



CEGIR NEWS

Updated diagnostic guidelines for Eosinophilic Esophagitis: Outcomes from AGREE

An international consensus conference was recently convened to assess the evidence and apply evolving understanding and new insights to the diagnostic criteria previously established for pediatric and adult Eosinophilic Esophagitis (EoE). The guidelines that were established as a result of this conference were recently published in Gastroenterology.

Although guidelines established in 2007 and updated in 2011 considered EoE and gastroesophageal reflux disease (GERD) to be mutually exclusive conditions, recent clinical experience has uncovered a shared complex relationship between the 2 entities. Therefore, the team of experts- including adult and pediatric gastroenterologist, allergists, and pathologists- conducted extensive assessments of the evidence in order to update the current diagnostic algorithm for EoE. (Morr,2018)

Read More: <https://www.ncbi.nlm.nih.gov/m/pubmed/30009819/>



For more information:
15th Annual Casino Night

Fall 2018

Patient Advocacy Group Resource Spotlight



Congratulations to CURED for 15 years of dedication to the EGID community!

What CURED is?

CURED is Campaign Urging Research for Eosinophilic Diseases.

- CURED is a 501c3 foundation
 - CURED advocates
 - CURED educates
- CURED spreads awareness
 - CURED hosts the largest patient/research conference every other year

- CURED educates doctors and nurses and bring patients and families together to learn from leading doctors and researchers from all over the world

- CURED helps get legislation passed for formula coverage
 - CURED has raised and donated nearly 4 1/2 Million Dollars to research!

We have had many people join in our efforts by hosting fundraiser's in their communities. CURED donates 100% of our profits to research. CURED is an all volunteer foundation donating 100% of all profits to research.

It is our heartfelt belief that CURED can make a difference for the individuals and their families who are touched by these diseases.

Find out how you can get involved:
www.curedfoundation.org

Meet three new CEGIR Trainee Scholars



Dr. Greuter completed his medical school in 2013 and Internal medicine residency training in 2016 at University Hospital Zurich, Switzerland. Part of his medical studies he spent at Duke Medical School in Durham, NC. He then completed a two-year postdoctoral research fellowship in Gastroenterology/Hepatology at Mayo Clinic, Rochester, MN, which was funded by the Swiss National Science Foundation. He returned to Zurich late 2018, where he will finish his gastroenterology training and his sub specialization in esophageal diseases. Besides his clinical training, he currently builds up his own basic science/translational research lab with a focus on fibrosis in EoE. His long-term clinical and research goal is to improve maintenance EoE treatment and to prevent/treat fibrostenotic EoE.



Quan Nhu, MD, PhD is a Gastroenterology/Hepatology Fellow from Scripps Clinic, La Jolla, CA, where he also trained in the ABIM Physician-Scientist Internal Medicine Program, with appointment as a KL2 Clinical Scholar at The Scripps Research Institute (TSRI). He is also a Visiting Scholar at the University of California, San Diego (UCSD) School of Medicine, where he collaborates closely with Seema Aceves, MD, PhD, and with Fouad Moawad, MD at Scripps Clinic, to develop a clinical and translational research program for eosinophilic esophagitis (EoE) in adults. His research centers around understanding the mechanisms of inflammation and remodeling in EoE and developing clinically relevant therapeutic agents for EoE. Dr. Nhu's current research directions build on his prior training in Immunology and in Immunopathology. His research has been funded by an NIH CTSA KL2 Pilot Award, several intramural Scripps Clinic Medical Group Research & Education Awards, and more recently by an NIH LRP Award.



Dominique Bailey, MD, MS Ed is a pediatric gastroenterologist with a background in both basic science and interdisciplinary clinical research. Her interactions with patients and families affected by eosinophilic esophagitis (EoE) have inspired her long-term research and clinical goal to improve the quality of life for children with EoE. Her experiences have directed her current research in the laboratory of Dr. Jianwen Que, MD, PhD, where she addresses the cellular and molecular mechanisms underlying the pathophysiology of EoE. It is her hope that this research will lead to future treatment regimens or novel biomarkers for pediatric EoE. In addition to her current work with Dr. Que, Dr. Bailey collaborates with subspecialists in the Division of Allergy, Immunology & Rheumatology and Pediatric Transplant Hepatology at Columbia University Irving Medical Center, Morgan Stanley Children's Hospital to further our understanding of the role of the immune system in patients that develop eosinophilic gastrointestinal diseases after liver transplantation.

CEGIR 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 they receive this communication and stay up to date on future opportunities.

CEGIR STUDIES-Now Recruiting

7801: OMEGA - 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)

7802: Six Food vs One Food Eosinophilic Esophagitis Elimination Diet followed by Swallowed Glucocorticoid Trial - SOFEED

7803: A Preliminary Open-Label Trial of Losartan Potassium in Participants with Eosinophilic Esophagitis (EoE) With or Without a Connective Tissue Disorder

7808: Use of Unsedated Transnasal Esophagoscopy to Monitor Dietary Management of Eosinophilic Esophagitis in Children

7809: Effect of Elemental Diet on Adult Patients with Eosinophilic Gastroenteritis (ELEMENT)



www.rdcrn.org/cegir



www.apfed.org



www.curedfoundation.org



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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References:

Morr, Madeline (July 28, 2017). Updated Diagnostic Guidelines for Eosinophilic Esophagitis: Outcomes From AGREE, Retrieved from:<https://www.clinicaladvisor.com/gastroenterology-information-center/updated-international-consensus-guidelines-for-proton-pump-inhibitors-in-eosinophilic-esophagitis/article/783457/>