Driving Change

Dear friend:

APFED is comprised of our community members. We are individual patients and caregivers, families, health care providers, research partners, and caring friends working together to educate, advocate, and accelerate research, all while providing one another the support we all need.

In this update, you will read how APFED has moved its mission forward this year, thanks to the generous support of our donors and education partners. On behalf of the patients and families we serve, thank you for championing our cause!

Mary Jo Strobel
Executive Director

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.

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
**2017 Advances: Research**

**HOPE** gives us courage.  
**HOPE** gives strength.  
**HOPE** lets us imagine a different tomorrow.

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. Researchers submit proposals and a committee of peers review and score the proposals. The most promising research is selected to receive an APFED HOPE Grant.

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### 2017 APFED HOPE Pilot Research Grant Award

**Recipient:** John Garber, MD  
Assistant in Medicine, Massachusetts General Hospital; Instructor in Medicine, Harvard Medical School

**Award Amount:** $100,000

**Project Term:** 2 years

Dr. Garber’s research project entitled, “Determinants of Integrin Signaling in Eosinophilic Esophagitis,” seeks to better understand the important questions: *How do eosinophils start to migrate from the blood to the esophagus? How do protein receptors on the eosinophils interact with the receptors on the cells of the esophagus, to allow them to get into the esophagus, become active, and cause inflammation?* Dr. Garber’s team will study whether a protein that has been found in the tiny vessels of the esophagus in active EoE, promotes recruitment of circulating eosinophils via the α4β7 protein found on eosinophils. Dr. Garber’s team will also study if CD11 protein on eosinophils interact with the esophageal protein periostin to activate and hold on to eosinophils in the esophagus.

This research would help us better understand the mechanisms of eosinophil recruitment into the esophagus, which may then lead to development of treatments that stop the migration of eosinophils into the esophagus.

“The APFED HOPE Pilot Grant will provide key support for studies of eosinophil integrins, which are molecules on the surface of eosinophils that determine how these cells move through the blood, migrate to specific tissues and cause diseases such as eosinophilic esophagitis. Integrin biology in the setting of eosinophilic disorders is not well understood, but with the support of the APFED, we hope to advance our fundamental knowledge of how integrins regulate and drive eosinophil functions. We expect that insights from this work will rapidly open new approaches to the diagnosis and treatment of eosinophil-mediated disorders.”

~ John Garber, MD

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APFED’s HOPE on the Horizon Research Program is funded entirely by donations! Thank you for your support!
2017 APFED HOPE Pilot Research Grant Award

Recipient: Aaron Kobernick, MD, MPH  
Assistant Professor, Allergy and Immunology  
Department of Dermatology  
University of Utah

Award Amount: $100,000

Project Term: 2 years

Dr. Kobernick’s project, entitled “Detection of eosinophilic inflammation in patients with Eosinophilic Esophagitis by oral administration of Tc-99m Heparin,” focuses on finding a noninvasive way to detect and monitor eosinophilic esophagitis (EoE). Dr. Kobernick’s team has developed a technique where small amounts of a radioactively labeled substance called heparin is swallowed, and binds to the proteins released by eosinophils in the esophagus. The bound heparin is detected by a camera outside the body—in preliminary data, EoE, but not reflux disease, is associated with this heparin binding in the esophagus and is picked up by the camera. Dr. Kobernick’s team is focusing on finding the lowest amount of radioactivity that can make this test as safe as possible to use clinically while being sensitive enough to pick up active EoE disease.

This research shows great promise in the development of a noninvasive method for doctors to examine tissue inflammation caused by eosinophil-associated diseases and monitoring EoE without endoscopy and biopsy.

“I am grateful and honored to receive the APFED Hope award. For many children and adults afflicted with EoE, detection of disease remission or progression relies on repeated endoscopy. With this grant, our team will advance detection of EoE using nuclear imaging with computerized tomography. We are eager to share our results and make a difference in the lives of our patients.”  
~ Aaron Kobernick, MD, MPH

APFED 2017 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.

2017 AAAAI/APFED Best Oral Abstract on EGIDs  
Annual Meeting of the American Academy of Allergy, Asthma & Immunology (AAAAI), March 2017, $750 award

• Dr. Benjamin L. Wright, Mayo Clinic Arizona; Scottsdale, AZ. Peripheral Blood Eosinophil Degranulation Is Inhibited in Eosinophilic Esophagitis Implications for Non-Invasive Assessment of Disease Activity

• Dr. Justin C. Wheeler, MD, Cincinnati Children’s Hospital Medical Center; Cincinnati, OH. Role of Hormone Signaling in Eosinophilic Esophagitis: 17-Beta Estradiol Attenuation Of IL-13 Induced Barrier Dysfunction in Esophageal Epithelium

2017 NASPGHAN/APFED Best Oral Abstract on EGIDs  
Two $750 awards will be presented at the annual meeting of the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN), November 2017.
Other Ways APFED Supported Research This Year

**Professional Meetings.** APFED facilitates education for health care providers by financially supporting seminars and meetings. This year, APFED provided financial support for the 10th Biennial Symposium of the International Eosinophil Society (IES) that took place in July 2017 in Gothenburg, Sweden. Scientists and clinicians traveled from around the world to discuss information and ideas about eosinophils and their role in diseases. APFED was invited to present to the group the status and impact of medical coding for EADs. The Advocacy section of this newsletter provides more information about our initiative in this area.

**Patient Perspective.** APFED facilitates focus groups and interviews between patients and researchers so that research is optimized for success and clinical endpoints are meaningful. A white paper was published in the August issue of *Clinical Gastroenterology and Hepatology*, addressing the current state of therapy, unmet needs, and suggestions for future directions in drug development for eosinophilic esophagitis. This paper was developed based on key takeaways from 2016 Drug Development Conference sponsored by the Center for Diagnostics and Therapeutics of the American Gastroenterological Association that was held last fall. APFED attended the meeting to share the patient perspective and needs, such as financial burden, pediatric assessment challenges, and barriers to clinical trials.

**Consortium Grant.** APFED provides annual supplemental funding to support the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR). CEGIR is a collaborative effort made possible through awards by the NIH to research eosinophilic disorders and train investigators in how to conduct clinical research. CEGIR is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research. The RDCRN advances medical research by providing support for clinical studies and facilitating collaboration, study enrollment and data sharing for more than 200 rare diseases. APFED provided key components of the CEGIR grant application, and contributes to the development of CEGIR study protocols, coordinates patient feedback, and supports communications between CEGIR and the patient community. APFED provides similar support and services to grants made possible through the Patient Centered Outcomes Research Initiative (PCORI).

**Co-Authored Research**


- “Lack of Knowledge and Low Readiness for Health Care Transition in Eosinophilic Esophagitis and Eosinophilic Gastroenteritis,” *July 2017 - Volume 65 - Issue 1 - p 53–57*

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**Your Gift Makes It Possible!**

Please make a tax-deductible donation TODAY so that APFED can continue its programs and services.

**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.

**Fundraising Events:** To help plan or a fundraising event to support APFED, please contact Julie Forrest at jforrest@apfed.org.

Your support makes ALL the difference!
APFED is a global resource for credible, accurate information about eosinophil-associated diseases. By working together, EADs are now better recognized, diagnostic delays have decreased, and there is a better understanding of treatment options. Patients, caregivers, providers, and others also now have a growing array of multi-media content and platforms from which to learn about EADs and how to manage the condition, as well as connect with others for support.

Eos Connection 2017: APFED’s 15th Annual Patient Education Conference on EGIDs

Held July 7-8 in Greenville, SC, APFED’s annual conference once again brought together patients, families, and stakeholders to learn and share the latest in disease research and therapies, and participate in dynamic sessions focusing on practical management. Portions of the program were open to a virtual audience. The program included more than 25 presentations from leading researchers, healthcare professionals, and patient advocates, focusing on a variety of topics, such as diagnostic and treatment advancements, nutrition, coping, school advocacy, transitional care, and more. The conference’s youth programs provided children, tweens and teens with fun, age-appropriate activities, and several social events took place, including a HOPE on the Horizon Walk for Eos in Cleveland Park, and an anniversary celebration.

APFED’s Educational Webinar Series

Our popular e-library featuring recorded interviews, conference segments, and webinars continued to grow this year. APFED, in partnership and collaboration with the Center for Managing Chronic Disease at the University of Michigan, released more than 70 new segments that address topics such as clinical trials, treatment, esophageal dilation, transitioning to adult care, patient perspective, and coping. APFED’s Educational Webinar Series is made possible thanks to the support of our Education Partner EleCare®.

Hypereosinophilic Syndromes

Thanks to a generous grant from the Allen E. & Patricia M. Murray Foundation, APFED published a new patient-friendly brochure about hypereosinophilic syndromes. The material is available on apfed.org and hard copies are being disseminated to clinicians to share with their patients.

Eosinophilic Asthma

Together with our partner PeerViewInstitute, APFED developed new material to educate patients and providers about eosinophilic asthma. The material is available on apfed.org and includes a webpage, downloadable fact sheet and brochure, and a portal to an online CME program for health care providers. Support for the development of these resources was provided by a grant from Teva Pharmaceuticals.
2017 Advances: Education & Awareness

National Eosinophil Awareness Week

In celebration of National Eosinophil Awareness Week (NEAW), May 14-20, 2017, APFED invited individuals, organizations, health care professionals, schools and other supporters to help us spread awareness in their communities, and offered an online toolkit featuring resources to help with efforts.

APFED launched an action-oriented social media campaign during NEAW called READ for EAD: Rally Around Eosinophil Associated Diseases. Participants dedicated words of inspiration to a loved one and shared on social media using the hashtag #READ4EAD, and challenged their friends and family members to participate and/or make a donation to APFED. We loved all the ways the Eos community used words to inspire, educate, and remind patients that they are not alone!

2017 Professional Meetings Attended

APFED continues to be a resource for education for eosinophil-associated disorders in the health care community. This year, we participated in a number of professional meetings that offered lectures and workshops designed to help providers give optimal care to patients with eosinophil-associated diseases, and to facilitate discussion about research, theories, and therapies. APFED participates in these meetings in a number of ways, from disseminating educational materials to attendees, to actively engaging in special committees and taskforces to advance research, advocacy, and awareness of EADs, and to presenting patient perspective.

- American Academy of Allergy, Asthma & Immunology
- American College of Allergy, Asthma & Immunology
- Consortium of Eosinophil Gastrointestinal Disease Researchers
- Digestive Disease Week
- International Eosinophil Society
- World Congress of Gastroenterology at ACG 2017
- North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN)

Are You Up to the Challenge?

Join APFED in celebrating our 15th anniversary by participating in the $150,000 HOPE Challenge! APFED supports our research community through our HOPE on the Horizon Research Fund. Will you help us reach our goal of raising $150,000 this year? All individual donations, matching gifts, and proceeds from fundraising events for APFED in 2017 will count toward our goal! [Learn more at apfed.org](http://apfed.org).
2017 Advances: Advocacy

For 15 years, APFED has worked diligently to advocate for patients who have eosinophil-associated disease. Over the years we have advocated for federal funding for research, proper medical coding of eosinophilic gastrointestinal diseases, insurance coverage of medical foods, and more.

Insurance Coverage of Medical Foods

The cost of elemental formula is a financial burden for some families. To help families have affordable access to prescribed medically-necessary foods to treat their EGID, APFED has supported state and federal mandates for insurance coverage.

APFED continues to serve as a resource for advocates around the U.S. who are working on the state level to introduce legislation that would mandate insurance coverage of medical foods in areas where no such mandate currently exists. This year, APFED continued its work in support of Medical Nutrition Equity Act, which was reintroduced into Congress earlier this year. The legislation would require medical foods, such as elemental formula prescribed to treat eosinophilic disorders to be covered under Medicaid, Medicare, the Federal Employee Health Benefit Program, and private insurance.

In addition to launching grassroots campaigns to encourage Congressional co-sponsorship of the legislation, APFED has also made a number of visits to Capitol Hill to meet with elected officials and their staff to share patient stories and encourage support of this legislation.

Currently, the bill has 13 Congressional co-sponsors from California, Georgia, Massachusetts, Minnesota, New York, North Carolina, Ohio, Tennessee and Washington.

Protections for Rare Disease Patients in National Health Care Legislation

APFED continues to actively advocate for protections for rare disease patients as Congress revises the Affordable Care Act. To date, there have been a number of legislation proposals that could negatively impact rare disease patients by undermining patient protections, increasing costs, decreasing coverage, cutting Medicaid, and removing crucial pre-existing condition protections.

APFED contacted elected officials to voice concerns, signed onto letters of support as part of a larger initiative of rare disease-focused patient and professional groups, and issued a Legislative Call to Action to urge families to voice their concerns, as well.

As an organization serving the needs of a rare disease community, APFED will continue to advocate for access to high-quality and affordable healthcare coverage that affords protections for those with pre-existing conditions.
Other Advocacy Initiatives APFED Supported in 2017

APFED joined several other patient and professional organizations to make our voices heard on issues that affect the rare disease community, such as:

- Ending the NIH/FDA hiring freeze to avoid significantly hampering research into rare disease treatments and the subsequent approval process.

- Opposition of H.R. 1313, the *Preserving Employee Wellness Programs Act*, legislation that would attempt to tie financial incentives to employee wellness programs at the expense of the crucial privacy and anti-discrimination protections afforded employees with genetically-detectable diseases, including eosinophil-associated diseases and other rare diseases.

- Support of the Orphan Drug Tax Credit (ODTC), urging Congress to keep this critical tax credit in place to provide incentives for drug companies to develop products for rare diseases.

- Support for *Addendum Guidelines for the Prevention of Peanut Allergy in the United States*, compiled this year by the National Institute of Allergy and Infectious Diseases. APFED served as a participant on the coordinating committee.
APFED FUNdraisers

We are grateful to the dedicated volunteers who organized fundraisers to support APFED, and for event sponsors who helped our cause. These events not only raise critical funds, but also spread awareness in local communities.

From top to bottom, left to right: APFED’s HOPE on the Horizon Walk for Eos, Greenville, SC; APFED’s HOPE on the Horizon Walk for Eos, Fall River, MA; 4th Annual Tee Off for EoE, Paw Paw, MI; Adam Rantz Memorial Golf Outing, Green Lane, PA; APFED’s HOPE on the Horizon Walk for Eos, Kingsville, MD; APFED’s HOPE on the Horizon Walk for Eos, Littleton, CO.

To bring an event to your community, contact
fundraise@apfed.org

Coming to NYC on Nov. 10...

“Charit-EoE Concert for a Cure for Eosino... What???” will feature Mike DelGuidice and Big Shot, celebrating the music of Billy Joel.

A brighter tomorrow begins with a donation today. Please make a tax-deductible gift online at apfed.org