

Welcome to the 2nd edition of CEGIR E-news!

We are proud to provide you with the 2nd Edition of CEGIR (Consortium of Eosinophilic Gastrointestinal Researchers) E-News, which includes:

- Information about research opportunities
- Spotlight on CURED (Campaign Urging Research for Eosinophilic Diseases)
- Information on upcoming events

We encourage you to bookmark and visit the CEGIR website (<u>www.rdcrn.org/cegir</u>) to stay up to date on the latest information.

Clinical Trial Now Enrolling

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

Study Summary

The purpose of this interventional study is to test and compare the effectiveness of two elimination diets—the 1-food elimination diet (1FED; milk only) and the 6-food elimination diet (6FED; milk, egg, wheat, soy, tree nut/peanuts, and fish/shellfish). The study will also test the effectiveness of swallowed glucocorticoid therapy in some of the study participants for whom diet therapy was not effective.

For Diseases

Eosinophilic Esophagitis (EoE)

About this Study

This is an interventional study of 120 individuals with EoE between the ages of 18 and 60 years of age. Participants will be seen at one of the clinical sites around the United States. Participants will be in the study for approximately 10 weeks to 17 weeks, depending on how they respond to the dietary therapy. Participants will be randomly assigned to one of the two elimination diet therapies, the 1FED or the 6FED. If a participant's EoE is in remission after receiving 6 weeks of 1FED or 6FED therapy, the participant will be done with study participation. If a participant's EoE is still active, the participant will continue on to either 6FED therapy (if they were previously on 1FED) or swallowed glucocorticoid therapy (if they were previously on 6FED) for 6 weeks.

Patient Advocacy Group Spotlight CURED

CURED is a not-for-profit foundation dedicated to those suffering from Eosinophilic Gastrointestinal Diseases (EGID), including eosinophilic esophagitis (EoE), eosinophilic gastritis (EG), eosinophilic colitis (EC) and other eosinophilic disorders.

CURED is committed to raising substantial funding to aid in research, advocating on behalf of EGID patients and their families, and working to educate and increase awareness about this complex group of diseases. It is our heartfelt belief that CURED can make a difference for the individuals and their families who are touched by these diseases.

CURED has donated 4 Million Dollars to medical research in the hope of finding better treatments and a cure for all those suffering with an EGID. With your help, CURED can continue to give hope to others who are suffering. Please contact us to see how you can help!

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

Targeted Enrollment

To be eligible to participate, you must:

- Be male or female age 18-60
- Be diagnosed with: Eosinophilic esophagitis (EoE)
- Have symptoms of EoE
- Have esophageal eosinophilia (eosinophils in your esophagus)

Go to the link below for more information to get involved:

https://www.rarediseasesnetwork.org/cms/cegir/7802

Microbiome Study: A Sub-Study of OMEGA

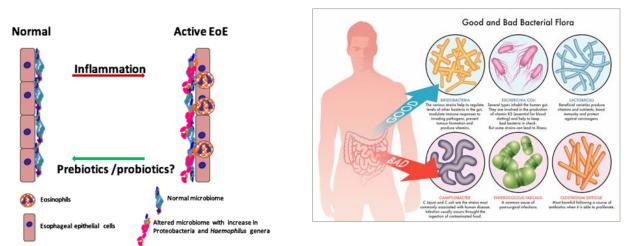
Study Summary

This study aims to study individuals with Eosinophilic Esophagitis (EoE), Eosinophilic Gastritis (EG), and Eosinophilic Colitis (EC) and compare them with individuals who do not have EoE, EG, or EC. We think that the GI tissue, serum and stool from EoE, EG, and EC subjects will have a distinct imbalance (uneven) of gut bacteria (microbiome) with more bad bacteria than good as compared with the GI tissue, serum and stool from without EoE, EG, and EC. We think that EoE, EG, and EC will have both similar and unique patterns of imbalanced gut bacteria from one another.

What is the Microbiome?

The microbiome or bacterial flora is a collection of bacteria that live in and on every person.

- both good and bad bacteria are in the microbiome
- every person has different microbiome
- there may be a link between amounts and types of bacteria in the gut and having an Eosinophilic Gastrointestinal Disease.
- stool is an ideal way to study bacteria in the gut



Analysis of stool along with cells collected during your endoscopy will help us study what things might change your microbiome in good ways. One question we might answer is, do prebiotics and probiotics change your microbiome?

Analysis of stool has potential to lead to a non-invasive test for EGID.

Go to the link below for more information on how to get involved.

https://www.rarediseasesnetwork.org/cms/cegir/7801

Do you know other families living with an EGID? Encourage them to join the CEGIR Contact Registry at: https://www.rarediseasesnetwork.org/cms/cegir/Get-Involved/Contact-Registry



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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