



CEGIR NEWS

Spring 2019

CEGIR PUBLICATION SPOTLIGHT

Gastroenterology has just published an article by Dr. Sandeep Gupta, et al. reviewing current CEGIR projects. Updates on both the OMEGA study (Outcome Measures for Eosinophilic Gastrointestinal Diseases across Ages) and the SOFEED trial (Six Food versus One Food Eosinophilic Esophagitis Elimination Diet) are outlined in the article. In addition, four novel pilot studies are briefly discussed, including investigating the use of losartan in eosinophilic esophagitis (EoE) patients, elemental diets in eosinophilic gastritis patients, transnasal endoscopies for monitoring EoE, and gaining further knowledge of the microbiome found in eosinophilic gastrointestinal disorders (EGIDs). The article explains how CEGIR's training/career development program is strengthening the EGID research community via new investigators, projects, publications and funding while spreading knowledge to the greater medical community through its on-line educational videos. Through the aid of cloud technology and the sharing of thousands of slides, a new central Pathology Core has begun utilizing novel histology scoring systems. These have led to the improvement of diagnostic parameters in EoE and non-EoE EGIDs. Collaborations with Patient Advocacy Groups and the patient contact registry have propelled CEGIR toward clinical trial readiness and focused studies at improving the quality of life for EGID patients.

Source: Gupta SK, Falk GW, Aceves SS, Chehade MA, Collins MH, Dellon ES, Gonsalves N, Hirano I, Mukkada VA, Peterson KA, Spergel J, Yang G-Y, Furuta GT, Rothenberg ME, on behalf of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR), Consortium for Eosinophilic Researchers (CEGIR): Advancing the Field of Eosinophilic GI Disorders Through Collaboration, *Gastroenterology* (2018)

To Read More: <https://doi.org/10.1053/j.gastro.2018.10.057>

Patient Advocacy Group Resource Spotlight

Eosinophilic Family Coalition (EFC)

The EFC is a registered 501(c)3 organization whose mission is to support and enhance the lives of families living with Eosinophilic Disorders. This is accomplished through a multi-faceted model that includes both professional and peer to peer support. Families are provided opportunities to connect through a wide variety of activities. The EFC sponsors Camp CouragEOS® the first and only camp dedicated to families living with Eosinophilic Disorders. In addition, the EFC sponsors the CouragEOS® Capes program in which every child and adult living with an Eosinophilic Disorder is provided with a superhero cape kit to honor the challenges that families face in living with this disorder.

For more information, please visit: www.eoscoalition.org



Enrolling CEGIR Studies

We want to hear from you! Please check your email inboxes for a new CEGIR survey (3 questions)! Thank you for your participation!

Eosinophilic Esophagitis

Open-Label Trial of Losartan in Participants with EoE: The purpose of this clinical study is to evaluate the impact of treatment of EoE with the drug losartan, which is a medication used in patients to control high blood pressure. Specifically, the study will look to see if losartan therapy reduces eosinophil number in the esophagus as well as improving EoE symptoms as measured by a questionnaire.

Use of Unsedated Transnasal Esophagoscopy to Monitor Dietary Management of EoE in Children: This study will use 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 will not 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 will complete an elemental (formula-based) diet treatment for at least 6 weeks to see if your 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. Do you qualify to participate?

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 physicians 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

Published Research from CEGIR

Since CEGIR's formation, investigators have published a number of studies related to the consortium's work. You can find the list of publications by visiting www.rdcnrn.org/cegir

Educational Videos

Did you know that CEGIR's website offers educational videos about eosinophilic gastrointestinal diseases? The videos feature expert presentations on a variety of topics, such as nutritional management of EoE, biological therapy in EoE, and psychosocial implications in EGIDs to name just a few.

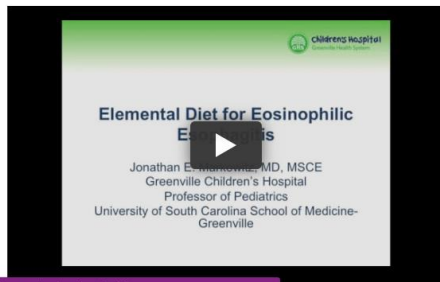


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EDUCATIONAL VIDEOS

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Elemental Diet for Eosinophilic Esophagitis - Dr. Jonathan Markowitz



Endoscopic Assessment of Eosinophilic Esophagitis - Dr. Ikuo Hirano



Resources

CEGIR's website also offers educational resources about eosinophilic gastrointestinal diseases? The patient resources page includes links to current practice guidelines, and a few patient centered blogs on food elimination.

[Learn More](#)

Upcoming Events

Save the Date!
EosConnection 2019
July 25-27, 2019
Washington, D.C.
Mark your calendars for APFED's National Patient Education Conference!

Held in collaboration with

Children's Hospital of Philadelphia

CEGIR
Consortium of Eosinophilic Gastrointestinal Disease Researchers

Apfed
American Partnership for Eosinophilic Disorders

SAVE THE DATE
5th CURED Patient Education Research Conference
November 7 – November 10, 2019
Cincinnati, OH

Cincinnati Children's

CURED
Campaign Urging Research for Eosinophilic Disease
www.CuredFoundation.org

CEGIR
Consortium of Eosinophilic Gastrointestinal Disease Researchers

Learn more about Eosinophilic Gastrointestinal Diseases:



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.

CEGIR (U54AI117804) is a part of the NCATS Rare Diseases Clinical Research Network (RDCRN). RDCRN is an initiative of the Office of Rare Diseases Research (ORDR), NCATS, funded through a collaboration between the NCATS, the NIAID and the NIDDK. CEGIR is also supported by patient advocacy groups including APFED, CURED and EFC.

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by the U.S. Government. www.RareDiseasesNetwork.org