About APFED

The American Partnership for Eosinophilic Disorders (APFED) was founded in December 2001. Our mission is to passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy.

What We Do

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

APFED’s Core Values

- Passion for improving the lives of those with EADs
- Integrity in all operations
- Transparency in accordance with nonprofit guidelines
- Accuracy with continuous expert review of content

Gifts in Action

Dear friend:

APFED is education, advocacy, support, and research in motion. Our incredible community of patients and families, healthcare providers, research partners, and other supporters propels us.

We’d like to share with you some key accomplishments we have made throughout 2018. These achievements would not be possible without the generous support of our donors and education partners.

On behalf of the patients who benefit from progress thank you to all of those who have championed change for our community by donating to APFED or hosting a fundraiser.

Mary Jo Strobel
Executive Director

Will you help us continue to make advances for patients who depend on it? See inside for ways to offer support!

APFED is a 501(c)3 organization. Tax ID: 76-0700153. A copy of our financial statements may be found on apfed.org and guidestar.org.
Research Advances

APFED funds research that leads us to a better understanding of eosinophil-associated diseases. Our Hope on the Horizon Research Program is supported entirely by donations. Under this funding mechanism, researchers may submit proposals for a committee of peers to review and score the proposals. The most promising research is selected to receive an APFED HOPE Grant.

2018 APFED HOPE Pilot Research Grant Award

Recipient: Joshua B. Wechsler, MD
Assistant Professor in Pediatrics, Northwestern University Feinberg School of Medicine and Attending Physician, Ann & Robert H. Lurie Children’s Hospital of Chicago

Award Amount: $100,000
Project Term: 2 years

Dr. Wechsler’s research project is entitled, “Defining Mast Cell Phenotype, Activation Pathways and Cellular Interactions that Drive Chronic Symptoms and Endoscopic Changes in Eosinophilic Esophagitis.”

With this grant, Dr. Wechsler seeks to understand the role of esophageal mast cell activation in EoE symptoms, along with endoscopic abnormalities in EoE and the effect of treatment. His work will analyze novel pathways in individual mast cells from a biopsy, to determine factors that drive persistent endoscopic abnormalities. He will also define interactions of mast cells and their mediators with the structural epithelial cell, relevant to what is seen in the biopsy.

This project will help uncover fundamental aspects of mucosal mast cells signaling and cellular interactions critical to driving clinical phenotype in EoE, which could in turn contribute to novel therapies to improve treatment response.

“This work seeks to improve patient care by delving into critical pathways at play between individual mucosal mast cells and the epithelium. We believe these interactions are key to ongoing endoscopic and histologic abnormalities in a subset of patients with EoE. This award will greatly facilitate the success of my research career and help me achieve extramural funding.”

—Joshua B. Wechsler, MD

APFED’s HOPE on the Horizon Research Program is funded entirely by donations! Thank you for your support!
2018 APFED HOPE Pilot Research Grant Award

Recipient: Fei Li Kuang, MD, PhD
Allergy & Clinical Immunology Fellow
National Institute of Allergy and Infectious Diseases,
National Institutes of Health

Award Amount: $50,000
Project Term: 2 years

Project: Dr. Kuang’s project entitled “Effects of Eosinophil Depletion on Pathogenic Lymphocytes in Hyper-eosinophilic Syndrome (HES)/EGID Overlap” will utilize multi-parametric flow cytometry and gene expression sequencing on peripheral blood and gut tissue to determine if eosinophils exert a negative regulatory role on pathogenic lymphocytes.

Patient Impact: This project will provide a better understanding of the relationship between eosinophils and lymphocytes in HES/EGID with the goal of illuminating new research avenues, bringing us closer to improved therapeutics for patients suffering from this chronic disease.

APFED 2018 Best Oral Abstracts on EGIDs

APFED works with medical societies to provide small monetary awards and recognition to the best research abstracts presented at the national conferences for these professional organizations. The awards offset travel costs to the researchers so that they may present their findings about eosinophilic gastrointestinal diseases to the medical community. Abstract award winners may go on to successfully compete for grants from APFED or from other funding mechanisms.

2018 AAAAI/APFED Best Oral Abstract on EGIDs
Annual Meeting of the American Academy of Allergy, Asthma & Immunology (AAAAI), March 2018, $750 award each to the best-scoring abstract by a Fellow-in-Training and by a Member

Peter S. Capucilli, MD (Fellow-in-Training)
Children’s Hospital of Philadelphia, Philadelphia, PA
Abstract: “A Comparison of Comorbid Diagnoses in Children with and without Eosinophilic Esophagitis in a Large Primary Care Population”

Ichiro Nomura, MD (Member)
National Research Institute for Child Health and Development,
Tokyo, Japan
Abstract: “Elevated Serum TSLP, IL-33, 6Ckine and MCP-3 Levels in School Children or Older Patients with Eosinophilic Gastroenteritis”

Did you know that when you donate to APFED, you may choose to direct your gift to specific programs, such as to research or education? Learn more and make your gift at apfed.org!
2018 HOPE APFED/AAAAI Pilot Grant Award

Recipient: Mirna Chehade, MD, MPH
Mount Sinai Center for Eosinophilic Disorders, Jaffe Food Allergy Institute, Icahn School of Medicine at Mount Sinai

Award Amount: $140,000

Project Term: 2 years

Dr. Mirna Chehade has been selected to receive funding for her promising work on the effects of proton pump inhibitor (PPI) therapy on genes associated with eosinophilic esophagitis (EoE).

Dr. Chehade’s project entitled “Impact of Proton Pump Inhibitors on the Esophageal Transcriptome in Eosinophilic Esophagitis Subtypes” will receive funding through the grant award, which is co-funded equally between APFED and the American Academy of Allergy, Asthma and Immunology (AAAAI).

Dr. Chehade and her team will research the effects of proton pump inhibitor treatment on the EoE transcriptome in an attempt to identify EoE from PPI-responsive esophageal eosinophilia. Addressing this important issue may provide new insights into the how EoE-associated genes are suppressed with PPI therapy. Identification of transcriptome markers of PPI responsiveness would have a high impact in the clinical setting.

APFED is excited to once again partner with AAAAI to fund this research study by Dr. Chehade, which has the potential to result in improved and targeted treatment options for our community.

“I’m honored to receive this award and grateful to APFED and AAAAI for the opportunity to pursue this research. Through this grant, I hope to better understand which patients might benefit from PPI therapy, and therefore reduce some of the trial and error treatment approaches we currently follow in eosinophilic esophagitis. This project will help pave the way for personalized medicine for patients suffering from EoE.”

~ Mirna Chehade, MD, MPH

Help Us Replenish Our HOPE Research Fund!

Please make a tax-deductible donation TODAY so that APFED can continue to support researchers in their quest to provide us with better diagnostic tools, therapy advancements, and answers!

Donate online: apfed.org

Donate via mail:
APFED
PO Box 29545
Atlanta, GA 30359

Matching Gifts: If your employer has a Matching Gifts program, you may maximize your gift to APFED! Your employer will have the forms needed to make the request for a match.

Help us to rebuild our HOPE Research Fund! The more we raise, the more research we can fund! Donate online at apfed.org and earmark your gift to research.
Research Consortium
In February, APFED attended a research meeting with other key partners of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR), held at the National Institutes of Health (NIH). Discussion focused on future research plans and a review of research developments undertaken by CEGIR. Thanks to the ongoing studies across the U.S. and the publications resulting from this research, the knowledge base on EGIDs is growing rapidly, as is the awareness of these disorders. The consortium is funded by awards from NIH and patient advocacy groups, including APFED. APFED provides supplemental funding for CEGIR’s training program to support investigators who are new to rare disease research.

Professional Meetings
APFED facilitates education for health care providers by financially supporting seminars and meetings. In March, several APFED-funded researchers shared their findings and discussed eosinophilic gastrointestinal disease features, etiology, and clinical associations with their peers during the CEGIR/TIGERs EGID Symposium at the Joint Congress of the American Academy of Allergy, Asthma & Immunology (AAAAI) and the World Allergy Organization in Orlando, FL.

Research Needs
Last summer, APFED took part in a taskforce to review the current state of progress in eosinophil-associated disease research and resources and compare it to unmet needs today. In April, the findings of this task force resulted in an important review paper entitled “Revising the NIH Taskforce on the Research Needs of Eosinophil-Associated Diseases (RE-TREAD),” which serves as a progress report on the unmet needs of our patient community. APFED has long advocated for federal research priority for EADs and has supported related efforts. In 2012, we actively planned the “Taskforce on the Research Needs of Eosinophil Associated Diseases (TREAD) Workshop,” which proposed and prioritized unmet EAD research needs. This resulted in a pivotal paper known as the “TREAD document,” co-authored by APFED, that highlighted areas of need for EAD research to guide the distribution of funds as they became available. Representing our community on these taskforces and helping to identify research priorities and advance clinical care are key parts of APFED’s mission.

Patient Needs and Care
APFED has funded new research shedding light on what patients and caregivers with eosinophilic gastrointestinal disease perceive to be unmet needs and barriers to care. APFED supported Dr. Girish Hiremath’s work and closely collaborated with other CEGIR participants in authorship of a new study in Clinics and Research in Hepatology and Gastroenterology. The findings will help guide future programs, services, and resources for improved patient-centered EGID care.

CHIP Funding Extended—Thanks to You!

APFED, working in partnership with other organizations dedicated to rare disease, issued a call to action in January urging families to request that members of Congress vote to extend long-term funding for the Children’s Health Insurance Program (CHIP). Failure to act would have resulted in putting approximately 9 million children at risk of losing healthcare coverage.

APFED’s Medical Advisory Panel also signed on to a letter APFED sent to key Congressional leaders urging a funding extension. We are pleased to announce that Congress voted to extend CHIP funding for another six years. Thank you to all concerned citizens who participated in our call to action. Your voice was heard!

Medical Nutrition Equity Act

The Medical Nutrition Equity Act (H.R. 2587 and S. 1194), also known as MNEA, is bi-partisan legislation introduced to Congress in May 2017. It would require insurance plans to provide coverage of medical foods for both children and adults diagnosed with inborn errors of metabolism and other certain digestive disorders. Elemental formula prescribed to treat eosinophilic gastrointestinal diseases is included. To support this legislation, APFED is working collaboratively with a coalition known as Patients & Providers for Medical Nutrition Equity.

APFED has attended numerous meetings on Capitol Hill to meet with members of Congress and their staff to share with them the importance of medical foods coverage to our patient community, and to urge support of MNEA. On June 1, APFED financially supported and participated in a “Hill Day,” where we invited community members to join us for a day of meetings at the House and Senate offices in Washington, DC. Currently MNEA has 22 congressional co-sponsors. APFED and members of the coalition are working to increase support and we need your continued help (see below)!

Ask your members of Congress to co-sponsor the Medical Nutrition Equity Act (H.R. 2587 and S. 1194). Visit http://apfed.org/advocacy/medical-nutrition-equity-act/ for a list of Congressional targets, directions on how to make contact, talking points to share, and links to the House and Senate language.

If your employer offers a matching gifts program, you can to double your gift to APFED!
HES Patient Conference

On March 23, 2018, APFED hosted a Hypereosinophilic Syndromes Patient Education and Drug Development Conference in Rockville, MD.

The meeting was a unique opportunity for patients and providers to learn about treatments and research advances for hypereosinophilic syndromes (HES), and to share perspectives with the FDA and other key stakeholders about the impact of HES on patients and families, as well as how patients view current treatment approaches.

Patient panelists kicked off discussion by sharing their journeys and how the disease and treatment has affected their lives. This was followed by a facilitated discussion inviting comments from other patients and conference participants in the audience. Webcast participants also had an opportunity to provide input through webcast comments, and patients and caregivers were invited to submit their perspective in advance to be read aloud and/or shared in post-event reporting to the FDA and other stakeholders.

A recording and a transcript of the meeting may be found on apfed.org. We finalizing a “Voice of the Patient” report that summarizes the commentary shared at the conference. This whitepaper will be submitted to the FDA and made available to all stakeholders.

New Resources about Hypereosinophilic Syndromes

Thanks to two grants, APFED produced a new brochure for Hypereosinophilic Syndromes as well as an educational toolkit to help patients and families who are newly diagnosed with the condition. APFED is distributing the material to clinicians around the U.S. to share with their patients, and is available to the public for free download on apfed.org.

Raising Awareness

APFED celebrated the 11th annual National Eosinophil Awareness Week May 20-26 this year. APFED brought together institutions and organizations to increase awareness and provided free materials for partners to share on their platforms. In addition, we made free resources available to the public, offered giveaways on social media, shared information with the press, and launched a series of subset-specific, social media-friendly infographics that reached more than 130,000 people through APFED’s channels alone. These infographics are made available on the corresponding “About EAD” pages on apfed.org.

Community fundraisers help support APFED. If you can help, please email Julie Forrest at jforrest@apfed.org to get started!
Families Gather in Denver for APFED’s Eos Connection Patient Education Conference

In early July, the Eos community converged in Denver, CO for APFED’s 16th Annual Patient Education Conference. Every year, Eos Connection gives individuals and caretakers the chance to learn from the experts and connect with others who understand what it’s like to live with eosinophil-associated disease.

This year’s conference was held in collaboration with Children’s Hospital Colorado (CHC) and the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR). Under the guidance of Drs. Glenn Furuta and Dan Atkins, co-directors of the Gastrointestinal Eosinophilic Diseases Program at CHC, the two-day program included more than 25 presentations from leading researchers, healthcare professionals, and patient advocates, focusing on a variety of topics, including advancements in diagnosis and treatment, nutrition, coping with various aspects of EAD, transitional care, and more. The youth program provided children, tweens, and teens with fun, age-appropriate educational and team-building activities.

Many families arrived before sessions started for a family-friendly pool party, a meet-and-greet, and a tour of the lab at Children’s Hospital Colorado. On Friday, attendees, families, and friends joined us for APFED’s HOPE on the Horizon Walk in General’s Park, with proceeds benefiting APFED’s research program. Children and teens created and carried awareness-raising signs and participants enjoyed an evening in the park, socializing and meeting new friends while raising funds for a great cause.

The conference included programming focusing on clinical and research updates and practical management. Attendees customized their conference experience to suit their needs by choosing from a variety of breakout sessions. Virtual attendees connected to the conference’s general sessions on Friday and Saturday and participated in Q&A opportunities with the panel of speakers.

We closed the conference with a family-friendly celebration that included music, dancing, games, crafts, cotton candy, and a raffle and silent auction to benefit APFED’s HOPE on the Horizon Research Fund.

It’s always amazing to share in the energy and enthusiasm of conference attendees and their families. We hope everyone returned home feeling enriched, inspired, and supported!
APFED Unveils Two New Educational Resources

◊ **New Toolkit for EoE Patient and Caregivers:** Do you or a loved one have eosinophilic esophagitis (EoE)? Our new toolkit new is designed to help those navigating an EoE diagnosis and includes answers to commonly asked questions, a glossary, tips for daily management, research progress summary, and much more! [Get your EoE toolkit.](#)

◊ **Teaching Kids About EGID:** APFED has partnered with the Eosinophilic Family Coalition on a new handout designed to teach elementary school-aged children how to support a classmate who has eosinophilic gastrointestinal disease. The handout may be downloaded, reproduced, and distributed freely. [Download a copy.](#)

**NASPGHAN Annual Meeting:** In November, APFED was onsite at the 2018 Annual Meeting of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) in Hollywood, FL. NASPGHAN is the professional society for pediatric gastroenterologists in North America, serving a membership of more than 2,200 clinical gastroenterologists and scientists from the U.S., Canada, and Mexico. Meeting attendees gather each year to learn about advances in the field and to discuss current topics in clinical applications. A series of lectures were delivered by faculty associated with the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR).

In addition, two APFED Outstanding EGID Abstract Awards were presented to researchers with the best scoring abstracts on EGID. Dr. Kelly Whelan of Fels Institute for Cancer Research & Molecular Biology at Temple University in Philadelphia, PA, presented the abstract titled, "Rapamycin-mediated Autophagy Activation Ameliorates EoE-Associated Alterations in Epithelial Tissue Architecture." Dr. Edaire Cheng of University of Texas Southwestern Medical Center in Dallas, TX presented the abstract titled, "AK/STAT6 Are Potential Therapeutic Targets for Esophageal Remodeling in EoE."

**Summary of Updated Diagnostic Criteria for EoE**

In July, APFED shared a publication entitled “Updated international consensus diagnostic criteria for eosinophilic esophagitis: PPIs better classified as treatment vs. a diagnostic criterion (Outcomes from the AGREE Conference).” This pivotal paper, to which APFED was a contributor, included an updated diagnostic algorithm for EoE, removing the requirement of a trial of PPI (proton pump inhibitor) before a diagnosis of EoE is determined.

This fall, we were pleased to offer a summary document that highlights key points of this important work, which we are disseminating to doctors around the globe. [Download a copy.](#)

**APFED Receives 2018 Top-Rated Non-Profit Seal**

Thanks to your positive reviews on [greatnonprofits.org](http://greatnonprofits.org), APFED has been honored to receive a Top-Rated Award of 2018 from GreatNonprofits. Thank you to all who rated us so highly!
Thank You to Our Community Fundraisers!

We are deeply grateful to the community members around the nation who fundraise to help support APFED’s mission and advance research. Not only do these events raise needed funds, but they also provide the opportunity for community members to gather together for networking and support.

Here are a few of the community members who hosted an event in 2018 to benefit APFED:

Deneen K.: APFED’s HOPE on the Horizon Walk, Kingsville, MD

Alex: APFED’s HOPE on the Horizon Walk, East Islip, NY

Ethan R.: Adam Rantz Memorial Golf Outing, Green Lane, PA

Jessica E: Shopping for Charit-EoE, Atlanta, GA

Michaela: Luna Lung Meets HES Book Launch Fundraiser, Westport, MA

Elizabeth L.: 5th Annual Tee Off for EoE, Gobles, MI

Stay Tuned for 2019 Events!

Our community leaders are planning events for 2019! For details about these events and others, visit apfed.org/events/community-partner-events/

Will You Help?

Community-led fundraising greatly helps APFED to replenish its research fund, enabling us to support more projects. To help plan a fundraiser of any size to support APFED, please contact Julie Forrest at jforrest@apfed.org for help.
Help HOPE Grow

APFED passionately embraces, supports, and improves the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy. The work we do and the research we fund is made possible by donations. Please make a tax-deductible gift online at apfed.org.

Facebook Makes Fundraising Easy!

Making a donation to APFED is now as easy as clicking the "Donate" button on our Facebook page! Just follow the button on the upper right side of our page to make a quick, secure donation to help us continue the work we do for those living with eosinophil-associated diseases: https://www.facebook.com/APFED/.

You can celebrate a birthday, anniversary or other special event with your own fundraiser on Facebook and ask people to donate to a cause close to your heart. Just click on the "Fundraisers" tab on the left column of your Facebook page. Select APFED as your charity, and share your fundraiser with friends and family. The entire process takes less than five minutes.

Thank you for supporting APFED!

Donations to APFED are tax-deductible. Make your gift today!
Each member of APFED’s Board of Directors has a personal connection to eosinophil-associated diseases and voluntarily contributes time and talents to our cause.

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2018 Financial Summary

Revenue and other support

- Investment Income: $155
- Contributions: $192,783
- Grants: $298,045
- Memberships: $3,620
- Other Income: $17,613

Expenses

- Administrative: $34,234
- Fundraising: $39,897
- Program Services: $556,965

Net Assets Totals

Beginning of year: $416,513
End of year: $266,138

A full copy of our independently audited financial statement for 2018 appears online apfed.org.