

# CEGIR NEWS



Fall 2017

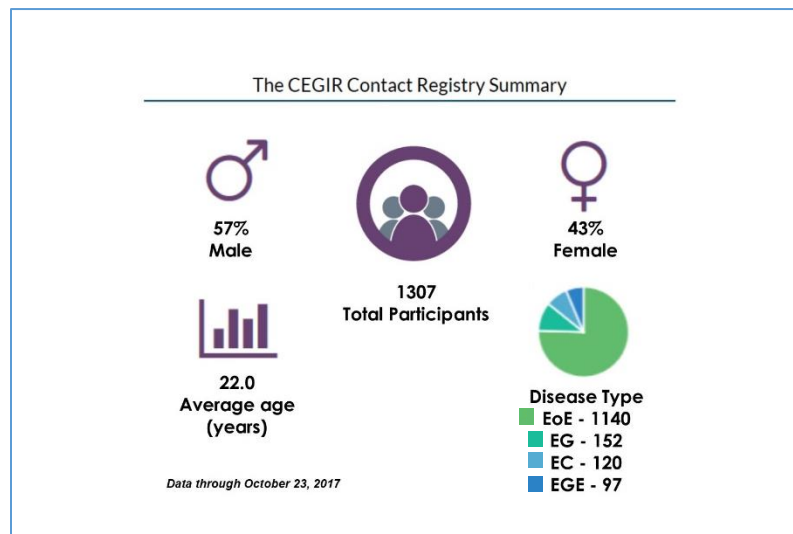
## CEGIR Contact Registry Update

The Consortium of Eosinophilic Gastrointestinal Disease Researchers ([CEGIR](#)) was established in 2014 through awards from National Institutes of Health (NIH) and patient advocacy group funding. CEGIR is a collaborative effort between scientists and health care providers around the nation, the National Institutes of Health, professional organizations, and advocates.

The aims of CEGIR's research are guided by outcomes that patients feel are important. Participating centers are currently enrolling patients into a variety of clinical studies, including sub-studies in select locations. You may read more about these opportunities on the next page.

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

If you know of other patients and families that live with eosinophilic gastrointestinal diseases, please share this information with them, and encourage them to enroll into CEGIR's Contact Registry so that they may stay up-to-date on future opportunities.



## Patient Advocacy Group Resource Spotlight

*American Partnership for Eosinophilic Disorders (APFED)*

### Answers from Experts Patient Involvement in Research

*How are patients protected?  
What questions should you ask  
before participating?  
How can patients accelerate  
research?*

These questions and more are answered by Dr. Wendy Book in [this video playlist](#) from APFED's Educational Webinar Series.



Find more resources at  
[apfed.org](http://apfed.org)



EOS Connections Support Community

6,100+ members strong and growing

25,000+ member posts

Join the discussion at [APFED.Inspire.com](http://APFED.Inspire.com)

## Published Research from CEGIR

Since CEGIR's formation, investigators have published a number of studies related to the consortium's work. Here we highlight four studies that were published this summer. To view others, visit [rdcrn.org/cegir](http://rdcrn.org/cegir).

1. In EoE, there is an increase of a molecule known as “transforming growth factor- $\beta$ 1 (TGF- $\beta$ 1)”. New data suggests that this molecule participates in esophageal barrier dysfunction of the esophagus through the dysregulation of another molecule, known as claudin-7 (CLDN7).  
*Nguyen N, et al. “[TGF- \$\beta\$ 1 alters esophageal epithelial barrier function by attenuation of claudin-7 in eosinophilic esophagitis.](#)” *Mucosal Immunol.* 2017 Aug 23. doi: 10.1038/mi.2017.72.*
2. Investigators looking at the likelihood of complete clinical tolerance in patients with EoE who reintroduced all foods after an elimination diet found that 0.5% of these patients achieved complete tolerance to food triggers. The authors concluded “although very uncommon, some patients with EoE can have significant periods of complete clinical tolerance.”  
*Ruffner MA, et al. “[Clinical tolerance in eosinophilic esophagitis.](#)” *J Allergy Clin Immunol Pract.* 2017 Aug 12. pii: S2213-2198(17)30519-6. doi: 10.1016/j.jaip.2017.06.035.*
3. Researchers now have a better understanding of the cells involved in esophageal barrier disruption, and cell production and signaling. The study authors note, “Experimental modeling has defined a cooperative role of activated eosinophils, mast cells, and the cytokines IL-5 and IL-13, mediated by allergies to multiple foods...Understanding these processes is opening the way to better treatment...”  
*O'Shea KM, et al. “[Pathophysiology of Eosinophilic Esophagitis.](#)” *Gastroenterology.* 2017 Jul 27. pii: S0016-5085(17)35952-8. doi: 10.1053/j.gastro.2017.06.065.*
4. Previous studies in adults with EoE have shown decreased esophageal distensibility (how “stretchy” or “flexible” the esophagus is). This study looked at esophageal distensibility in children. Researchers found that age positively correlated with esophageal distensibility in children who did not have EoE, but not in children who did have EoE. Those with EoE had reduced distensibility and factors such as active inflammation, tissue scarring, and other issues such as stricture, history of food impaction, and circumferential rings.  
*Menard-Katcher C, et al. “[Influence of Age and Eosinophilic Esophagitis on Esophageal Distensibility in a Pediatric Cohort.](#)” *Am J Gastroenterol.* 2017 Sep;112(9):1466-1473. doi: 10.1038/ajg.2017.131. Epub 2017 May 16.*

## 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.

Learn More 



## Enrolling CEGIR Studies

### Eosinophilic Esophagitis

**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.

**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.

### 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?

**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.

**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](http://rdcrn.org/cegir)**

### Learn more about Eosinophilic Gastrointestinal Diseases:



[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.

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