



Summer 2019

CEGIR Findings Presented at Annual Gastroenterology Meeting

Digestive Disease Week® (DDW) is an annual meeting for professionals working 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.

A variety of talks and abstracts on eosinophilic gastrointestinal diseases were presented at the 2019 meeting, which was held in May in San Diego. CEGIR researchers presented some of their findings at this event. Here, we summarize some highlights.

- Using data collected from the CEGIR Contact Registry, investigators analyzed patient reported symptoms and co-morbidities in EoE relative to non-EoE EGIDs: eosinophilic gastritis, eosinophilic gastroenteritis and eosinophilic colitis. The study authors noted that weight loss and gastroparesis were more frequently reported by those with non-EoE subsets of EGID, and that these patients were more likely to report higher frequency of nausea, stomach pain, diarrhea, constipation, bloating, fatigue, feeling of isolation, and deep muscle or joint pain.

“Significant differences exist in the symptoms and co-morbidities experienced between those with EoE versus a non-EoE EGID(s), with more severe symptoms and higher frequency of comorbidities experienced by those with non-EoE EGIDs,” the authors write. “Additional investigation is needed to elucidate the factors that may contribute to the high disease burden of these poorly-understood conditions.”

“High patient-reported disease burden for eosinophilic gastrointestinal disorders.” Jensen ET, Abonia JP, Aceves SS, et al.

- Researchers set out to develop and validate a diagnostic panel for eosinophilic gastritis (EG) diagnosis and management to help better understand that pathogenesis of EG. The authors noted that preliminary evidence showed that this diagnostic panel score better correlated with symptoms than eosinophil counts for patients with intermediate tissue eosinophil levels (≥ 30 HPF).

“Development of the eosinophilic gastritis molecular diagnostic panel.” Shoda T, Wen T, Caldwell JM, et al.

Continued on next page

Patient Advocacy Group Spotlight



EOS Connection 2019, APFED's 17th Annual Patient Education Conference, will be held **July 25-27** in the Washington, D.C. area. This event is held in collaboration with CEGIR and Children's Hospital of Philadelphia. CEGIR-specific sessions will be held on Saturday, July 27, with CEGIR researchers presenting both days.

Eos Connection provides attendees the opportunities learn about the latest eosinophil-associated disease, gain practical strategies to manage it, and to interact with patients, caregivers, and healthcare and industry professionals.

For more information or to [register](#), visit apfed.org



WASHINGTON, D.C.
APFED'S 17TH ANNUAL
PATIENT EDUCATION CONFERENCE
ON EOSINOPHIL-ASSOCIATED DISEASES

CEGIR Findings, continued from page 1

- CEGIR investigators aimed to prospectively evaluate endoscopic features in patients with eosinophilic gastritis so that there is a better understanding of endoscopic manifestations and develop a scoring instrument. The study authors note, “A strong and significant correlation between [these] scores and physician global assessment of endoscopy severity was demonstrated.”

“Prospective evaluation of a novel, endoscopic activity assessment system for eosinophilic gastritis.” Hirano I, Collins, MH, King E, et al.

Enrolling CEGIR Studies

Eosinophilic Esophagitis

Use of Unsedated Transnasal Esophagoscopy to Monitor Dietary Management of EoE in Children: This study uses unsedated (not put to sleep) transnasal endoscopy to learn more about how long it takes esophageal eosinophils to come back after a new food is started in children with EoE. Children in this study will have eliminated one to four foods as treatment for their EoE and may be taking steroid therapy.

Eosinophilic Gastritis, Eosinophilic Gastroenteritis

Effect of Elemental Diet on Adult Patients with Eosinophilic Gastroenteritis (ELEMENT): CEGIR investigators in Chicago are conducting a study to see if avoiding certain foods will improve EG or EGE. Participants complete an elemental (formula-based) diet treatment for at least 6 weeks to see if their EGID gets better after at least 6 weeks of dietary treatment.

Eosinophilic Esophagitis, Eosinophilic Colitis, Eosinophilic Gastritis, Eosinophilic Gastroenteritis

Outcome Measures for Eosinophilic Gastrointestinal Diseases across Ages - OMEGA: Why do patients still have EGID symptoms even if their scopes are good, or vice versa? The OMEGA clinical trial seeks to find answers to this question and more.

Validation of Online Cohort of Eosinophilic Gastrointestinal Disorder Patients Enrolled in RDCRN Contact Registry: The purpose of this study is to determine the accuracy of self-reported EGID information provided by the CEGIR Contact Registry Participants compared to their physician’s report. Another purpose of this study is to determine the agreement between pathology report confirming EGID diagnosis and patient report.

These studies are being conducted at centers across the country. For more information, or to find the CEGIR institution closest to you, visit rdcrn.org/cegir

Upcoming Events

Education:



EosConnection 2019 • Washington, D.C.
APFED's 17th Annual Patient Education Conference
on Eosinophil-associated Diseases

July 25-27
DoubleTree Hotel
Bethesda, MD

Apfed
American Partnership
for Eosinophilic Disorders

In collaboration with:  Children's Hospital of Philadelphia  CEGiR
Consortium of Eosinophilic
Gastrointestinal Disease Researchers



REGISTER NOW!
**5th CURED Patient Education
Research Conference**
NOVEMBER 7TH-10TH, 2019 -- CINCINNATI, OH
REGISTER AT WWW.CUREDFOUNDATION.ORG

 Cincinnati Children's  CURED
Campaign Urging Research for Eosinophilic Disease www.CuredFoundation.org  CEGiR
Consortium of Eosinophilic
Gastrointestinal Disease Researchers

[Learn more and register: apfed.org](http://apfed.org)

Fundraisers:

August 18, 2019

[Tailgate to Tackle Eosinophils](#), benefiting APFED's HOPE on the Horizon Research Program
Pontoon Brewing
Sandy Springs, GA

November 7, 2019

[Charit-EoE Concert for a Cure for Eosino...what???](#), benefiting APFED's HOPE on the Horizon Research Program
TGA NYC
New York, NY 10018

CURED Foundation Calendar: <https://curedfoundation.org/fundraising/fundraisers/#r=off>



www.rdcrn.org/cegir



www.apfed.org



www.curedfoundation.org



www.eoscoalition.org

The Rare Diseases Clinical Research Network will make every effort to enroll all the patients we can, but we cannot make any guarantees that we will be able to enroll everyone in a study who wants to participate. Participation in research studies is voluntary. Deciding not to participate in a research study does not affect your ability to receive care at any of our Clinical Centers or from other physicians. The Rare Diseases Clinical Research Network (RDCRN) was established by the Office of Rare Diseases Research, NCATS, National Institutes of Health (NIH) to develop research studies for rare diseases, and to encourage cooperative partnerships among researchers at over 150 clinical centers around the world. This increased cooperation may lead to discoveries that will help treat and perhaps prevent these rare diseases, as well as produce medical advances that will benefit the population in general. The Rare Diseases Clinical Research Network is comprised of a Data Management and Coordinating Center and 22 consortia studying over 200 rare diseases.

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