



Visit us: www.RareDiseasesNetwork.org/CEGIR

Welcome to CEGIR E-news

We hope you enjoy the first newsletter issue of the Consortium of Eosinophilic Gastrointestinal Researchers (CEGIR). The Consortium is made up of eosinophil disease researchers and patient advocacy groups (PAGs).

This newsletter is designed to keep you up to date with the latest CEGIR news as well as research opportunities for which you may be eligible to participate.

Each edition will also highlight a Patient Advocacy Group to help you connect with organizations that are available to support you. You will also read about upcoming events that may be of interest to our patient community.

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

Clinical Trial Now Enrolling

A Prospective, Multicenter Study to Compare and Validate Endoscopic, Histologic, Molecular, and Patient Reported Outcomes in Pediatric and Adult Patients with Eosinophilic Esophagitis (EoE), Gastritis (EG), and Colitis (EC) - OMEGA

What is the goal of OMEGA? CEGIR is conducting this study because they want to learn more about Eosinophilic Gastrointestinal Diseases (EGIDs). As part of that goal, one area of study will compare how well a patient feels - their symptoms - with what the tissue samples look like under a microscope. The study aims to answer a series of questions, including the following:

- What if the tissue looks good, but you are still experiencing symptoms?
- What if the symptoms have subsided, but the eosinophil counts haven't changed?

This study is designed to give researchers and clinicians a better idea of the correlation of symptoms to the tissue, help them find clues about

Patient Advocacy Group Spotlight

Eosinophilic Family Coalition

The Eosinophilic Family Coalition (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

the disease in the tissue samples, and assess how this information could be used in the future to help guide diagnosis and treatment plans.

OMEGA is a multicenter, longitudinal study of children and adults with EoE, EG, and EC.

Will participating in the OMEGA trial interfere with your current treatment plan? No. The OMEGA study is an "observational" research study. It will not interfere with, change, or otherwise intervene with your treatment plan.

If you participate in OMEGA, what is involved? If you consent to participate in this study, researchers will follow the progress of your treatment plan. As part of the standard monitoring process for EGIDs, patients have periodic endoscopies and/or colonoscopies with biopsies. If you participate in OMEGA and are scheduled to have an endoscopy/colonoscopy, researchers may request your permission to take additional tissue and/or blood/saliva samples for the study. Also, as a study participant, you will periodically be asked to complete questionnaires. These questionnaires may take 30-45 minutes to complete.

Please contact a study site for more details of what is involved with participation

Targeted Enrollment

To be eligible to participate, you must:

- Be male or female age 3 to 65
- Be diagnosed with one of the following:
 - Eosinophilic Esophagitis (EoE)
 - Eosinophilic Gastritis (EG)
 - Eosinophilic Colitis (EC)
- Have symptoms of EoE, EG or EC

You are not eligible to participate if:

- You have a history of intestinal surgery
- You are enrolled in a blinded investigational study
- You have other identifiable causes for eosinophilia, infections, Gastrointestinal (GI) cancer, other GI inflammatory disease

A glossary of terms may be found on CEGIR's website:

www.rarediseasesnetwork.org/cms/cegir/Learn-More/Glossary

Learn more about the U.S. sites that are enrolling patients into the OMEGA trial:

www.rarediseasesnetwork.org/cms/cegir/7801

Do you know other families living with an EGID? Encourage them to join the CEGIR Contact Registry:

www.rdcnrn.org/cegir/registry

Learn more about Eosinophilic Gastrointestinal Diseases:



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 particular 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.

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