mailto:mail@apfed.org)**



**Mailing Address:**

APFED  
American Partnership for Eosinophilic Disorders  
PO Box 29545  
Atlanta, GA 30359

**Phone:**

Office: 713-493-7749  
(8am – 4pm CST, Monday – Friday)

**Social Media**

Facebook: [APFED](#)  
Twitter: [@APFEDorg](#)



APFED is a 501(c)3 organization dedicated to patients and their families coping with eosinophilic disorders. APFED strives to expand education, create awareness, and fund research while promoting advocacy among its members.

Tax ID: 76-0700153

## Quick Facts about Eosinophilic Disorders

A group of uncommon diseases, eosinophil associated diseases are rapidly emerging as a healthcare problem worldwide. Yet many patients suffering from these disorders go undiagnosed for years due to the lack of information or awareness of these disorders.

- ◆ These diseases are characterized by having above normal amounts of eosinophils, a type of white blood cell, in one or more specific places in the digestive system, tissues, organs, and/or blood stream, which causes inflammation and damage.
- ◆ Diagnosis can only be made through biopsies of affected areas.
- ◆ These diseases are chronic and often debilitating.
- ◆ Delays in diagnosis are common and often patients are misdiagnosed.
- ◆ There is not an approved treatment for most eosinophil associated diseases and there is NO CURE!



### Quick Facts:

Click on the links below for facts about specific eosinophil associated disorders.

[Eosinophil Associated Disorders Fact Sheet](#)

[Hypereosinophilic Syndrome \(HES\)](#)

[Eosinophilic Esophagitis \(EoE\)](#)

[Churg Strauss Syndrome \(CSS\)](#)

[Eosinophilic Gastritis \(EG\)](#)

[Eosinophilic Fasciitis](#)

[Eosinophilic Gastroenteritis \(EGE\)](#)

[Eosinophilic Pneumonia](#)

[Eosinophilic Colitis \(EC\)](#)

[Eosinophilic Cystitis](#)

## About APFED - The American Partnership for Eosinophilic Disorders

### Mission Statement

APFED is a non-profit organization dedicated to patients and their families coping with disorders. APFED strives to expand education, create, and support research while promoting advocacy among its members.



### About APFED

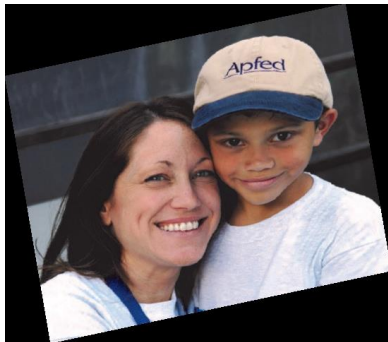
APFED assists and supports patients and families affected by eosinophilic disorders, including eosinophilic esophagitis, eosinophil-associated gastrointestinal disorders, hypereosinophilic syndrome, and Churg-Strauss Syndrome.

- ◆ APFED is the largest patient advocacy organization dedicated specifically to eosinophil associated diseases.
- ◆ The growth of the organization has increased at a rapid rate in the last 10 years, due to the increasing diagnosis of these diseases in both children and adults.
- ◆ Our website, educational materials, books and promotional items are all developed to be easy-to-read, up-to-date, accurate and user-friendly.
- ◆ APFED's [Medical Advisory Panel](#) reviews all of the medical information APFED publishes for its content and accuracy. Because of this high standard, the organization has been featured, quoted, cited and referenced in medical journals and teaching manuals for medical students and professionals, television news stories, newspaper articles and magazines covering the subject of eosinophilic gastrointestinal disorders.

## About APFED - The American Partnership for Eosinophilic Disorders

### History

APFED was born as an idea in late September 2001 by a group of mothers of young children living with Eosinophilic Disorders with the intent to provide support, reliable information and spread awareness.



APFED's founder, Beth Mays  
& her son Charlie

APFED was incorporated in December 2001 and received 501c3 status in June of 2002.

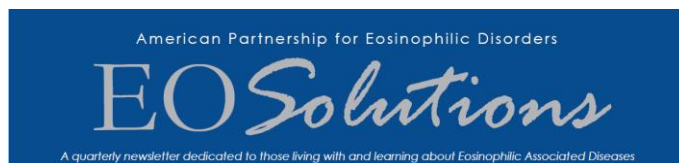
“APFED was created to become a place where families (adults and kids) could come together to share knowledge, educate themselves, arm themselves with credible information, meet and support one another, raise public awareness and generate research dollars. APFED would be that glimmer of hope. A four-point mission of education, awareness, support and research, each being no more important than the other.”

- APFED's Founder, Beth Mays

## How APFED Helps - Programs and Services

### Education

APFED offers free online educational materials, an annual patient education conference, education for healthcare providers, and a quarterly newsletter for our members. APFED's [Medical Advisory Panel](#) reviews all of the medical information APFED publishes for its content and accuracy. Because of this high standard, the organization has been featured, quoted, cited and referenced in medical journals and teaching manuals for medical students and professionals, television news stories, newspaper articles and magazines covering the subject of eosinophilic gastrointestinal disorders.



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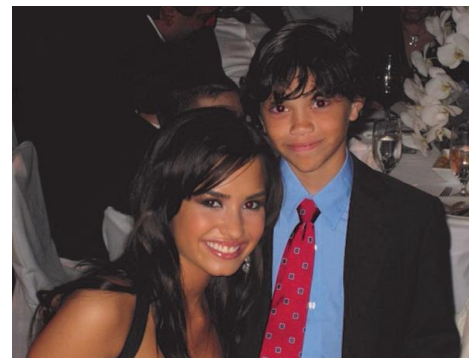


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## How APFED Helps - Programs and Services (cont)

### Awareness

APFED raises awareness of eosinophilic disorders, and keeps the public informed via social media. We participate in conferences, and support fundraising events. APFED led the effort to officially designate the third full week of May as [National Eosinophil Awareness Week](#).



Demi Lavato, APFED's 2009 Honorary Ambassador of Education, with Charlie Mays

### Research

APFED's [Hope on the Horizon](#) Research Grant Program provides the seed money to investigators to pursue unique research ideas and collect preliminary data that may be used to apply for larger grants. We work in conjunction with federal agencies to ensure the research needs of patients with eosinophilic disorders are met. Current research could mean less invasive diagnostic measures and more effective treatments for those suffering from these debilitating disorders.

### Support

APFED is here for patients who have questions or need to talk to someone who "gets it." We offer families an opportunity to connect with one another in person at our annual education conferences and on-line through message boards and social media.

### Advocacy

APFED led the effort to develop [ICD-9 codes for eosinophilic gastrointestinal disorders](#), which are crucial for insurance coverage of therapy and for ongoing research. In 2007, APFED authored the bill for National Eosinophil Awareness Week (third week of May) and worked with the community to get it passed. APFED continues to work on the legislative front as well. APFED ensures our community has a common voice.



## Financial Information

APFED receives funding to support our mission through corporation donations; educational grants; membership dues; sales of APFED merchandise; fundraisers; public donations.

- ◆ APFED's Tax ID (EIN) is 76-0700153
- ◆ APFED received its IRS Determination as a 501(c)3 organization in 2002.
- ◆ APFED's IRS 990's are available at [Guidestar.org](http://Guidestar.org)



## Board of Directors

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*Executive Director: Mary Jo  
Strobel*

## Testimonials

*"During my lifetime, I have worked with, supported, and benefited from numerous non-profit organizations. Few, if any, have taken patient advocacy and disease awareness to the level APFED has done."*

*"APFED's work made it so children like mine can receive insurance coverage for the very important elemental formula they need to survive. Without APFED we'd have no real voice."*

*"APFED has been invaluable in helping us deal with our daughter's chronic disease. Their website alone is a tremendous source of information, covering topics from research, to education, to advocacy."*

