

CEGIR NEWS

CEGIR Meets to Discuss Research Initiatives

The Consortium of Eosinophilic Gastrointestinal Disease Researchers ([CEGIR](#)) is a collaborative effort between scientists and health care providers, the National Institutes of Health, professional organizations, and patient advocates.

In early March, CEGIR met in Atlanta to discuss the consortium's study aims, trial recruitment, and early results from ongoing CEGIR studies and trials.

The meeting allowed investigators and patient advocates to share information, review progress, and continue toward a better understanding of these diseases and how best to care for patients.

Newly Developed and Validated Eosinophilic Esophagitis Histology Scoring System and Evidence that It Outperforms Peak Eosinophil Count for Disease Diagnosis and Monitoring

CEGIR investigators designed and tested a scoring system for esophageal biopsies that better evaluates abnormalities in the tissue that may result from eosinophilic esophagitis (EoE). This system provides pathologists a method to objectively evaluate the changes the esophagus undergoes due to EoE. It also helps them to make a more definitive diagnosis beyond counting the number of eosinophils in a tissue sample. The researchers continue to evaluate this new scoring system as a part of a CEGIR project.

[Collins, et al., "Dis. Esophagus, 2016.](#)

Visit [CEGIR's website](#) for a full list of publications.

Upcoming Events

For a list of upcoming events of interest to the EGID community visit [CEGIR's website](#).

Patient Advocacy Group Spotlight

APFED

The American Partnership for Eosinophilic Disorders (APFED), a 501c3 nonprofit, passionately embraces, supports, and improves the lives of patients and families affected by eosinophil-associated diseases (EADs) through education and awareness, research, support, and advocacy.

Examples of APFED's accomplishments include advocating for federal research funding, proper medical coding of EGIDs, establishing a federally-recognized National Eosinophil Awareness Week, advocating for insurance coverage of medical foods, participating in development of national guidelines for diagnosis and management of EoE, and funding research through a competitive, peer-reviewed process.

To learn more about APFED and EADs, access free resources and an e-newsletter, or make a donation, visit [apfed.org](#).

CEGIR Trainee Scholars

CEGIR is part of the Rare Disease Clinical Research Network (RDCRN), which supports investigators who are new to rare disease research. The CEGIR trainees are experienced medical professionals who are working to better focus their research efforts in eosinophil-associated disease.



Patricia C. Fulkerson, MD, PhD, Cincinnati Children's Hospital Medical Center

Dr. Fulkerson is measuring the level of cells in the blood which will likely become eosinophils in those with EoE. Her findings indicate that people with active EoE have greater numbers of these cells when compared to those with inactive EoE. A second study will confirm the findings and will track the cell levels in patients with EoE. Another project she is working on will provide a better understanding of why there is a high rate of EGIDs in people who have undergone solid organ transplant (e.g., liver, pancreas), and disease differences in these individuals compared to those who have not had a similar transplant. The findings may provide insight into why EGIDs develop.

[Learn More >](#)



Girish Hiremath, MD, Vanderbilt University Medical Center

Dr. Hiremath is validating the characteristics of patients who are enrolled in the CEGIR contact registry. This is an important step toward using the registry for a variety of research projects. He recently conducted a study to better understand the unmet needs of EGID patients and caregivers. The data is being analyzed with the goal of making recommendations for improved, patient-focused healthcare.

[Learn More >](#)



Amanda B. Muir, MD, The Children's Hospital of Philadelphia

Dr. Muir is measuring the amount of stretch of the esophagus. The stretch is a potential marker of early thickening and scarring of esophageal tissue in EoE (fibrosis). The data from the study will be used to establish what the normal values of stretch are for the pediatric population. It will also help determine if the stretch correlates with patient symptoms or with how tissue samples look under a microscope.

[Learn More >](#)



Robbie Pesek, MD, Arkansas Children's Hospital

Dr. Pesek is characterizing the demographics, medical histories, and clinical presentations of patients with eosinophilic gastritis, eosinophilic gastroenteritis, and eosinophilic colitis. He is analyzing the pathology information that was collected upon a patient's diagnostic endoscopy and will evaluate their prescribed treatments. This will lead to a better understanding how often these diseases occur, and how they are diagnosed and treated.

[Learn More >](#)



Joshua Wechsler, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Dr. Wechsler is examining the role of mast cells in EoE. Mast cells are immune cells that reside in tissue and are increased and activated in EoE. This causes inflammation that leads to chronic symptoms and fibrosis. This work will assess the clinical characteristics of these cells and the specific effects of their

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activation.

Enrolling CEGIR Studies

Six Food vs. One Food Eosinophilic Esophagitis Elimination Diet followed by Swallowed Glucocorticoid Trial - SOFEED

This interventional study will test and compare the effectiveness of two elimination diets for the treatment of EoE, as well as the effectiveness of swallowed glucocorticoid therapy in those for whom diet therapy was not effective.

Outcome Measures for Eosinophilic Gastrointestinal Diseases across Ages - OMEGA

Why do patients still have EGID symptoms even if their scopes or good, or vice versa? The OMEGA clinical trial seeks to find answers to this question and more. Do you qualify to participate?

Microbiome Study: A Sub-Study of OMEGA

Is there a link between amounts and types of bacteria in the gut and having an eosinophilic gastrointestinal disease (EGID)? Do patients with eosinophilic esophagitis, eosinophilic gastritis, or eosinophilic colitis have an imbalance of gut bacteria compared with those who do not have EGID? This study aims to find out through stool analysis, which has the potential to lead to a non-invasive test for EGID.

Learn more about Eosinophilic Gastrointestinal Diseases:



www.rdcnrn.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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