Your Support Makes a Difference!

Dear friend:

We are pleased to share with you this progress report of APFED’s activities for the first half of 2019.

Thanks to community support, we are making great strides in the areas of research, education, advocacy, and awareness of eosinophil-associated diseases.

Your generous donations to APFED and community fundraisers you host make all the difference. Thank you for championing change for the patients who live with these conditions!

Mary Jo Strobel  
Executive Director

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.

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.
Groundbreaking EoE Research from APFED HOPE Grant Recipient

APFED HOPE Grant recipient Dr. Ting Wen recently completed his research project titled, “Defining Esophageal Lymphocyte Phenotype and Function in Eosinophilic Esophagitis.”

“The T helper lymphocyte type 2 (Th2) is a type of white blood cell capable of producing Th2 cytokines and that supports accumulation of another type of white blood cell, eosinophils,” Dr. Wen explains. “We found that certain human gastrointestinal bacteria metabolites (short-chain fatty acids) could enhance the Th2 cytokine production by Th2 lymphocytes, potentially causing EoE, and our proposed studies are expected to provide a detailed understanding of the regulatory role of short-chain fatty acids to Th2 cytokine production by Th2 lymphocytes.”

A team at Cincinnati Children’s, led by Wen (pictured below) and senior author Marc Rothenberg, MD, PhD, recently published results of a tissue study that reveals the cells that drive EoE. The researchers developed a 10- to 12-hour process that isolated and studied single living cells from tissue samples collected from patients with EoE.

The study found eight types of immune system T cells in the esophageal tissue. Two cell types (T7 and T8) show up in higher numbers in the diseased tissue. The study finds that one of these two cell types responds to allergens by generating large amounts of type 2 cytokines, an inflammation-causing substance. One of these cell types (T8) is nearly non-existent in healthy tissue, making it a promising target for treatment.

New Non-invasive Imaging Device Studied for Pediatric Patients

A paper published this spring describes a new tethered spectrally-encoded confocal endomicroscopy (SECM) capsule suited for pediatric patients (similar to the SECM device being developed for adults). Thanks to donations to our HOPE on the Horizon Research Fund, APFED provided funding in 2016 to Dr. Guillermo J. Tearney, co-author of this study, to support the development of the pediatric SECM capsule. A SECM capsule is an imaging device designed to be swallowed by an unsedated patient. The device can visualize cellular changes associated with gastrointestinal tract diseases. This technology could provide a non-invasive way to detect and monitor esophageal eosinophilia, as opposed to endoscope/biopsy.

Study Compares Restricted Diets for Children with EoE

A preliminary summary has been shared on the project, "Comparing Two Restrictive Diets for Treating Eosinophilic Esophagitis in Children," funded by the Patient Centered Outcomes Research Initiative (PCORI). The summary noted “both diets resulted in improved symptoms, quality of life, and well-being. Symptoms improved more in children who removed four foods from their diet compared with children who removed only one food. In addition, 40% of children in both groups showed remission. In remission, few allergy-related cells are found in the esophagus.” APFED supported this work by contributing to the development of study protocols, coordinating patient feedback, and supporting communication between PCORI and the patient community.

CEGIR Retrospective on EG, EGE, and EC

A recent publication features a retrospective study of data collected from six centers in the Consortium of Eosinophilic Gastrointestinal Researchers (CEGIR) over ten years. Investigators aimed to “characterize the rates of diagnosis, clinical features, and initial treatments for patients with as eosinophilic gastritis (EG), eosinophilic gastroenteritis (EGE), and eosinophilic colitis (EC).” APFED is an active CEGIR participant, providing supplemental funding and offering the patient perspective in all areas of its work (learn more on page 5).

Help us build our HOPE on the Horizon Research Fund!
The more we raise, the more research we can fund! Donate online at APFED.org.
**Professional Meetings:** APFED facilitates education for health care providers by financially supporting seminars and meetings. In March, several APFED-funded researchers led sessions specific to eosinophilic gastrointestinal disorders (EGIDs) at the annual meeting of the American Academy of Allergy, Asthma & Immunology (AAAAI). APFED also attended the AAAAI EGID Task Force Committee (pictured right), which works to initiate and advance education and awareness of EGIDs among health care providers to improve patient care. Finally, as an exhibitor at AAAAI (pictured right), APFED connected with thousands of attendees from the areas of allergy, asthma, and immunology. APFED was also onsite in May for Digestive Disease Week® (DDW) in San Diego. This event brings together doctors and researchers in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery. The meeting showcases more than 5,000 abstracts and hundreds of lectures on the latest advances in GI research, medicine and technology. Highlights from a variety of talks and abstracts on eosinophilic gastrointestinal diseases (EGIDs) can be found at [apfed.org](http://apfed.org).

### 2019 AAAAI/APFED Best Oral Abstract on EGIDs
APFED provides small monetary awards and recognition to the best research abstracts presented at the national conferences for professional organizations. The awards offset travel costs to the researchers so that they may present their findings to the medical community. Abstract award winners may go on to successfully compete for grants from APFED or from other funding mechanisms. The following award winners were presented with a $750 award each at the Annual Meeting of the American Academy of Allergy, Asthma & Immunology.

**Recipient:** Basil M. Kahwash, MD (Fellow-in-Training), The Ohio State University, Columbus, Ohio

**Abstract:** “Peripheral Blood Microarray Analysis in Pediatric Patients with Eosinophilic Esophagitis”

**Recipient:** Catherine Sonaly Ferreira Martins, MD (Member), Division of Clinical Immunology and Allergy, Hospital das Clínicas, University of Sao Paulo, Brazil

**Abstract:** “EoE, OIT and Anaphylaxis: An Unsolved Puzzle”

### Support HOPE
Please make a 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](http://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.

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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](http://APFED.org)!
Advocacy & Awareness: January-July 2019

APFED on Capitol Hill for Medical Nutrition

Patients, caregivers, and advocates from across the country met with lawmakers on Capitol Hill in May to support the Medical Nutrition Equity Act (MNEA). APFED was joined by several members of the Eos community who shared their medical foods stories and let legislators know how much we need national insurance coverage for medical food.

The event was organized by Patients and Providers for Medical Nutrition Equity (PPMNE), a coalition of which APFED is a member. APFED provided financial support to help defray the costs of the event.

In May, the Medical Nutrition Equity Act (MNEA) was reintroduced in the House of Representatives (the new bill number is H.R. 2501). Get the latest MNEA updates on APFED’s website.

Show Your Support for MNEA

- Share your story and highlight why insurance coverage of medical foods is important to you.
- Tell your legislators to co-sponsor MNEA! If you are represented by a legislator who is not a current co-sponsor, send an email directly from the PPMNE website to encourage co-sponsorship.

New ICD-10-CM Codes Proposed for Subsets of Eosinophilic Diseases

Over the past year, APFED and the International Eosinophil Society (IES) have partnered to propose and jointly advocate for eight distinct ICD-10-CM Codes for subsets of eosinophilic diseases and for four amendments to existing codes. In March, APFED Board Member Kathleen Sable and IES President Dr. Bruce Bochner presented justification for the new codes/amendments to members of the ICD Coordination and Maintenance Committee. The proposal for the new codes/amendments was well received, and a decision will be made following a review period. Learn more about the proposed codes and amendments.

National Eosinophil Awareness Week

On May 19-25, we celebrated the 12th annual National Eosinophil Awareness Week (NEAW)! APFED invited individuals, institutions, and organizations across the country to spread the word about eosinophil-associated diseases. We made free resources available to the public, offered giveaways on social media, and shared a series of awareness-raising infographics. We loved all the ways the Eos community inspired and educated others and reminded patients that they are not alone!
CEGIR Investigator Meeting

In March, APFED attended the annual investigator meeting for the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) at the National Institute of Allergy and Infectious Diseases in Rockville, MD. The purpose of this meeting was to discuss data and findings from CEGIR’s current studies, as well as talk about future research directions if CEGIR’s application for a second cycle of funding is approved this year. APFED presented at the meeting and shared our current initiatives with investigators, including our advocacy work for new medical codes for EADs (more details below) and our active engagement with the Rare Disease Clinical Research Network and its Coalition of Patient Advocacy Groups.

APFED provides annual supplemental funding to support 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. 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.

RDCRN Patient Advocacy Meeting

The Coalition of Patient Advocacy Groups (CPAG) is comprised of more than 100 patient advocacy groups that are directly affiliated with a Rare Disease Clinical Research Network (RDCRN) consortium, and collectively represents the perspective and interests of rare diseases patients.

In April, members of the RDCRN-CPAG met onsite in Rockville, MD for their annual meeting. APFED helped to plan and participated in this meeting as a patient group representative for the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR).

APFED Board member Kathleen Sable (pictured left) and Executive Director Mary Jo Strobel (pictured right) both served as panelists at the meeting, sharing information about APFED’s successes in establishment of medical codes/classification for subsets of eosinophil-associated diseases and the impact of the European Union General Data Protection Regulations on patient advocacy groups, respectively.

Did you know you can set up a recurring donation at APFED.org? Choose the amount and frequency in which you’d like to make your gift.
Thank You to Our Fundraisers!

We are deeply grateful to the community members around the nation who fundraise to benefit APFED. Special thanks to the following community members who hosted fundraising events in the first half of 2019!

- **Deneen Kettell**: APFED’s HOPE on the Horizon Walk for Eos, Kingsville, MD, May, 2019
- **Suzanne Hammett**: APFED’s HOPE on the Horizon Walk for Eos, Birmingham, AL, May 2019
- **Ethan Rantz**: Adam Rantz Memorial Golf Outing, Green Lane, PA, May 2019
- **Shelly Parks**: Pints for a Purpose Fundraiser, Yorklyn, DE, May 2019

YOU CAN RAISE MONEY, FUND RESEARCH, CHANGE LIVES!

Make an impact by organizing a HOPE on the Horizon Walk for Eos or other fundraising event in your area.

Not sure where to begin? We have ideas to help you plan a fun and successful fundraiser. Contact Julie Forrest at jforrest@apfed.org to get started!

Get details about upcoming community events.

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**Save the Date!**

**Charit-EoE Concert for a Cure for Eosino...What?**

**Featuring the Steven Page**

*Founding Member, Barenaked Ladies and 2019 Inductee to Canadian Rock & Roll Hall of Fame*

**November 7, 2019 | 7:00-10:00 PM**

TGA NYC | 320 West 36th St. New York, NY 10018

Event Co-Chairs:
Arlene and Lance Steinberg
Juliet Ross

Questions? Contact Event Director
Julie Forrest at jforrest@apfed.org

**Tickets:** $60 per person
**Event Registration:** www.apfed.org/tailgate2tackle
Includes unlimited beer tasting & delicious snacks fit for a winning team
PLUS 10 raffle tickets ($15 value)
Tickets without raffle tickets - $50
Event is for ages 21 and up

Proceeds benefit APFED’s HOPE on the Horizon Research Program.
APFED is a registered 501(c)3 organization.
Learn more about APFED at www.apfed.org
Tax ID: 76-0700153

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Support and Community Building