

# HYPEREOSINOPHILIC SYNDROMES

A patient's guide to resources and hope



CONNECTING THE EOSINOPHILIC COMMUNITY  
[apfed.org](http://apfed.org)

Dear friends,

Hypereosinophilic syndromes (HES) are a group of rare disorders in which high numbers of a type of white blood cell called eosinophils are found in the blood and tissue for a prolonged period of time (6 months or more) without a known cause. The excessive number of eosinophils can in turn result in tissue inflammation and progressive organ damage. HES is chronic and lifelong, but with proper ongoing care and treatment those with HES can manage their condition.

This kit was developed by the American Partnership for Eosinophilic Disorders (APFED) to help those affected by HES. APFED is a nonprofit organization that assists and supports patients and families affected by eosinophil-associated disorders such as HES by providing education, creating awareness, supporting research, and promoting advocacy. This kit includes:

- **Getting started checklist.** Navigate a new diagnosis with this checklist to guide you as you learn.
- **Glossary.** Learn terms commonly used when discussing HES to help you understand the materials you read and discussions you have with your medical team.
- **Frequently asked questions.** Read answers to questions that are commonly asked by patients and caregivers.
- **Types of doctors.** Learn about the team of doctors or specialists that you may need to treat HES.
- **Treatment.** Review current treatment options for HES, as well as promising new therapies in the pipeline.
- **Research progress.** Discover how HES research is progressing and learn about recent discoveries.
- **Tips for living well.** Access tried and true tips to help improve your quality of life with HES.
- **Helpful resources.** Connect with others and tap into a supportive community of patients, caregivers, and resources.
- **Shop.** Spread awareness for eosinophil-associated diseases with items in APFED's Gift Shop.
- **Community fundraising.** Learn how to get involved and support the patient community in ways both great and small.

We hope these resources will help you be better prepared to manage your HES diagnosis. For more information, or for questions or support, please visit [apfed.org](http://apfed.org) or contact us at [mail@apfed.org](mailto:mail@apfed.org).

Sincerely,



Mary Jo Strobel  
Executive Director  
American Partnership for Eosinophilic Disorders (APFED)

**CONNECTING THE EOSINOPHILIC COMMUNITY**

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# HES: Getting started checklist



A diagnosis of hypereosinophilic syndromes (HES) is life-changing and can feel overwhelming. Here are some tips to help you get started on your journey.

## Educate yourself

- ✓ **Read the information in this kit.** The material inside is designed to help patients, families, and others understand HES and how to manage it.
- ✓ **Watch educational videos and webinars about HES.** Access APFED's e-library at [apfed.org](http://apfed.org), or visit our YouTube channel at [youtube.com/APFED](https://youtube.com/APFED).

## Find a doctor

- ✓ **Find the right doctor.** Dealing with a chronic illness requires a strong doctor-patient relationship, so it is worth looking for the right doctor to work with and getting a second opinion. Explore options in APFED's Doctor Finder at [apfed.org/find-support-treatment/doctor-finder/](http://apfed.org/find-support-treatment/doctor-finder/).
- ✓ **Assemble a team of specialists.** HES may be diagnosed and monitored by a team of specialists, such as an allergist/immunologist, pulmonologist, hematologist, and/or cardiologist, or others. The doctor who diagnosed you can help you determine which specialists you need.
- ✓ **Ask your doctor(s) questions.** Write down your questions before your next appointment with your doctor. Having a list will help keep you organized and help you to remember all of your questions. Getting answers will help you make informed decisions. Some questions to consider include:
  - What type of HES do I have?
  - What organs are affected?
  - What are the symptoms I may experience? How might HES affect my daily activities?
  - What treatments do you recommend, and why? What are the potential side effects of the treatments?
  - What other types of specialists will be involved in my care? How will information be shared with others?
  - Will I need special accommodations at work or school?
  - How often will I need follow up appointments? Is a care coordinator available to help facilitate this?

## Make a treatment plan

- ✓ **Speak to your doctor about treatment options.** Treatments may vary based on the organs involved, disease severity, and other medical conditions.
- ✓ **Develop a written plan to follow for prescriptions.** Make sure to include the dose and frequency for each medication and what you should do if you forget a dose.

## Build a support system

- ✓ **Find a support group.** While APFED does not have affiliated support groups, we provide a list of volunteer-led support groups at [apfed.org/find-support-treatment/find-support-treatment/](https://apfed.org/find-support-treatment/find-support-treatment/)
- ✓ **Sign up for APFED's online support community, "EOS Connections"** on the Inspire Network at [apfed.inspire.com](https://apfed.inspire.com). Join the HES board to connect with other patients and caregivers for peer-to-peer support.

## Be part of the cure

- ✓ **Enroll in APFED's patient registry, Eosinophil.Connect** at [apfed.org/registry](https://apfed.org/registry). APFED's patient registry connects patients who need a cure with the researchers who are working on one. The more scientists can learn directly from patients, the faster they can work to develop improved diagnostics and therapies, and one day, a cure!

# HES: Glossary

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**Absolute eosinophil count:** The total level of eosinophils in your blood count.

**Asymptomatic:** Absence of symptoms.

**Adrenal insufficiency, primary:** Adrenal glands produce insufficient quantities of regulatory hormones leading to low blood pressure, low blood sugar and fatigue (weakness) particularly during times of illness.

**Adrenal insufficiency, secondary:** Adrenal insufficiency related to long-term steroid use. Symptoms similar to primary adrenal insufficiency.

**Antibody(ies):** A protein produced by the body's immune system that helps neutralize germs by recognizing and destroying a specific antigen.

**Complete blood count (CBC):** A blood test that includes a count of all the red and white blood cells, platelets, as well as hemoglobin and hematocrit count. Statistics about the red blood cells are also calculated and included in the test results.

**CD52:** An antigen that is found on the surface of many cells, including eosinophils (its function is not yet known).

**Chemotherapy:** Drugs that destroy a cell's ability to grow. Most often used to destroy cancer cells.

**Clinical remission:** Period of time during which signs and symptoms of a disease are absent.

**Clinical trial:** Clinical trials are designed to test new medications in people before the medications are approved by the Food and Drug Administration. The trials may involve a placebo group (inactive 'medicine') to see if the new medication offers an advantage over current standard treatment. Some trials are 'open label', in which all participants receive active medications or experimental treatment.

**Corticosteroid:** See *steroid*.

**Cyclosporine:** A potent medication that suppresses the immune system and is used primarily to prevent organ rejection in people who have had organ transplants.

**Cytokine:** A therapy that stimulates white blood cell growth, such as eosinophils.

**Eosinophil:** A type of white blood cell that is important to our immune system, because they help us fight off certain types of infections.

**Eosinophil-associated disease:** When a person has elevated numbers of eosinophils in their digestive system, tissues, organs, and/or bloodstream, without a known cause. Eosinophil-associated diseases are chronic and require long term management.

**Eosinophilia:** High numbers of eosinophils in the blood.

**Flare:** A time during which active disease is present.

**Gastrointestinal tract (GI or GI tract):** All of the muscular organs involved in eating, digesting foods, and eliminating solid food wastes, including the mouth, esophagus, stomach, small intestine, and large intestine.

**Glucocorticoid:** See *steroid*.

**Hypereosinophilic syndromes (HES):** A group of rare disorders in which high numbers of a type of white blood cell called eosinophils are found in the blood and tissue for a prolonged period of time (6 months or more) without a known cause. The excessive number of eosinophils can in turn result in tissue inflammation and progressive organ damage.

**Idiopathic:** No obvious cause.

**Inflammation:** A non-specific term describing a reaction at the cellular level resulting from injury or irritation. Inflammatory responses lead to repair. Inflammation can occur anywhere in the body and from many different causes.

**Interferon alpha (IFN- $\alpha$ ):** A biological therapy given as an injection (usually in the thigh or abdomen) to suppress symptoms related to HES. It may slow down or stop eosinophil cells from dividing.

**Lymphocyte:** A type of white blood cell that functions as part of the immune system. Types of lymphocytes include: T cells, B cells, and natural killer cells.

**Monoclonal antibody therapies:** Therapies that involve lab-created antibodies that are designed to target and destroy specific cells by selectively binding to specific proteins.

**Osteoporosis:** A loss of bone mineral density, leading to weak bones that easily fracture. Some causes include a drop in testosterone or estrogen levels, certain medications, improper nutrition, malabsorption, certain diseases (e.g., IBD, Addison's disease, hypothyroid, hyperparathyroid), and possibly other causes. Protein deficiency can lead to loss of bone density, as can calcium and other mineral deficiencies. A bone density test (DEXA scan) is required for diagnosis. Special osteoporosis medication may be needed to slow the progression of bone density loss.

**Remission:** Period of time when no disease activity is present.

**Steroid:** A type of medication that is a synthetic version of cortisol or other hormones. When based on cortisol, this type of medication suppresses the immune system and may be prescribed to treat allergies, asthma, eosinophil-associated diseases, autoimmune diseases, some forms of cancer, organ transplant rejection, and other diseases. It may also be prescribed to provide adrenal gland support in cases of adrenal insufficiency.

**Tyrosine kinase inhibitors:** A therapy that can be used to control malignant cell growth by blocking abnormal protein production. Examples include imatinib and dasatinib.

**White blood cell (WBC):** A type of blood cell that is involved in the immune system response to invading organisms (e.g., bacteria, virus, parasite). The different types of white blood cells include basophils, neutrophils, lymphocytes, eosinophils, and monocytes.

**White blood cell count with differential (WBC with diff):** A type of blood test in which the total number of white blood cells in a measured amount of blood are counted, and then each of the different types of white blood cells are counted and listed separately in the test results. This is more routinely referred to as a CBC with diff, and includes RBC/HGB/HCT/platelets.

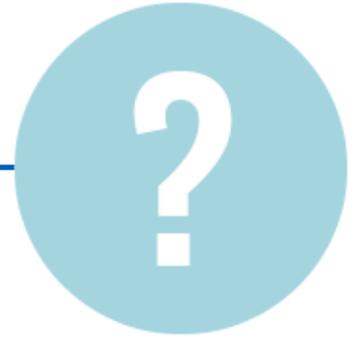
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**For more definitions of terms about eosinophil-associated diseases, visit [apfed.org/about-ead/glossary/](https://apfed.org/about-ead/glossary/).**

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*This document was revised in January 2018. Sources for medical terms and definitions in this document include the consumer version of the online Merck Manual, Stedman's Medical Dictionary, 24th edition, and other professional medical websites. Questions may be directed to [mail@apfed.org](mailto:mail@apfed.org).*

# HES: Frequently asked questions



The following are questions frequently asked by patients and caregivers about hypereosinophilic syndromes (HES).

## Are all cases of HES the same?

No, not all HES is the same. People have different symptoms, organ involvement, and causes, which require varying treatments. To date, there are five known categories or variants of HES:

- 1. Myeloproliferative HES (M-HES):** Accounts for an estimated 15% of all HES cases. This variant is most frequently associated with a genetic deletion causing the chromosomal rearrangement of two genes (PDGFRA and FIP1L1). M-HES is not inherited.
- 2. Lymphocytic HES (L-HES):** Accounts for approximately 10-15% of all HES cases. This variant is associated with an increase of clonal T cells that drive eosinophil production and become active.
- 3. Associated HES:** Accounts for approximately 10% of all HES cases. A secondary and treatable cause of HES can be identified in this category.
- 4. Overlap HES:** Accounts for approximately 10-15% of all HES cases. This category includes disorders with single organ disease (e.g., eosinophilic gastrointestinal disorders) or clinical overlap with HES (e.g., eosinophilic granulomatosis with polyangiitis).
- 5. Idiopathic HES (I-HES):** Approximately 50% of estimated prevalence is considered idiopathic. This subtype does not have a defined cause.

## Is HES hereditary? Are my children and grandchildren more likely to have HES?

Most cases of HES are not inherited, although some cases appear to be passed down. The exact underlying genetic cause of HES is not yet known.

## Is there a cure for HES?

HES is a chronic and lifelong condition. While there is no cure, there are treatments that will help control symptoms and manage the disease. Currently, treatment goals are to reduce the eosinophils in the blood, prevent organ damage, and slow the disease progression. Treatments vary based on the disease severity and organs involved (e.g., stomach and intestines, heart, lungs, skin, liver, spleen, eyes). HES may be debilitating and can be life-threatening if left untreated.

The prognosis of HES has greatly improved since the mid-1970's, thanks to earlier detection of complications, improved surgical management of cardiac and valvular disease, and a wider selection of therapies to help decrease the eosinophil counts in the blood, and may continue to improve with current and future therapeutic strategies.

## What are some common side effects of steroids (e.g., prednisone)?

Long-term steroid use (especially at doses greater than 10 mg/day) is associated with serious side effects such as adrenal insufficiency, avascular necrosis, osteoporosis, infections, and stunted growth.

## How can I connect with other patients or families who live with HES?

To connect with other HES patients for peer-to-peer support, join the HES board in APFED's online support community "EOS Connections" on the Inspire Network at [apfed.inspire.com](https://www.apfed.org/inspire).

Patients and families are also invited to connect with one another through APFED's Facebook page ([facebook.com/APFED](https://www.facebook.com/APFED)). You may also reach APFED directly at [mail@apfed.org](mailto:mail@apfed.org) for help connecting with other community members.

## How can I help advance research?

The more scientists can learn directly from patients, the faster they can work to develop improved diagnostics and therapies, and one day, a cure. You can help researchers learn about HES by enrolling in APFED's patient registry, Eosinophil.Connect at [apfed.org/registry](https://www.apfed.org/registry). The registry connects patients who need a cure with the researchers who are working on one.

You can also help advance research by becoming a member of APFED. For more information about membership benefits or to make a tax-deductible gift to support our work, visit [apfed.org](https://www.apfed.org).

## Where can I learn more about HES?

To learn more about HES and watch educational videos, visit APFED's website at [apfed.org/about-ead/hypereosinophilic-syndrome](https://www.apfed.org/about-ead/hypereosinophilic-syndrome).

# HES: Types of doctors

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People with hypereosinophilic syndromes (HES) may have more than one doctor or specialist involved with their care. These specialists may include the following:

## Allergist

Specializes in diagnosis and treatment of allergic disorders, including asthma, allergic skin rashes, allergic rhinitis, and sometimes food allergies.

## Cardiologist

Specializes in diagnosis and treatment of heart disorders.

## Dermatologist

Specializes in diagnosis and treatment of skin disorders.

## Endocrinologist

Specializes in diagnosis and treatments of endocrine organs whose primary function is hormone secretion, such as adrenals, ovaries, pancreas, pituitary, thyroid, and testes.

## Gastroenterologist

Specializes in diagnosis and treatment of digestive disorders.

## Hematologist

Specializes in diagnosis and treatment of blood disorders.

## Immunologist

Specializes in diagnosis and treatment of diseases involving the immune system. Some Immunologists are also called Environmental Medicine Specialists.

## Neurologist

Specializes in diagnosis and treatment of conditions affecting the nervous system, including the brain.

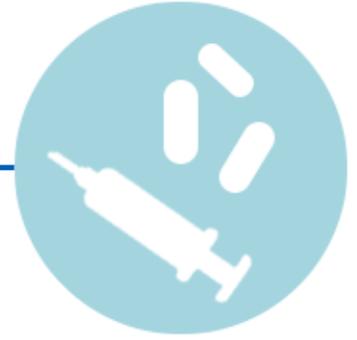
## Psychologist

Specializes in mental health wellness and can help provide strategies to cope with issues pertaining to chronic illness, such as anxiety and depression.

## Pulmonologist

Specializes in diagnosis and treatment of disorders involving the respiratory tract.

# HES: Treatment



Treatment for hypereosinophilic syndromes (HES) vary based on the organs involved, disease severity, and other medical issues. When treating HES, the goal is to **reduce the eosinophils in the blood, prevent organ damage, and slow disease progression.**

- **Corticosteroids** (e.g., prednisone) are the current standard of care for HES. Most L-HES and I-HES patients can be maintained on oral corticosteroids for long periods of time with fairly good success. Corticosteroids fight inflammation and decrease the number of eosinophils. However, the eosinophils and symptoms generally return once steroids are stopped. Long-term steroid use (especially at doses greater than 10 mg/day) is associated with serious side effects such as adrenal insufficiency, avascular necrosis, osteoporosis, infections, and stunted growth.
- **Interferon alpha (IFN- $\alpha$ )** injections are used to suppress symptoms related to HES. Most patients experience flu-like symptoms from these injections (e.g., fever, chills) and therapy may need to be discontinued due to side effects.
- **Cyclosporine** suppresses the immune system. In some patients, there may be evidence that the immune cells have a role in supporting HES, and cyclosporine may have a role as a therapy.
- **Anti-neoplastic agents or chemotherapy** (e.g., chlorambucil, cladribine, cyclophosphamide, etoposide, hydroxyurea, methotrexate, vincristine) kill fast growing cells, such as eosinophils in HES. These therapies provide an alternative approach for severe/advanced cases of HES. These agents have potentially harmful side effects.
- **Imatinib mesylate** is a tyrosine kinase inhibitor for controlling malignant cell growth. Approximately 10-20% of patients with M-HES have a genetic abnormality involving tyrosine kinase that causes their HES. Genetic testing can help determine if a patient might benefit from this therapy. M-HES is typically treated with imatinib.
- **Monoclonal antibody therapy** involves lab-created antibodies that are designed to target and destroy specific cells. Mepolizumab and reslizumab are drugs that target interleukin-5, the major eosinophil active cytokine. Alemtuzumab targets the CD52 molecule, an antigen that is found on the surface of many cells. Monoclonal antibody therapy has shown some benefit to some with HES, and is reserved for patients who do not respond to other treatments.

It is important to work with your healthcare provider(s) to determine the type of treatment, dosage, and duration of treatment based on your individual needs.

# Investigational therapies

Improved treatment options for HES are an area of ongoing study.

Recent research has identified a number of investigational drugs that block eosinophils and/or lower eosinophil counts. Clinical trials for HES currently include the efficacy and safety of potential new treatments, as well as studies that help investigators to better understand the natural history of HES and markers of disease progression.

As of January 2018, clinical trials to study the efficacy and safety of two experimental drugs, benralizumab and mepolizumab, were enrolling patients. Dexpramipexole is another investigational drug that is being studied. Clinical studies of this therapy are expected to begin enrollment in 2018.

Clinical trials are designed to test new medications in people. Clinical trials may involve a placebo group (inactive “medicine”) to see if the new medication offers an advantage over current standard treatments. Some trials are “open label”, in which all participants receive active medications or experimental treatment. Participation in a trial is an individual, and important, decision.

There are many advantages to participating in clinical trials. Participants in clinical trials at a minimum receive the current standard of care for their disease from medical teams experienced with the disease. Clinical trials also offer the opportunity to try a new medication long before it is approved by the Food and Drug Administration.

If you choose to participate in a clinical trial, you have the right to understand fully what is expected of you, what the trial will involve, and the potential risks to your health. You also have the right to withdraw your consent to participate at any time. Learn more about clinical trials at [clinicaltrials.gov](http://clinicaltrials.gov).

For a list of trials and studies that are enrolling patients with HES, visit [apfed.org/research/clinical-trials/](http://apfed.org/research/clinical-trials/).

## Answers from experts: Patient involvement in research



*How are patients protected? What questions should you ask before participating? How can patients accelerate research?*

These questions and more are answered by Dr. Wendy Book in a video playlist from APFED’s Educational Webinar Series. Watch the videos on APFED’s YouTube channel at [youtube.com/user/APFED](https://youtube.com/user/APFED).

# HES: Research progress

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The term "hypereosinophilic syndrome" (HES) was introduced in 1968 to categorize a group of patients that had chronically elevated eosinophil levels in their blood and related organ damage, a condition that had been recognized for many years prior. Since then, the research into HES has vastly improved our understanding of the condition and how to best treat it and the group of rare disorders is now being known plurally as hypereosinophilic syndromes. Professional consensus guidelines are now available to guide diagnosis, categorization, and treatment and research continues to advance.

## What we know today

- The severity of HES can be diverse. Some patients with HES may not exhibit symptoms (asymptomatic), or have only mild symptoms. Others may experience life-threatening issues due to major organ involvement (commonly the heart) or acute leukemia.
- Identification and categorization of different variants of HES has helped researchers better determine which patients may be at higher risk of developing serious, disease-related conditions, such as heart involvement and malignant disease, so that an appropriate course of treatment can be started.
- Most cases of HES are not inherited, although some cases appear to be passed down. The exact underlying genetic cause is not yet known.
- Identification of potential therapeutic targets, including potential alternative treatments for patients who do not respond to conventional therapies, will lay the groundwork for ongoing and future research efforts.

## Ongoing areas of research

- Safety and efficacy of targeted therapies that disrupt/destroy eosinophils
- Steroid-sparing treatments for HES
- Biomarkers to improve diagnostics
- Predictors of which people with HES will and will not respond to steroids, and why

More information about clinical trials and investigational therapies can be found on the “Investigational therapies” page in this kit.

# HES: Tips for living well



If you or someone you love is diagnosed with hypereosinophilic syndromes (HES) it is important to:

**Stay informed.** Subscribe to APFED's e-newsletter at [apfed.org](http://apfed.org) for regular updates, news, and events of interest to the eosinophilic patient community.

**Connect with others.** Interacting with people who have HES, or have a loved one with HES, who can in turn provide emotional support and guidance is invaluable. Stay connected with other HES patients for peer-to-peer support on APFED's online community "EOS Connections" on the Inspire Network. Join now at [apfed.inspire.com](http://apfed.inspire.com).

**Take care of yourself.** Take some time each day to do something you really enjoy. If you feel up to it, and your doctor agrees, start a mild exercise program, like walking or stretching.

**Focus on what you can control.** Feeling sad, anxious, or even angry about a disease is okay; in fact it's normal. Rather than letting these feelings overwhelm you, acknowledging and expressing them can help give you a sense of control.

**Ask for help.** When dealing with a chronic and lifelong condition you are going to need some help along the way, whether it's emotional support or help with physical tasks on days you don't feel well. Build a support network of people who can help, such as family or friends. If you feel you need help coping with a chronic illness, your doctor may have a recommendation for a therapist, counselor, or palliative care services that can offer additional resources to help you cope with the stress of a chronic illness.

**Wear medical identification jewelry.** Medical identification jewelry is designed to alert emergency responders to your unique medical situation. Medication allergies should also appear on the bracelet.

**Know your rights in the workplace and school.** Two laws to become familiar with regarding workplace rights include:

**Family and Medical Leave Act** which allows employees to take up to 12 weeks of unpaid leave each year for medical or family emergencies. Learn more at [dol.gov/whd/fmla/](http://dol.gov/whd/fmla/).

**Americans With Disabilities Act of 1990 (ADA)**, which was amended in 2008 to expand the rights of disabled individuals. ADA requires employers to make reasonable accommodations for disabled workers who meet their definition of "disabled", and such accommodations may include additional time off or modified work schedules. ADA, as amended, applies to employers that have 15 or more employees. Learn more at [ada.gov/ada\\_intro.htm](http://ada.gov/ada_intro.htm).

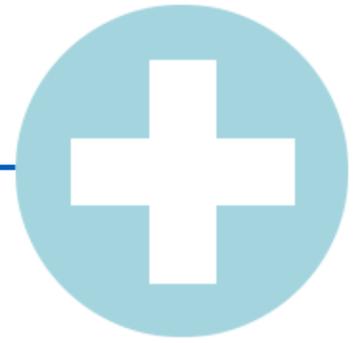
Every school-age child, whether meeting the definition of disabled or not, is legally entitled to a free, appropriate, and meaningful education (Section 504 of the Rehabilitation Act of 1973, as amended, 29 U.S.C. 794), and reasonable accommodations may be requested and granted. Examples of such accommodations that may be helpful for HES patients include a reasonable time period to make up work and absences without penalty when related to the disorder.

For more information about these laws, visit:

- Office for Civil Rights  
<https://www2.ed.gov/about/offices/list/ocr/504faq.html>
- APFED offers a school advocacy toolkit that includes information and templates  
[apfed.org/advocacy/school-advocacy](https://apfed.org/advocacy/school-advocacy)

**Join us.** Become a member of APFED to help support our work. For more information about membership benefits or to make a tax-deductible gift to APFED, visit [apfed.org](https://apfed.org).

# HES: Helpful resources



Check out these resources for those affected by hypereosinophilic syndromes (HES).

## Online support



**EOS Connections:** APFED's online support community on the Inspire Network provides a forum for patients, caregivers, and family members to connect with others for support and to share information. Join the conversation today at [apfed.inspire.com](https://apfed.inspire.com).



**Facebook:** There are multiple ways to interact with APFED on Facebook.

- Follow APFED on Facebook  
[facebook.com/APFED](https://facebook.com/APFED)
- Participate in National Eosinophil Awareness Week (3rd week of May)  
[facebook.com/NationalEosinophilAwarenessWeek](https://facebook.com/NationalEosinophilAwarenessWeek)

## Support groups



**Support group directory:** As a courtesy, APFED provides a list of eosinophilic support groups that are volunteer-led (APFED does not have affiliated support groups). Groups provide emotional and educational support and information about local programs, services, and events for families and individuals with eosinophil-associated diseases. Find a support group at [apfed.org/support-groups](https://apfed.org/support-groups)



**Support group development assistance:** APFED offers resources to help patients and caregivers start their own support group, and publishes an e-newsletter for support group leaders to highlight efforts of groups across the U.S., to provide tips and ideas to make the most of their meetings, and to share news of interest with community members. For more information, contact [mail@apfed.org](mailto:mail@apfed.org).

## Videos



Watch educational videos and webinars about HES on APFED's YouTube channel at [youtube.com/user/APFED](https://youtube.com/user/APFED) and website at [apfed.org/about-ead/videos-and-webinars-2](https://apfed.org/about-ead/videos-and-webinars-2).

## Additional patient friendly resources

The following organizations/websites have patient-friendly resources available about HES and/or rare diseases.

- American Academy of Allergy Asthma and Immunology  
[aaaai.org/conditions-and-treatments/related-conditions/hypereosinophilic-syndrome](http://aaaai.org/conditions-and-treatments/related-conditions/hypereosinophilic-syndrome)
- Cure HES, Patient Blog  
[curehes.org](http://curehes.org)
- Genetic and Rare Diseases (GARD) Information Center  
[rarediseases.info.nih.gov/diseases/2804/hypereosinophilic-syndrome](http://rarediseases.info.nih.gov/diseases/2804/hypereosinophilic-syndrome)
- Global Genes  
[globalgenes.org](http://globalgenes.org)
- National Institute of Health (NIH)  
[rarediseases.info.nih.gov/diseases/2804/hypereosinophilic-syndrome](http://rarediseases.info.nih.gov/diseases/2804/hypereosinophilic-syndrome)
- National Organization for Rare Disorders  
[rarediseases.org](http://rarediseases.org)

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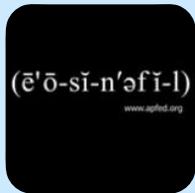
## Share your story!

Everyone whose life has been touched by an eosinophil-associated disease has a story to share, and we can all learn from one another! In our newsletter, on our social media pages and on our website, APFED highlights perspectives from patients and family members who live with HES and other eosinophilic disorders. We'd love to hear from you, too! Send your story to [mail@apfed.org](mailto:mail@apfed.org).

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# SHOP APFED

Shop for eosinophil-associated items and resources at [apfed.org/shop](http://apfed.org/shop).



## Eosinophil gear

Spark conversations and raise awareness with the phonetic spelling of eosinophil on your phone, a t-shirt, or a bracelet



## Find your way t-shirts

Raise awareness for how APFED helps patients and families navigate their eosinophil journey with our t-shirts



## Awareness buttons

Spread awareness for eosinophil-associated diseases by wearing our Eosinophil Associated Disease Awareness buttons



## Educational materials

Inform people about eosinophil-associated disorders



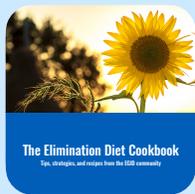
## Support hope cooler

Make eating on the go easier with our fully insulated cooler



## Notecards

Spread hope, thanks, and holiday cheer with our collection of notecards



## Elimination Diet Cookbook

Learn tips, strategies, and recipes for managing an elimination diet



## Children's books

Help children learn through reading books with lively illustrations



## Living Well book

Learn about EGID, and get coping tips and ideas for school and work

# COMMUNITY FUNDRAISING

Fundraising can be a fun and rewarding way to support APFED and make a difference for those living with eosinophil-associated disorders! Every dollar makes a difference.



## TURN YOUR PASSION INTO ACTION

Do you play a sport? Love to scrapbook? Enjoy card games? Turn your passion into action by coordinating a fundraising event to support research, education, and awareness of eosinophil-associated diseases.

In addition to providing critical support to APFED, these events also raise disease awareness in local communities. Best of all, you may choose specific APFED programs and services that you would like to support or direct proceeds to a general fund.

APFED will work with you to make your event a success! Check out some of the community fundraisers that volunteers have organized:

- Golf tournament
- APFED Hope on the Horizon Walk for EOS
- Office donation collection (donate lunch or coffee break money)
- 10% community day at a local business
- Home-based retail party proceeds donation
- Social media campaign to ask friends and family to support APFED

Visit [apfed.org/take-action/fundraise](http://apfed.org/take-action/fundraise) to explore ideas and learn how APFED puts your donations to work. APFED can help by providing flyers, donation request letters, and press releases, as well as letting other community members know about your event.

## Apfed

American Partnership  
for Eosinophilic Disorders

*Connecting the Eosinophilic Community*

For more information about fundraising, please visit [apfed.org/take-action/fundraise](http://apfed.org/take-action/fundraise) or email [fundraise@apfed.org](mailto:fundraise@apfed.org).



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