



CEGIR News Special Edition

Welcome to a Special Edition of CEGIR News! This edition will celebrate the week by highlighting the Patient Advocacy Groups that focus their efforts on supporting the Eosinophilic Community and provide you with opportunities to get involved during the week.

History of National Eosinophil Awareness Week (NEAW)

On May 15, 2007, the United States House of Representatives passed HB296 which designated the third week of May as National Eosinophil Awareness Week. NEAW provides the opportunity to educate the general public and medical community about eosinophil-associated diseases and their impact on patients that live with them.

Patient Advocacy Groups (PAGs) across the country are honoring NEAW in a wide variety of ways. Continue reading to learn more about each PAG and how you can participate.

American Partnership for Eosinophilic Disorders (APFED)

Celebrating its 15th anniversary, APFED is a 501(c)3 non-profit organization whose mission is to passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy. APFED serves as a credible source of information for health care providers and for patients, and works to unite both communities so that they each have a better understanding of one another. The organization has made a number of advocacy achievements, including working in support of federal funding for research, proper medical coding of eosinophilic gastrointestinal diseases, insurance coverage of medical foods, and more. APFED's Hope on the Horizon Research program, supported entirely by donations, provides research grants through a competitive peer-review process, and supports a variety of research initiatives. Learn more about APFED's programs and services and ways to connect at www.apfed.org.

To celebrate the 2017 NEAW, APFED is disseminating educational materials to the patient and medical communities, raising funds for research, and partnering with organizations, businesses and institutions to raise awareness.

Here are some ways you can get involved with APFED's celebration of NEAW this year!

- [Access APFED's NEAW Toolkit](#)
- [Become a NEAW Partner](#)
- [Participate in an event to support research funding](#)
- [Join the \\$150,000 HOPE Challenge](#)
- [Follow APFED on Facebook for NEAW news and announcements](#)

Campaign Urging Research for Eosinophilic Disorders (CURED)

CURED is a 501(c)3 non-profit foundation that is dedicated to finding a better treatment and cure for those suffering with an Eosinophilic Disease. Since 2003 CURED's volunteers have worked tirelessly to raise substantial funding, with over 4 million dollars raised and donated. CURED believes it is only through research that better treatments, quality of life and a cure will be found. In addition to fundraising, CURED offers invaluable support through their website, brochures, presentations, social media outlets and a bi-annual education/research conference for patients, caregivers and the medical community. CURED has been an integral part of passing formula legislation in many different states and is determined to connect patients, medical personnel and government officials with educational resources. CURED has made a significant impact on the EGID community and they hope to continue to advance their mission with your support www.curedfoundation.org.

Here are some ways that CURED will be celebrating this year!

- Education of patients, care givers and medical professionals through the newsletter and social media outlets
- [Learn more about or participate in a CURED Fundraiser](#)
- [Purchase an awareness item in the CURED Gift Store](#)
- [Follow CURED on Facebook](#)
- [Follow CURED on Twitter](#)

Eosinophilic Family Coalition (EFC)

Founded in 2011, the EFC is a 501(c)3 non-profit organization with a mission to support and enhance the lives of families living with Eosinophilic Diseases. The numerous programs of the EFC focus primarily on addressing the need for patients living with these diseases to connect with others that share the unique set of challenges that EGID brings. The diverse programming of the EFC provides not only professional support through experts in the field of EGID, but also peer to peer support. The EFC sponsors Camp Courag"EOS"®, the first and only camp for families living with Eosinophilic Diseases. This weekend long experience provides families with an opportunity for fun, education and self-esteem building as well as increasing and strengthening independence. The EFC also sponsors the Courag"EOS"® Capes program in which we provide every child living with an Eosinophilic Disease a kit that includes a superhero cape and patches. The goal of the program is to empower children, give them strength, a positive experience and allow them some control while coping with a condition that frequently challenges that sense of control. You can learn more about the many other programs of the EFC by visiting www.eoscoalition.org

Here are some ways that you can join the EFC in their celebration of NEAW!

- [Learn more about and download an application for the Courag"EOS"® Capes Program](#)
- [Connect to learn more about starting a chapter in your local area](#)
- [Learn more about how you can help support the programs of the EFC](#)

You can find out more about other events hosted by CEGIR institutions and Patient Advocacy Groups by checking out the [CEGIR Events Page](#).

Enrolling CEGIR Studies

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.

[Learn More](#)

Outcome Measures for Eosinophilic Gastrointestinal Diseases across Ages - OMEGA

Why do patients still have EGID symptoms even if their scopes or good, or vice versa? The OMEGA clinical trial seeks to find answers to this question and more. Do you qualify to participate?

[Learn More](#)

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.

[Learn More](#)

A Preliminary Open-Label Trial of Losartan Potassium in Participants with Eosinophilic Esophagitis (EoE) With or Without a Connective Tissue Disorder

Can the drug Losartan, which is a medication used in patients to control high blood pressure, have an impact on the treatment of EoE? This clinical study will evaluate if Losartan therapy reduces the number of eosinophils in the esophagus and improves the symptoms of EoE.

[Learn More](#)

These studies are being run at research facilities across the country. To find the CEGIR institution closest to you, check out the interactive map [here](#):

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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