June 2020

Dear Supporter,

I hope this update finds you and your loved ones healthy and secure. APFED is aware of the dramatic impact the coronavirus pandemic and recent societal events have had on patients, families, and health care workers around the globe. Despite the challenges that our communities face, we continue with our important mission 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.

Our progress is the direct result of the ongoing support from you and all our generous supporters. Your contributions of money, volunteerism, and participation have assured that our community can continue to thrive and serve all those affected by eosinophil-associated disease.

I am excited to share with you the accompanying document that outlines the progress APFED has made in the first half of 2020. We are proud of the accomplishments we have made this year thus far and are eager to continue making significant contributions to research, education, and advocacy initiatives to improve the landscape for the people we serve.

Please consider a mid-year donation to APFED to help us continue this terrific momentum. Your contribution to our HOPE on the Horizon Research Program will enable us to invite researchers this fall to submit proposals for innovative research projects for funding consideration.

APFED is proud of our transparent, ethical, and professional oversight of community donations, directing funds to areas of unmet research needs. Our grants program is structured so that each research proposal is reviewed and scored by an independent and impartial committee of research peers to help us select the most impactful research projects that make the most of our donors’ contributions.

Please help us to build HOPE by donating to APFED today. Gifts may be mailed to our address below or made online at apfed.org. We offer recurring gift options and information about employer matching donation programs.

Thank you for your continued generosity, kindness, and support.

Sincerely,

Mary Jo Strobel
Executive Director
Tax ID: 76-0700153
Connecting the Eosinophilic Community
APFED is a non-profit patient advocacy organization with a 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 2020 Mid-Year Progress Report:

Education & Awareness

Rare Disease Day – APFED was invited to serve on the planning committee for the NIH Rare Disease Day 2020 event held on the NIH Campus in Bethesda, MD on February 28. The day’s agenda included updates from the NIH, novel approaches to improving access to knowledge and research, shortening the diagnostic journey, and inspiring patient stories. The event was well attended, welcoming nearly 750 people onsite and more than 1,000 live viewers engaged via VideoCast. Leading up to the event, APFED participated in an NIH-led Twitter Chat about Rare Disease Day.

COVID-19 Resources – Under the guidance of our Health Sciences Advisory council members, APFED disseminated information about the potential impact of COVID-19 on the higher-risk patients in our patient community. We created a coronavirus resource page on apfed.org to house resources, related webinars, and information for patients about accessing elemental formula. We developed and launched a new resource in collaboration with clinical psychologists for patients and caregivers to help manage stress and anxiety amid the pandemic. APFED provided feedback to our Health Sciences Advisory council members and to the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) regarding patient questions and concerns related to COVID-19, and shared information to help clinical teams better facilitate telehealth services.

New Educational Brochures – APFED created a new patient-friendly brochure for EGPA and updated our brochure for eosinophilic asthma. These resources are freely available on apfed.org.

Ask the Expert – In May, APFED welcomed guest expert, Dr. Kristle Lynch, a gastroenterologist at the University of Pennsylvania, who hosted a special COVID Q&A on our EosConnections community on the Inspire network. Patients and caregivers posted questions for Dr. Lynch during the week, and her responses were posted for all users to access.

National Eosinophil Awareness Week – APFED celebrated National Eosinophil Awareness Week (May 17-23) by increasing outreach efforts and making educational resources freely available for our community to use in their efforts to expand awareness. In addition to APFED’s platforms, we also maintained and created content for the National Eosinophil Awareness Week Facebook group, which is an unbranded platform that APFED offers as a public service. We reached more than 100,000 people during this special week.

Professional Education Series on EGIDs – APFED participated in a complimentary web-based education series for health-care professionals titled “The ABCs of EGIDs” and developed by NASPGHAN (North American Society for Pediatric Gastroenterology, Hepatology & Nutrition), the NASPGHAN Foundation, and CEGIR (Consortium of Eosinophilic Gastrointestinal Disease Researchers). The webinars cover the basics of research processes to the study of rare diseases, engagement of patient advocacy groups and cutting-edge information on EGIDs.

Address: P.O. Box 29545, Atlanta, GA 30359 • Phone: 713.493.7749 • Email: mail@apfed.org • Website: www.apfed.org

Registration Is Open for APFED’s Virtual Patient Education Conference!
Due to COVID-19, we made the difficult decision to cancel our planned patient conference in San Diego, scheduled for July. We are pleased to provide an all-virtual program this year, to be hosted July 9-11, 2020. If you are an APFED member, check your email for a special code to waive the registration cost for this unique event, which will include sessions on eosinophil-associated disease led by experts in the field, Q&A with presenters, live interaction with exhibitors, and networking opportunities with other attendees. Register now!
High-risk population protections during pandemic – APFED advocated for protections for high risk populations during the pandemic at both the state and federal levels. As such, we signed onto letters to Governors, Medicaid Directors, Insurance Commissioners, and Executive Directors of Boards of Pharmacy to urge protections such as emergency regulations to lift barriers to accessing medication from out-of-network pharmacies, coverage of off-formulary prescription drugs if no formulary drug is available; and ensuring prior authorization and reauthorization requirements do not impede access to care and treatment.

Medical Foods - APFED continues its support of the Medical Nutrition Equity Act, working as part of the Patients and Providers for Medical Nutrition Equity coalition. Since pandemic-related restrictions made it necessary to cancel our planned visits to Capitol Hill to meet with lawmakers, APFED participated in a series of phone calls with Hill staff during the week of May 17-23 to educate them about the need for the legislation and to seek co-sponsorship of the bill.

ICD-10 Codes – APFED continues to advance ICD-10 codes for subsets of eosinophil-associated diseases that currently do not have a code. We are expecting to soon receive an update regarding what changes are to be implemented in September.

Food Labeling – To help minimize impact of food supply chains and product availability during the COVID-19 pandemic, the FDA issued guidance to provide temporary flexibility in food labeling requirements. The guidance allows manufacturers to make minor adjustments to ingredient formulations without updating the ingredient list. To advocate for patients in our community who often avoid less-common food allergens, APFED joined other patient advocacy groups to convey concerns to the FDA and to ask that the FDA require manufacturers to publicly post ingredient substitutions for consumers to access (e.g., via a manufacturer’s website or social media channels). We are continuing ongoing discussions with the FDA about this issue.
APFED 2020 Mid-Year Progress Report: 

Research

APFED is dedicated to HOPE by funding research that leads us to a better understanding of eosinophil-associated diseases. Our Hope on the Horizon Research Program is supported entirely by donations and advances eosinophil disease research initiatives through a variety of mechanisms, which are highlighted below.

CEGIR Scientific Meeting – APFED attended the annual in-person scientific meeting of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) on March 3 in Rockville, MD. The meeting enables members of CEGIR to meet in person to discuss findings related to research conducted by the consortia and future directions. APFED participated in the day-long meeting, providing patient perspective and leading discussion on communicating research opportunities and news to patients.

2020 APFED HOPE Pilot Grant – APFED awarded its 2020 HOPE Pilot Grant to Edaire Cheng, MD, Assistant Professor of Pediatrics, University of Texas Southwestern Medical Center, Dallas, TX. Dr. Cheng for her project entitled, "The Development of the EoE Food Trigger Assay."

2020 APFED/CEGIR Co-funded Pilot Grant Award - APFED and CEGIR co-funded pilot grant award to Paneez Khoury, MD, MHSc, of the National Institute of Allergy and Infectious Disease's Human Eosinophil Section, for a promising research study that will provide the first examination of gastric motility in patients with eosinophilic gastritis (EG).

2020 AAAAI/APFED Best Abstract on EGIDs Awards – APFED funded two $750 awards to the best-scoring abstracts on eosinophil-associated gastrointestinal diseases (EGIDs) presented at the annual meeting of the American Academy of Allergy, Asthma & Immunology (AAAAI) this year: Benjamin L. Wright, MD, Mayo Clinic, for his abstract entitled “Peanut Oral Immunotherapy Induces Gastrointestinal Eosinophilia in a Longitudinal Randomized Controlled Trial,” and Margaret Collins, MD, Cincinnati Children’s Hospital Medical Center, for her abstract entitled “Budesonide Oral Suspension Improves Histologic Features in Patients With Esophagitis: Results From A Phase 3 Randomized, Double-blind, Placebo-Controlled Trial.”

Perspectives of Patients and Caregivers Elemental Formula For EGID: In partnership with researchers at Mt. Sinai hospital in NYC, APFED conducted a survey to gain patient and caregiver perspective of formula usage for EGID treatment. The abstract was released online as part of the virtual annual meeting of the American Academy of Allergy, Asthma & Immunology.

HOPE gives us courage. HOPE gives strength. Your donation to the HOPE on the Horizon Research Program lets us imagine a different tomorrow.
APFED 2020 Mid-Year Progress Report:
Organization & Community

**Health Sciences Advisory Council** – Increased the number of APFED medical advisors for a more broad representation of the many specialties serving patients with eosinophil-associated disease. Our expansion includes dietitians, psychologists, clinicians in private practice, and specialists in academia that service patients with EGPA, eosinophilic asthma, EGID and other subsets of eosinophil-associated disease. A list of Health Sciences Advisors appears on our website.

**International Eosinophil Society (IES) Partnership** – APFED partnered with IES to invite their members to create a listing in APFED’s new Specialist Finder with a special digital badge to help visitors identify members of the Society.

**EosConnections Online Community on Inspire** – The Inspire platform, which houses APFED’s online support community, successfully launched its app in January. The app is available for Apple users, and there are follow up plans to release an Android version later this year. APFED served as a beta-tester of the app providing navigation feedback. APFED’s online community has more than 10,000 members.

**Committees and Coalitions** – APFED serves on a number of committees, providing patient perspective and input on a variety of initiatives. In 2020, we participated in discussions for CEGIR committees (recruitment, diversity in clinical trials, scientific advisory, and steering), Patients & Providers for Medical Nutrition Equity, Rare Disease Day at NIH Planning Committee, Takeda’s One×One Summit, and the EGID Task Force Committee of the American Academy of Allergy, Asthma & Immunology.