



Summer 2018

## New Study Findings Could Lead to Personalized Medical Treatments for Eosinophilic Esophagitis (EoE)

Using data from 185 patients participating in ongoing CEGIR clinical studies, researchers have identified 3 different subtypes (endotypes) of EoE. This finding may help scientists develop more targeted treatments for the disease.

In a May 2, 2018 [press release](#), Dr. Marc Rothenberg noted, “This is an important stride forward for the allergy and gastroenterology fields. With emerging new therapies for allergic diseases, including a new class of anti-eosinophil drugs, as well as anti-inflammatory biological agents that block specific components of allergic inflammation, this is good news for patients, as this brings the field one step closer to personalized and precision therapy.”

This discovery highlights the importance of patient participation in clinical studies! Your support of CEGIR and its work is changing what is known and understood about eosinophilic gastrointestinal diseases (EGIDs).

[The study](#) is published online in *The Lancet Gastroenterology & Hepatology*.

## APFED Patient Conference To Be Held In Collaboration With CEGIR and Children’s Hospital Colorado

EOS Connection 2018, APFED’s 16<sup>th</sup> Annual Patient Education Conference, will be held **July 6-7** in Denver, Colorado. CEGIR-specific sessions will be held on Friday, July 6, with CEGIR researchers presenting both days.

Attendees will learn about the latest disease research, current approaches to EGID management, and interact with patients, caregivers, and healthcare professionals.

Don’t miss out - [Register](#) today!

Patient Advocacy Group  
Resource Spotlight

**Apfed**  
American Partnership  
for Eosinophilic Disorders

Last year, CEGIR Scholar Dr. Girish Hiremath, in collaboration with other CEGIR participants, conducted a study on the unmet needs of EGID patients. Based on this [study](#), published in *Clinics and Research in Hepatology and Gastroenterology*, only 5% of respondents found there was adequate awareness of EGIDs in schools.

**Need information to share with your child’s school? APFED has numerous [resources](#) for you!**



## Annual CEGIR Investigator Meeting Held at National Institutes of Health (NIH)

In early February, CEGIR held its 2018 in-person meeting on the NIH campus in Bethesda, Maryland. CEGIR investigators, patient advocacy group representatives and NIH staff participated in this one day meeting. Presentations and workshops focused on future research initiatives and a review of ongoing studies.



## CEGIR 7801 (OMEGA) Study Meets EoE Patient Enrollment Recruiting Continues for EG and EC Patients

Have you or your child been diagnosed with Eosinophilic Gastritis (EG) or Eosinophilic Colitis (EC)\*? Researchers need YOU to help unlock answers to these rare diseases. Learn more about the OMEGA trial [here](#).

*\*The study is no longer accepting patients with Eosinophilic Esophagitis since enrollment has been met.*

## Other CEGIR Studies

In addition to [CEGIR 7801](#), CEGIR is currently recruiting patients for the following studies:

- [CEGIR 7802 \(SOFEED\)](#) - **Six Food vs. One Food Eosinophilic Esophagitis Elimination Diet followed by Swallowed Glucocorticoid Trial**  
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.
- [CEGIR 7803](#) - **A Preliminary Open-Label Trial of Losartan Potassium in Participants with Eosinophilic Esophagitis (EoE) With or Without a Connective Tissue Disorder**  
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 numbers in the esophagus as well as improving EoE symptoms, as measured by a questionnaire.
- [CEGIR 7808](#) - **Use of Unsedated Transnasal Esophagoscopy to Monitor Dietary Management of Eosinophilic Esophagitis in Children**  
This study will use unsedated (not put to sleep) transnasal endoscopy (TNE) to learn more about how long it takes esophageal eosinophils to come back after a new food is started in children with Eosinophilic Esophagitis (EoE). Children in this study will have eliminated one to four foods as treatment for their EoE and will not be taking steroid therapy.

## Other CEGIR Studies (continued)

- [CEGIR 7809](#) - Effect of Elemental Diet on Adult Patients with Eosinophilic Gastroenteritis (ELEMENT)

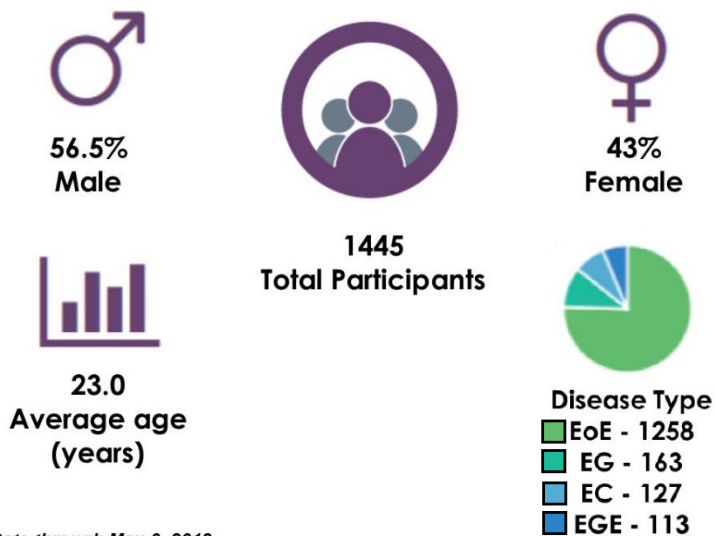
CEGIR investigators in Chicago are conducting a study to see if avoiding certain foods will improve EG or EGE. Participants will complete an elemental (formula-based) diet treatment for at least 6 weeks to see if your EGID gets better after at least 6 weeks of dietary treatment.

## Contact Registry Update

Please take a moment to log into CEGIR's Contact Registry to make sure your information is up to date and/or complete the EGID questionnaire, if you haven't already done it.

If you know of other patients and families that live with eosinophilic gastrointestinal diseases, please share the [CEGIR Contact Registry link](#) with them, and encourage them to enroll so that may stay up-to-date on future opportunities.

### The CEGIR Contact Registry Summary



Data through May 6, 2018



[www.rdcrn.org/cegir](http://www.rdcrn.org/cegir)



[www.apfed.org](http://www.apfed.org)



[www.curedfoundation.org](http://www.curedfoundation.org)



[www.eoscoalition.org](http://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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Initiative of the National Center for Advancing Translational Sciences (NCATS)